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## Factors Affecting Community Participation in Young Adults with Intellectual and Developmental Disabilities

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FACTORS AFFECTING COMMUNITY PARTICIPATION IN YOUNG ADULTS  
WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

by

Molly Bathje

A dissertation submitted to the Graduate College  
in partial fulfillment of the requirements  
for the degree of Doctor of Philosophy  
Interdisciplinary Health Sciences  
Western Michigan University  
December 2016

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# FACTORS AFFECTING COMMUNITY PARTICIPATION IN YOUNG ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Molly Bathje, Ph.D.

Western Michigan University, 2016

Young adults with intellectual and developmental disabilities (IDD) participate less frequently in communities than other disabled and non-disabled peers (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009) even though they express a desire to participate (Kampert & Goreczny, 2007) and federal policy mandates community inclusion (Haertl, 2014). Participation in one's community is linked to health and quality of life (World Health Organization, 2002). The broad goal of this three paper dissertation is to contribute to a deeper understanding of what facilitates and impedes community participation for young adults with IDD by (1) developing a new conceptual model, (2) evaluating a pilot intervention based on that model, and (3) investigating participation from the perspectives of adults with IDD.

A review of literature about community participation reveals that existing models focus on the important interplay between the individual and his or her environment, but do not fully integrate the concept of activity as a bridge between the individual and environmental opportunities. Additionally, few models provide a process to guide intervention. The first paper in this dissertation offers a conceptual model that builds on existing models but incorporates activity and process to capture additional factors that may influence community participation.

The second paper reports a study that uses a pre and post intervention design to explore a pilot community intervention based on the conceptual model from paper one. In this study, four

students in a post-secondary education program (all young adults with IDD; 2 males and 2 females) agreed to participate in weekly group intervention sessions. The Adolescent and Young Adult Activity Card Sort (Berg, McCollum, Cho, & Jason, 2015) was used as the outcome measure. Students sorted pictures into piles before and after the 4-week intervention to indicate activities in which they had participated within the past 6 months. The Wilcoxon signed-rank test showed no statistically significant differences in number of activities participated in pre and post intervention.

The third paper provides results of individual semi-structured interviews about community participation experiences with the four students. Transcripts were analyzed using Creswell's (2013) phenomenological approach. This revealed nine themes that students described as influencing their participation experiences: physical safety, support, presence of an activity, logistical challenges, understanding context, family as community, identifying with previous communities, positive outcomes, and desired futures.

Results of the studies are consistent with prior research identifying activity as a key factor in community participation and the importance of support from family and others to encourage participation. Young adults with IDD showed interest in increasing community participation and were able to engage in interventions to help facilitate this, but recruitment and retention are challenges that need to be investigated further. The proposed conceptual model may help guide future research on interventions to increase meaningful community participation in young adults with IDD.

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## CHAPTER I

### COMMUNITY PARTICIPATION IN YOUNG ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: AN INTRODUCTION

#### Introduction

There were an estimated 4,677,319 people with intellectual and developmental disabilities (IDD) in the United States in 2012 and only 10% of those people lived in Independent Care Facilities, nursing homes, and psychiatric facilities combined (Larson, Hallas-Muchow, Hewitt, Pettingell, & Anderson, 2014). This reflects the increasing number of people with IDD who are residing in smaller, community-based housing, partially due to deinstitutionalization efforts in the past few decades (Larson et al., 2014). Between 1960 and 2012, 207 of the 354 large state IDD facilities no longer operated as IDD facilities (Larson et al., 2014).

Deinstitutionalization efforts are guided by human rights initiatives to provide care to people with disabilities in the least restrictive environment (Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014). Several legislative efforts also have facilitated deinstitutionalization. The Americans with Disabilities Act (1990) supported deinstitutionalization by providing legal protection from discrimination. The Olmstead Supreme Court Decision (*Olmstead v. L.C. and E.W.*, 1999) provided additional legislation that required people with disabilities to receive care and reside in the community if they were able and wanting to do so. The Developmental Disabilities Assistance and Bill of Rights Act of 2000 was enacted to ensure individuals with developmental disabilities and their families have access to community services and supports that promote inclusion in community life (Administration for

Community Living, 2016). Each of these legislative efforts sought to ensure the rights of individuals with disabilities and support their full participation within their communities.

### **Individuals with IDD**

Individuals with IDD are a diverse group of people experiencing a wide range of challenges in independent functioning. The term *IDD* is used in this paper to refer broadly to a group of individuals who experience functional deficits due to cognitive and/or social deficits that began during early development. Terminology for this group of individuals can vary depending on professional orientation and historical points. The most recent version of the *Diagnostic and Statistical Manual of Mental Disorders* (5<sup>th</sup> ed.; *DSM-V*) adopted a new diagnostic category called neurodevelopmental disorders (American Psychiatric Association, 2013). This diagnostic category includes conditions with an onset in the developmental period that result in impairment in personal, social, academic, or occupational functioning. The impairments can vary and specific diagnosis within the diagnostic category include intellectual disability, autism spectrum disorder, attention-deficit/hyperactivity disorder, language disorder, social (pragmatic) communication disorder, learning disorder, and motor coordination disorder, among others.

The term *neurodevelopmental disorder* is not commonly used in scientific journals because of the more recent operationalization of the diagnostic category, and because numerous research publications about this group of individuals is produced by researchers in professions such as education, psychology, and social work, which are not traditionally aligned with the psychiatric/ medical model view of individuals. A more common term, *developmental disability*, originated in the 1970s as a part of the Developmental Disabilities Services and Facilities Construction Amendments of the 1970s, which expanded the previous laws that covered only

individuals with what was then called “Mental Retardation,” to individuals with other neurological conditions (Administration for Community Living, 2016; Haertl, 2014). The most recent legislative definition of developmental disability in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 is that it is a “severe, chronic disability of an individual that:

- (i) is attributable to mental and/or physical impairment or combination of mental and physical impairments;
- (ii) is manifested before the individual attains age 22;
- (iii) is likely to continue indefinitely;
- (iv) results in substantial functional limitation in 3 or more of the following areas of major life activity:
  - (I) Self care;
  - (II) Receptive and expressive language;
  - (III) Learning;
  - (IV) Mobility;
  - (V) Self-direction;
  - (VI) Capacity for independent living;
  - (VII) Economic self-sufficiency; and
- (v) reflects the individual’s need for a combination and sequence of special interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(Developmental Disabilities Assistance and Bill of Rights Act of 2000)

Examples of developmental disabilities included in this definition are similar to those identified under the *DSM-V* definition of neurodevelopmental disorder, including cerebral palsy, autism, intellectual disability, and Down syndrome. Although many of the neurodevelopmental disorders and developmental disabilities include intellectual disability, it is critical to note that

not all do. The American Psychiatric Association (2013) defines intellectual disability in the *DSM-V* as deficits in general mental abilities that result in impairments of adaptive functioning. This project will use the term *IDD* to refer to individuals with developmental disabilities, as defined by the *DSM-V* and federal definition of developmental disabilities, who also have intellectual disability.

### **Community Participation for Individuals with IDD**

Although more people with IDD are living in community-based settings, individuals with IDD still have not been integrated fully as members of communities. Research has shown that adults with IDD experience social isolation and engage in fewer daily activities than non-disabled peers (Bigby, 2008; Gray et al., 2014; Milner & Kelly, 2009). Additionally, individuals with IDD may not feel safe in their communities due to rejection, discrimination, and lack of support (Bray & Gates, 2003; Cummins & Lau, 2013). Despite this, interviews of individuals with IDD reveal their desire to be more involved in their communities (Kampert & Goreczny, 2007). Qualitative research indicates that simply being present within communities does not equate to full community inclusion. Thus, it is the responsibility of both society and individuals with IDD to create opportunities for community inclusion (Cobigo, Ouelette-Kuntz, Lysaght, & Martin, 2012; Cummins & Lau, 2013).

Research about community participation includes a majority of descriptive studies, which have identified barriers to community participation and social inclusion (Amado, Boice, & DeGrande, 2012; Craig & Bigby, 2015; Dusseljee, Rijken, Cardol, Curfs, & Groenewegen, 2011; Gray et al., 2014; Milner & Kelly, 2009; McClimens, Partridge, & Sexton, 2014). Other studies propose models for addressing community participation, most focused on the interactions between the individual and the environment (Cobigo et al., 2012; Simplican, Leader, Kosciulek,



& Leahy, 2015). Intervention studies mainly explore the impact of changes to systems, cultures, and caregivers or mentors (Bigby & Wiesel, 2015; Mahoney et al., 2013; Thorn, Pittman, Myers, & Slaughter, 2008; Wilson et al., 2013; Zakrajsek, Hammel, & Scazzero, 2014). A literature review of social inclusion research indicates that studies of interventions that focus on the role of individuals with IDD in increasing inclusion within their communities have not been conducted (Cobigo et al., 2012).

The broad goal of this three-paper dissertation is to develop a deeper understanding of the factors that may influence community participation for young adults with IDD from the individual's perspective and through application of a new conceptual model to a pilot intervention. The first paper proposes a conceptual model that builds on previous models focused on the individual and environment, but it expands the focus to incorporate activities of community participation. This conceptual model provides the foundation for the two papers that follow. The second paper is a report of the effects of a pilot community participation intervention based on the conceptual model on a measure of activity involvement. The third paper is a qualitative study of the unique perspective of young adults with IDD living in community settings related to community participation. The final chapter summarizes and considers the findings with reference to the conceptual model presented in Chapter II. This paper also makes recommendations for future research and presents implications for practice.

## **CHAPTER II**

### **DEVELOPMENT OF A CONCEPTUAL MODEL OF COMMUNITY PARTICIPATION IN ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES**

#### **Introduction**

Participation is recognized as a construct that is integral to health and wellness (World Health Organization [WHO], 2002). The WHO includes participation in the International Classification of Functioning, Disability and Health (ICF) model and defines participation as “involvement in life situations” (p. 16). The WHO further indicates that participation includes participation within one’s community. Designing interventions to achieve participation is challenging because participation is a complex construct closely related to other factors, including quality of life and autonomy, and it is dependent on contextual factors to be fully realized (Baum, 2011). Health professionals, researchers, and policy makers attempt to define and describe participation in community activities as a part of the larger discourse about how to support full participation in life activities for people with disabilities (Baum, 2011; Hemmingsson & Jonsson, 2005).

The purpose of this paper is to propose a conceptual model of community participation specific to young adults IDD. This paper builds upon previous research and other conceptual models. The goal is to propose a model and then use it to guide two empirical investigations—one quantitative and one qualitative—whose results will then influence further elaboration of the model.

## Community Participation

Several definitions of community participation exist, making the concept of community participation difficult to operationalize. The term *community participation* is used interchangeably in the literature with other terms such as *community involvement*, *community inclusion*, *community integration*, and *social participation* (Cobigo et al., 2012; Overmars-Marx et al., 2014). Additionally, aspects of community participation are found within definitions of other concepts such as *social inclusion* (Simplican et al., 2015). In this paper, I have adopted a broad definition of community participation in order to include findings about community inclusion, community involvement, community integration, social participation, and social inclusion to inform the development of this model.

Full participation in community life is conceptualized as a shared responsibility between society and individuals with disabilities (Cummins & Lau, 2003; Hammel et al., 2008; van de Ven, Post, de Witte, & van den Heuvel, 2005). The disability rights movement helped lead the incorporation of aspects of the social model of disability, including community participation, into the ICF (Hemmingsson & Jonsson, 2005). The social model of disability asserts that disability is the result of interactions between the individual and his or her environment, with the environment often being viewed as oppressive, serving as a key factor in turning a challenge or a difficulty into a disability. Thus, the concept of participation in the ICF model is categorized as a component of functioning that is impacted by environmental and personal factors. This relationship has been supported through research about community participation for people with disabilities. For example, Heinemann et al. (2011, 2013) identified that participation may be affected by personal preferences and by environmental, social, and economic factors. This understanding of participation highlights the complex interplay between individual

characteristics and the contextual barriers and opportunities, which must be represented in any proposed model. Such a model could direct research, intervention, and policy efforts toward addressing contextual barriers to community participation.

### **Community Participation in Adults with IDD**

Adults with IDD experience a number of challenges related to participation, beginning with limitations in the frequency and extent of participation. In particular, research has shown that adults with IDD experience more social isolation and less community participation than other disability groups (Bigby, 2008; Dusseljee et al., 2011; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). This does not appear to be for lack of interest in participation. Individuals with IDD have expressed a desire to be more involved in community activities (Iriarte, O'Brien, McConkey, Wolfe, & O'Doherty, 2014; Kampert & Goreczny, 2007). In a review of literature specific to adults with IDD and activity engagement, Channon (2014) summarized that adults with IDD experience low levels of engagement because of individual characteristics, individual abilities, and contextual determinants. Channon also identified that enriched physical and social contexts can have positive impacts, but are not sole determinants of participation levels. As noted earlier, adults with IDD are more isolated than non-disabled, despite the policy changes that have occurred in the past few decades advocating and supporting inclusion and participation. This finding indicates that community participation should be addressed comprehensively, not just with a focus on contextual issues.

### **Models of Community Participation**

The WHO's ICF model of disability helped lead to the development of new models of participation that encompass individuals and the contexts in which they exist (Baum, 2011). Van de Ven et al. (2005) proposed a model of community integration based on inquiry into the

perspectives of individuals with disabilities. This model identified five important elements of community inclusion: functioning ordinarily without receiving special attention, mixing with others who are not disabled, taking part in society, trying to realize one's potential, and directing one's own life. Similar to the concepts identified by van de Ven and colleagues, Hammel and colleagues (2008) identified overarching principles that create a sense of belonging within an individual's community using qualitative analysis of focus groups with people with disabilities. These overarching principles included engagement, evaluation, and enfranchisement (Heinemann et al., 2013). Authors defined engagement as the frequency of participation in activities, whereas evaluation included an individual's satisfaction with his or her participation. Enfranchisement was explained as a set of values that give meaning to participation, apply across domains of life, and include an individual's appraisal of his or her communities' respect for his or her participation. Both Van de Ven et al. and Hammel et al. acknowledged the important interplay between individuals and environments, but they also included the individuals' self-directed motivations and their individualized perspectives about their experience of community participation in their general disability models.

The models for social participation specific to individuals with IDD include many of the concepts from general models of social participation. Cobigo et al. (2012) completed a review of the literature related to social inclusion for people with IDD, which included the term *participation*. Authors concluded that social inclusion is complex and encompasses interactions between the environment and individual characteristics in which an individual can be viewed as competent. Also, the environment must include opportunities for the individual to (a) access public goods and services, (b) experience valued roles, and (c) engage in reciprocal interactions. Based on their findings, Cobigo and colleagues recommended that future research on social

inclusion for people with IDD should focus on integrating the individual's perspectives and values in social inclusion activities, using a developmental perspective, and developing a measure of subjective feelings of belonging. In another systematic review of social inclusion of people with IDD, Overmars-Marx et al. (2014) found that opportunities for neighborhood inclusion occur through a dynamic process of interactions between environmental factors and personal characteristics. Also, authors indicated that the perspective of individuals with intellectual disability and community residents without disabilities is essential to inclusion opportunities. Similarly, Simpican et al. (2015) proposed an ecological model of social inclusion for people with IDD that acknowledges individual, interpersonal, organizational, community and socio-political factors as contributing to social inclusion. This model defines community participation and interpersonal relationships as life domains that interact to achieve social inclusion. Similar to the models developed for diverse disabilities, these models for individuals with IDD highlight the importance of an individual's desire for and satisfaction with participation in addition to acknowledging the role of the environment and individual characteristics and abilities (Amado, Stancliffe, McCarron, & McCallion, 2013).

Although the above models have refined the ICF model's conceptualization of community participation, at least one important aspect of community participation has not been included in the models—activity. The results of some empirical findings about community participation for people with IDD have indicated that the activity an individual engages in within the community can be a facilitator of participation. The results of a two-year observational study of adults with intellectual disabilities participating in community groups indicated that the presence of an integrating activity increased involvement in the group (Craig & Bigby, 2015). In another study of adults with intellectual disabilities in day programs, researchers found that the

theme of *doing activity/initiating involvement* was one way participants expressed the experience of meaningful engagement in community groups (Mahoney, Roberts, Bryze, & Parker Kent, 2016). The importance of the activity or action embedded in the community participation process has been noted in the literature, but it is typically conceptualized as related to the individual's skills or as part of the environment. The characteristics, or simple presence, of the activity appear to influence participation levels and sense of belonging/meaning to the individual.

The profession of occupational therapy (OT), established in 1917, is rooted in the belief that engagement in meaningful activities leads to health. The profession uses activity participation as both a means and an end to engagement. The American Occupational Therapy Association (AOTA, 2014) conceptualized *occupations* as a combination of activities and tasks that an individual engages in. AOTA also asserted that occupations provide meaning, purpose, and a sense of identity for individuals. As noted earlier, an essential component of community participation is the individual's perception of the meaningfulness of participation (Hammel et al., 2008). Meaning can be enhanced through engagement in occupational tasks and activities. Therefore, the activity that an individual engages in within his or her community may play a larger role in participation than previously recognized.

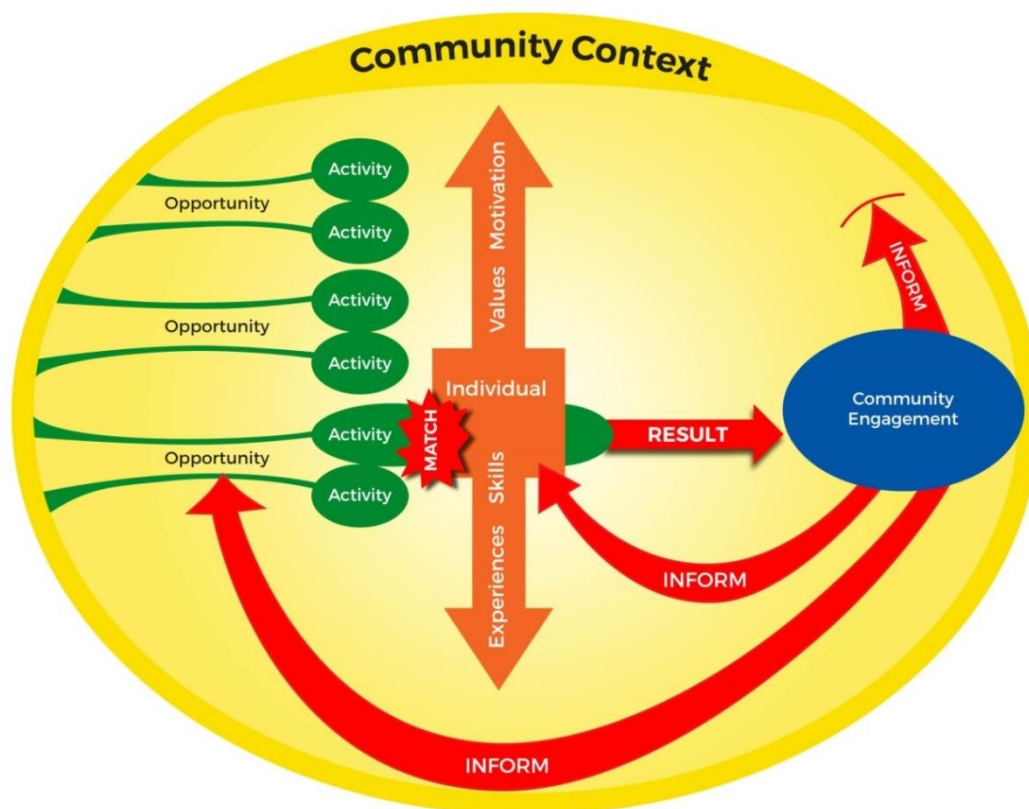
## **Methods**

### **Development of a Proposed Conceptual Model of Community Participation**

A review of the existing conceptual models and understandings of community participation for adults with IDD indicates that there are several convergent concepts as well as other important findings that have not been connected to existing models. In this paper I propose a conceptual model that attempts to integrate these concepts and provide a process for guiding

community participation interventions. The proposed model builds on my understanding of community participation as the process of engaging in self-identified activities within the community context that are meaningful and influence the community context and the individual.

The proposed model development occurred in two stages. An initial model was developed and proposed from a review of existing literature. An expert panel reviewed the initial model, provided feedback on the narrative and graphic display of the model, and suggested modifications and clarifications. The initial model is displayed below in Figure 1.

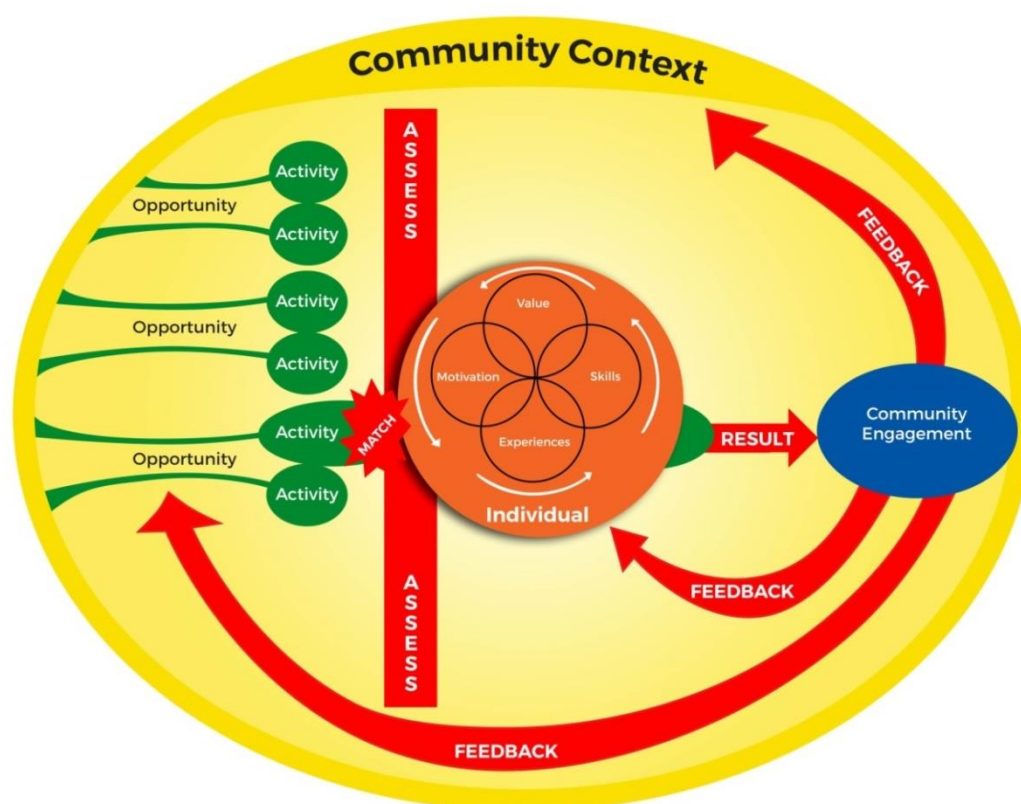


*Figure 1.* Community Participation Model

A panel of three experts provided feedback about the initial model. Feedback included guidance to represent the individual and self-assessment process in more detail, clarify the process features of the model, and provide definitions of model concepts in the narrative.



Changes to the initial model and narrative were completed based on feedback and the model was refined. The refined model is displayed in Figure 2 and the narrative explanation of the model follows.



*Figure 2.* Community Participation Model Revision

The model will continue to be refined through the completion of the research reported in the next three chapters of this dissertation. The model will be evaluated in relationship to the outcomes of two studies. The first study uses the model to guide a community participation intervention for young adults with IDD. The second study is a qualitative analysis of individual interviews with young adults with IDD. The results of each of these studies will contribute to the evaluation and refinement of the proposed conceptual model.

## Results

### A Proposed Conceptual Model

The proposed conceptual model builds on concepts established in previous literature, followed by expert panel review. The model continues to recognize that community participation is highly influenced by the context in which it occurs and incorporates the opportunities for community participation that are created within the environment, a structure recognized by the WHO (2002) ICF model. Similar to the ICF model, this proposed model situates the community participation process within the *Community Context*, which is represented with a yellow circular background. The community context includes the physical and social environment in addition to cultural conditions that a community exists in and is influenced by. The community context defines opportunities for individuals to become engaged with in their communities.

*Opportunities* emerge from the context, represented in the model with green images extending out of the surrounding community context. Previous research and models have demonstrated that community participation is influenced by the barriers and opportunities that a context provides (Heinemann et al., 2013). A context can produce several different types of opportunities for community participation, each with unique and specific activities defined.

An essential component of this model that has not been emphasized in other conceptual models is the *Activity*. Represented in green, the activities grow out of the opportunities present in the community context. Activities are components of larger, coordinated, goal directed actions in which individuals engage (AOTA, 2014). Activities are actions that are meaningful, relevant, and useful to individuals and communities (AOTA, 2014). Different types of activities can emerge from the opportunities produced by the community context. For example, the

opportunity of gardening can emerge from within a community context. The activities associated with gardening can include actual gardening, but also planning, planting, harvesting, preparing the soil, and other activities. These activities can occur independently or with others, depending on the community context and opportunity. The multiple activities produced by the opportunity allow an individual to engage in community participation in several ways.

The *Individual* is a dynamic component of the proposed conceptual model, something other models have also incorporated (Overmars-Marx et al., 2014; WHO, 2002). The proposed model also incorporates individual characteristics that influence participation including values, motivations, experiences, and skills, as supported by previous research and models (Craig & Bigby, 2015; Hammel et al., 2008; Simplican et al., 2015). The individual is represented in the model with a large circle encompassing concentric circles that represent the individual's values, motivations, skills, and experiences. The large circle that encompasses these interpersonal characteristics includes arrows that signify movement, which allows the individual to assess and align individual characteristics with activities during the self-assessment process (to be discussed later).

The activity becomes the link between the individual and the community context to create community participation engagement, as represented in the model by a red graphic indicating *Match*. The match between the activity and individual is important to creating successful community experiences both for the communities and for the individual. Individuals can learn new skills, or refine skills, to engage in the activities. Also, if an individual does not have the desire or skills to complete certain activities, the individual can choose not to participate in the community context through that specific activity, or may choose another activity.

The simple presence of opportunities, activities, and individuals within a community context will not produce meaningful engagement. The proposed model includes process components to demonstrate the implementation of community participation. The first process component, noted earlier, is the individual self-assessment process. Individuals engage in a self-assessment process that includes identifying their values, motivations, skills, and experiences as they relate to opportunities and activities in their community context, and match those to an activity. The *Individual* component in the model is placed upon a red self-assessment line, indicating that the process of self-assessment and matching to an activity occurs both within the individual, but also in comparison to the activities available within the community. The individual moves through the self-assessment process, in relationship to each activity available, looking for a match. As previous research has identified, the individual's autonomy in the process is key to facilitating engagement (Hammel et al., 2008), therefore, the process of self-assessment and choosing the best match is important to the community participation process.

The process components in the model are illustrated in red, with shapes containing white writing throughout the model. As noted in the literature review, there are several studies of the experience of community participation, and conceptualizations of the meaning, facilitators, and barriers of community participation, but most models do not include a process component to guide interventions. The model is presented in a left to right orientation, with process arrows guiding the reader from left to right as well as back to the beginning. The organization of the process components is structured upon an open systems approach, which indicates that components of the model should not be considered in isolation; rather, the model should be viewed as a dynamic whole where each component has an impact on other components and the overall process (Keilhofner & Burke, 1980; Von Bertalanffy, 1962). The open systems theory is

noted in the proposed model, indicating that when an individual engages in meaningful community participation this can affect the individual by informing his or her individual characteristics, including skills, values, motivations, and experiences, which can impact the self-assessment process. Also, engagement in meaningful community participation can impact the community context and the opportunities available. Applying the open systems theory to the proposed model captures the dynamic feature of changes in one component of the model producing changes in another. A process oriented model is presented to aid in the implementation of concepts through interventions.

### **Discussion**

Defining and conceptualizing community participation is a challenge due to multiple definitions and overlapping concepts. This paper has brought some consistency to this situation by defining community participation as the process of engaging in self-identified activities within the community context that are meaningful to the individual and influence the community context and the individual. This paper also brought some clarity by integrating previously known key concepts in community participation with less recognized components. These include the importance of a supportive community context that produces opportunities and the individual's self-assessment of his or her values, motivations, skills, and experiences. Unlike other models, this model uniquely utilizes the activity as the link between the individual, the community context, and meaningful participation.

The proposed model of community participation is different from previous models because of the inclusion of activity as the link between individuals and their communities. This new conceptualization also uses an open systems approach to community participation, emphasizing the influence that components of the model can have on each other. Lastly, the

model is designed as a process, which can aid in designing interventions to facilitate increased community participation. The model can support interventions to increase opportunities with the community context that are better matched for people with disabilities. Likewise, interventions focused on the individual, including the self-assessment process and skills attainment can be employed based on this model.

## **CHAPTER III**

### **A COMMUNITY PARTICIPATION PILOT INTERVENTION FOR YOUNG ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES**

#### **Introduction**

Since the 1970s more individuals with IDD are living in community settings, with a noted decline in individuals with IDD living in large, state-run residential facilities (Larson et al., 2014). Although individuals with IDD are residing in community settings, their engagement in community activities continues to be less than non-disabled peers and peers with others types of disabilities (Verdonschot et al., 2009).

Newer models of disability based on the social model of disability identify participation as a fundamental aspect of functioning. The WHO (2002) includes participation as part of the International Classification of Function (ICF) Model of Disability. The ICF model has been partially responsible for changes in policy that have resulted in more individuals with IDD living in community settings with physical access to community activities. Despite this, individuals with IDD still are not participating fully in community, social, and civic life. This leads to the question of whether better intervention methods might yield better outcomes.

The adoption of the social model of disability has resulted in an increased focus on the societal and contextual barriers to full participation for people with IDD (McClimens et al., 2014). Work over the past two decades that has focused on community participation in individuals with IDD has identified the need for adequate opportunities, attitudes, and supports from the environment to facilitate participation and inclusion in communities (Milner & Kelly, 2009). Research about the impact of contextual changes on community participation indicates

that increased presence of individuals within communities, expanded opportunities for involvement, providing structured activities, and training support staff/individuals to facilitate participation can increase engagement in community activities (Bigby & Wiesel, 2015; Overmars-Marx et al., 2014; Qian, Ticha, Larson, Stancliffe, Wuorio, 2015; Thorn et al., 2008; Wilson et al., 2013). Consistent with the social model of disability, most of the research about community participation has focused on changes in external factors, with the aim to increase individual participation.

Although contextual factors heavily influence community participation, other factors, including individual abilities, interests, and experiences; and the engagement in meaningful activities also can influence community participation. These factors are demonstrated in the conceptual model presented in Chapter II. Few intervention studies have been directed at facilitating participation by intervening within the individual to increase community participation. The majority of interventions described in evidence-based practice studies that aim to increase participation of individuals with IDD focus on developing specific skills such as leisure skills (Garcia-Villamizar & Dattilo, 2010) and social skills (Ward, Atkinson, Smith, & Windsor, 2013). In conducting a thorough review of the literature, I found no studies of interventions that were designed to increase community participation in individuals with IDD that emphasize the importance of activity and the self-assessment process to identify activities that match the individual and the community need. This study addresses that gap in research by investigating the impact and viability of a pilot community participation intervention for young adults with IDD based on the model described in Chapter II. The specific research questions were:



1. To what extent does a pilot community participation intervention increase reports of perceived community participation in young adults with IDD?
2. To what extent does a pilot community participation intervention increase interest in community participation in young adults with IDD?
3. What is the viability of a community participation pilot intervention for young adults with IDD?
4. Is the Adolescent and Young Adult Activity Card Sort an effective tool for measuring community participation and interested in young adults with IDD?

## **Methods**

### **Study Design**

A pre-post intervention quasi-experimental study was designed to examine the impact of a pilot community participation intervention in young adults with IDD. Additionally, the viability of the pilot intervention was explored by identifying recruitment and retention challenges and gathering subjective responses from participants about their experience of the intervention. Although the study was originally designed with a control group, the design was changed due to difficulty recruiting sufficient subjects to assign them to two groups.

The research team included the PI, who is a master's prepared faculty member in occupational therapy and candidate for doctor of philosophy who has experience working with this population and leading group-based interventions. Her advisors were also part of the research team. The research team also included four research assistants who were masters of science in occupational therapy students. This research was approved by Rush University's and Western Michigan University's Institutional Review Boards (IRB).

## **Pilot Intervention**

The pilot intervention was developed by the PI, based on the model described in Chapter II of this dissertation. The intervention incorporates findings from several studies on the barriers and facilitators of community participation. Important facilitators of community participation include an individual's sense of control, choice, and self-determination (Hammel et al., 2008; Konstam & Lehman, 2011; Mahoney et al., 2013; Van Asselt, Buchanan, & Peterson, 2015); individual abilities (Amado et al., 2013; Craig & Bigby, 2015; Iriarte et al., 2014; Van Asselt et al., 2015); access to support people or experts (Craig & Bigby, 2015; Qian et al., 2015); the opportunity to contribute to the community (Hammel et al., 2008; Konstam & Lehmann, 2011; Milner & Kelly, 2009; Myers, Ager, Kerr, & Myles, 1998); and the presence of a unifying activity (Craig & Bigby, 2015; Mahoney et al., 2016). Each of these concepts is woven into the pilot intervention plan.

The pilot intervention included four one-hour group sessions conducted weekly over a 4-week period. Each of the four sessions was based on concepts from the community participation model introduced in Chapter II that include *Individual*, *Opportunity*, *Activity*, *Community Participation Context*, *Self-Assessment Process*, and *Feedback*. The session themes were as follows: (1) individual abilities, (2) the community context, (3) activity, and (4) planning and appraisal. Each weekly intervention was designed to follow the seven-step group process outlined by Cole (2012). Cole's group process includes (1) introduction, (2) activity, (3) sharing, (4) processing, (5) generalizing, (6) application, and (7) summary. The group process encourages self-assessment of each of the group experiences. The intervention activities included discussion of the theme, hands-on activities related to the theme, reflection on the

process, and assignment of homework. See Appendix A for full group protocols for each of the sessions.

Week one of the intervention focused on the *individual* domain of the model. During week one, participants identified their skills, abilities, and interests as they related to various community participation activities. During the activity portion of the group, the leader passed out worksheets, each with a different type of community represented on them. The leader asked members to identify what community was being represented in each picture and identify if he or she were part of this type of community or were interested. Next, each participant reviewed a list of skills required to participate in each of the communities and placed a check mark next to the item if they agreed it that is a skill necessary for success in that particular community and were able to identify additional skills that might be required by writing them in. Participants passed the worksheets around and each participant reviewed each community and the skills required. The participants followed the same process for identifying if they had the skill that was required by each community. The group leader then led a discussion and review of the worksheets and asked for input and feedback from participants.

This week one activity was developed based on the *individual* component of the community participation model from Chapter II. In the model, the *individual* component includes the values, motivations, experiences, and skills an individual possesses. The week one activity provided the structure and learning activity for participants to identify these aspects of their individual selves and assess their individual characteristics related to community contexts and opportunities. The leader provided the structure and led the discussion to assist participants in this process.

Week two of the intervention focused on the *community participation context* domain of the model and aimed to increase participants' awareness of the communities around them. After review of the previous week and discussion about what a community is, participants discussed what communities are available to them. The group leader generated a list of the communities participants discussed on a large sheet of paper and hung it for participants to refer back to during the group activity. Next, participants created community maps that included communities that participants identified as members of and communities participants wanted to identify as members of. Each community map was developed from a handout that included the individual in the middle, with concentric circles around the individual. Participants placed their communities onto the community map according to how connected they felt to each community. Communities they felt closest to were placed in the first concentric circle, while others were placed in outer rings. Group participants also identified how safe they felt within communities by shading the community with green (safe), yellow (safe most of the time), red (not safe). Participants shared their community maps with the group and the group leader facilitated a discussion around this theme.

The theme of the second week, community context, was guided by the proposed community participation model. The activity facilitated awareness of communities available to individuals and methods to assess those communities and opportunities based on sense of safety and belonging. This activity is part of the assessment process an individual undertakes in evaluating the multiple *opportunities* available to them in different *community contexts*, similar to the proposed community participation model.

Week three of the intervention focused on the *activity* domain of the model and participants identified qualities of community participation activities. A review of the nature of

activities, a discussion about how activities change based on the context, and individual self-reflection were focuses of the group. Community activities were posted on signs throughout the room. Participants were provided descriptions such as “active,” “quiet,” and “with others” that they attached to each activity. The group leader facilitated a discussion about what characteristics were associated with each activity and why. Participants also assessed the fit between their values, skills, and goals for community participation with qualities of community participation opportunities and activities.

The week three activity continued to teach the *self-assessment* process that is included in the community participation model. Participants assessed another area of the model, *activities*, and compared it to their own values, motivations, experiences, and skills. The concepts in week three continue to build the assessment process.

Week four of the intervention included planning a community participation activity, problem solving potential barriers to participation, and appraising the potential outcomes. The group included reviewing previous concepts discussed and identifying a community participation goal. The participants then drew a picture representing participation in their community participation goal and discussed the potential positive effects of community participation. Participants also discussed possible barriers and provided feedback to each other, with guidance from the leader, about how to manage the barrier. The activity facilitated assessment of all three domains of the model as it related to each individual’s community participation goal.

The week four activity focused on the active engagement in *community participation* and the *feedback* process of the model proposed in Chapter II. In the model, feedback, both positive and negative, impacts the individual, the context, and the opportunities. The week four activity

focused on recognizing the feedback signs. The feedback can be internal, such as positive feelings toward self, or external such as helping others.

### **Participants**

A convenience sample of young adults with IDD who were enrolled in a specific post-secondary education program located in a Midwestern city were recruited. The post-secondary program is a three-year education program designed to meet the transitional needs of young adults (ages 18-28) who have been diagnosed with intellectual, learning, or developmental disability. Criteria for enrollment in the post-secondary education program include that individuals have been identified as having a high probability of difficulty if they were to be enrolled in a standard college curriculum, even with the provision of support services and accommodations. Students enrolled in the program also must have the capability to manage medication with limited support, be able to live in a residential setting safely without adult supervision, be interested in and able to participate in group learning, and have family members who are actively involved. From the total population of 24 young adults enrolled in the post-secondary program, 5 young adults and their parents consented for the students to participate in this study.

### **Procedure**

Young adults enrolled in the post-secondary education program were informed about and invited to participate in this study via flyers in their dorm area, personal invitations by the research team, and invitations from program residential staff. In response to interest, the young adults and their guardian(s) were invited to a meeting with the PI for further explanation and to complete informed consent.

After consent was obtained, participants met with a research assistant and completed the Adolescent and Young Adult Activity Card Sort (AYA-ACS; Berg, McCollum, Cho, & Jason, 2015). After completing the AYA-ACS assessment, participants were enrolled in weekly one hour group intervention sessions for 4 weeks. The PI led the intervention sessions in a common room of the dormitory on a weekday evening for 4 weeks. After the 4th week of the intervention, subjects met with a research assistant again and completed the AYS-ACS and answered questions about their experience as part of the pilot intervention. Participants received a \$10 gift cards for completing the pre and post intervention assessments and a \$10 gift card for attending all intervention sessions.

The research assistants engaged in 3 hours of training to administer the AYA-ACS prior to beginning the study. The training included reviewing the assessment guidelines, administering and scoring the assessment on each other once, and finally administering and scoring on a young adult with IDD not enrolled in the study. The research team discussed the challenges to administering the assessment, including keeping the cards organized and recording the results. The PI provided feedback about the research assistants' assessment administration and developed a common script for introducing the assessment and prompting responses.

### **Outcome Measures**

**Adolescent and Young Adult Activity Card Sort (AYA-ACS).** The AYA-ACS is an assessment of participation in everyday activities developed for individuals between the ages of 18-25 years (Berg et al., 2015). The assessment includes 70 items divided into seven domains: Chores, Leisure, Social, Education, Work, Health and Wellness, and Parenting. The evaluation process requires the participant first sort's pictures of each of the items from each domain into categories of "yes" and "no" in response to the question: "Have you participated in this activity

in the past 6 months?” Next, the participant sorts the pile of “no” responses into “I want to, I’m interested” and “I don’t want to, I’m not interested.” If participants respond that they are not participating but interested, they were prompted to identify a barrier to participation from a list of barriers provided. The AYA-ACS has demonstrated moderate to excellent test-retest reliability,  $k = .48-.85$ , in all domains except parenting (Berg et al., 2015). Moderate strength correlations between domains of the AYA-ACS and subdomains of the Vineland-II with a sample of young adults with Autism Spectrum Disorder have been found (McCollum, La Vesser, & Berg, 2015).

Researchers initiated a slight modification to the assessment administration. Researchers presented each of the domain cards separately to the subject, handing only a limited number of cards to the subject at a time. Once the subject sorted the entire domain into “yes and “no” piles, the next set of domain cards was presented. The list of barriers was adapted from the original list provided with the assessment. The adapted list of barriers categorized and presented the barriers on one piece of paper. Researchers assisted subjects in reviewing and choosing barriers from the list provided. They were allowed to select as many barriers as they wished for each activity in which they expressed interest even though they had not participated in it. Participants completed all domains of the AYA-ACS except the parenting domain, as none of them were parents. The total number of activities presented to the participants was 63, within 6 domains.

**Post Assessment Questions.** Participants were also asked to provide responses to questions about their experience of the group intervention during the post intervention assessment. The questions were generated by the PI with the intent to gather qualitative information about the viability of the intervention. The three questions were asked by the research assistants after the subjects completed the AYA-ACS and their responses were written down by the research assistant.



## Data Analysis

Descriptive statistics were used to describe the participant characteristics. Only data from participants who engaged in both the pre- and post-test were included in the data analysis to enable before and after comparisons. Therefore, one participant was not included in the results. Frequencies were used to describe the activities the subjects most often identified participating in, not participating in, and not participating in but being interested in. The percentage of the total number of activities in each domain that subjects identified participating in and not participating in but being interested in was identified was calculated. This percentage was determined by calculating the average number of activities subjects identified as participating in within each domain and dividing that average by the number of available activities in each domain.

The Wilcoxon signed-rank test was used to compare the AYA-ACS scores for subjects before and after the intervention. Scores were compared for the total number of activities across all domains subjects reported participating in (*participation*), before and after the intervention. Additionally, data about number of activities subjects reported participating in were combined with data about the number of activities subjects expressed interest in participating in to create the variable *participation plus interest*. The raw data for *interest in participation* were based on frequency counts for activities an individual indicated he or she is not participating in first. Therefore, if the interest in participation data were viewed independently, it may appear that interest decreased, but in reality it could be a result of the subject increasing participation, leaving fewer cards in the interested but not currently participating pile. The Wilcoxon signed-rank test, a non-parametric test, was chosen because the data did not meet the assumption of normality and the sample size was small. In addition to completing the Wilcoxon signed-rank for

participants across all domains, the leisure and social participation domains were each evaluated separately as well. The activities within the domains of leisure and social activities most closely reflect community participation activities, therefore they were considered individually. Effect sizes for the difference in before and after intervention on measures of *participation* and *participation plus interest* were calculated for results across all domains and specific to the leisure and social domains. Statistical analysis was performed using SPSS version 23.

## Results

All five subjects completed the AYA-ACS pre-intervention assessment. One participant left the educational program and this study; therefore, four of participants completed the intervention, the AYA-ACS assessment and provided responses to questions about their experience participating in the intervention. Of the four participants who completed the study, two completed all intervention sessions, one completed three of the sessions, and one completed two of the sessions.

The activities that subjects most frequently identified as participating in within the past 6 months, not participating in, and not participating in but being interested in are located in Table 1. Separate columns are provided for pre and post intervention.

The average number of activities the sample identified participating in, not participating in, and not participating in but being interested in was calculated. Based on the average for the sample, the percentage of activities subjects reported engaging in as compared to the total number of activities available in the AYA-ACS was calculated for each domain. Figure 3 presents the percentage of total available activities in each of the AYS-ACS domains that subjects reported participating in. Decreases in participation in domains of work, education,

Table 1

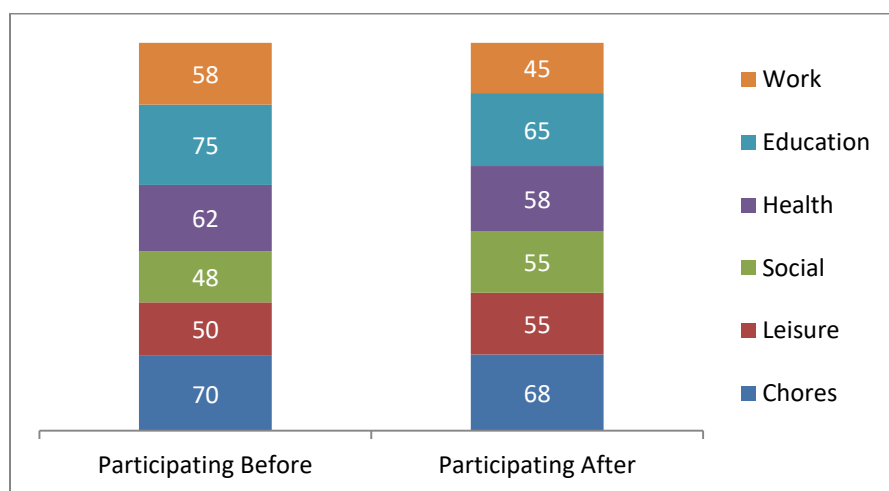
*Activities All or Most Subjects Identified Participating in, Not Participating in, and Not Participating but Interested in, Before and After the Intervention*

Before Intervention ( <i>n</i> )	After Intervention ( <i>n</i> )
<i>Participating in:</i>	<i>Participating in:</i>
Chores	Chores
Shopping (4)	Shopping (4)
Laundry (4)	Laundry (4)
General household chores (4)	General household chores (4)
Cleaning the bathroom (4)	Cleaning the bathroom (4)
Taking public transportation (4)	Taking public transportation (4)
Helping others (4)	
Leisure	Leisure
Surfing the internet (4)	Surfing the internet (4)
Watching TV (4)	Watching TV (4)
Listening to music (4)	Listening to music (4)
	Caring for a pet (4)
Social	Social
Calling/Texting/Social media (4)	Calling/Texting/Social media (4)
Meeting new people (4)	
Health and Wellness	Health and Wellness
Getting a full night's sleep (4)	Getting a full night's sleep (4)
Caring for self/Hygiene (4)	Caring for self/Hygiene (4)
	Eating health foods (4)
Education	Education
Using a computer for schoolwork (4)	Using a computer for schoolwork (4)
Paying attention to a lecture (4)	Completing Schoolwork(4)
Completing schoolwork (4)	
	Work
	Following worksite rules/regulations (4)
	Getting along with coworkers (4)
<i>Not participating in:</i>	<i>Not participating in:</i>
Chores	Chores
Paying bills (4)	Driving (4)
	Paying bills (4)
Leisure	Leisure
Playing an instrument (4)	Playing an instrument (4)
Going to a place of worship (4)	Going to a place of worship (4)
Praying/Spiritual reflection (4)	

Table 1—Continued

Before Intervention ( <i>n</i> )	After Intervention ( <i>n</i> )
<i>Not participating in:</i>	<i>Not participating in:</i>
Social Entertaining friends(4) Playing a team sport (4)	Social Playing a team sport (4)
Health and Wellness Addressing personal health (4)	Health and Wellness Addressing personal health (4)
Work Meeting physical demands of job (4)	Work Using work technology/equipment (4) Keeping up with work tasks (4)
<i>Not participating, but interested in:</i>	<i>Not participating, but interested in:</i>
Chores Driving (3)	Chores Driving (4) Paying bills (3)
Leisure Playing an instrument (3)	Work Applying for a job (3) Meeting work demands (3)
Social Entertaining friends (4)	

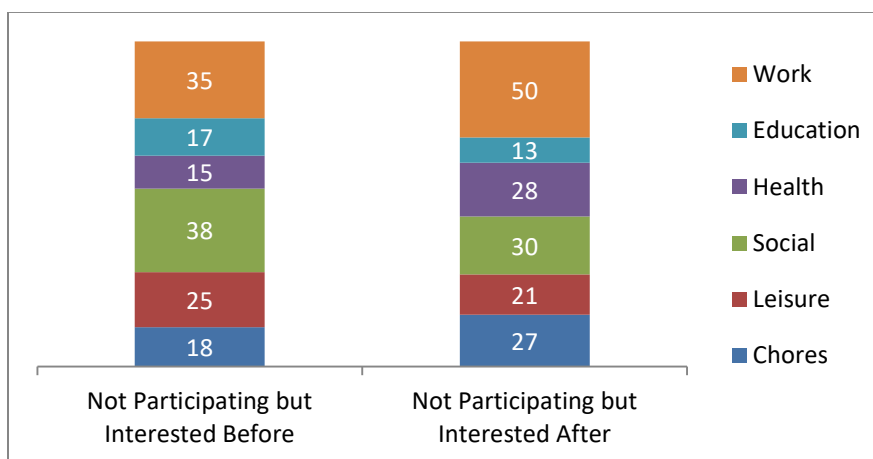
*Note.* *n* = the number of participants who categorized the activity in this way.



*Figure 3.* Percentage of Total Domain Activities Subjects Reported Participating in Before and After the Intervention

health, and chores were noted after the intervention, along with increases in domains of social and leisure participation after the intervention.

Figure 4 includes the percentage of total domain activities that participants indicated they were not participating in but were interested in. Of the domain activities that subjects were not participating in but interested in participating in, an increase was noted in domains of work, health, and chores, while decreases in domains of social, leisure, education, chores were noted after the intervention.



*Figure 4.* Percentage of Total Domain Activities Subjects Reported Not Participating in, but Interested in Before and After the Intervention

The barriers to participation in activities that participants were not participating in but were interested in were identified before and after the intervention. Prior to the intervention, the top barrier identified was “Never had the chance.” After the intervention the top barrier identified was “Difficulty with scheduling.” Results of the most frequently identified barriers to participation as identified by all subjects are displayed in Table 2.

Table 2

*Barriers to Participation for All Activities*

Barrier	Before <i>n</i> (%)	After <i>n</i> (%)
Never had the chance	9 (13%)	10 (13%)
Difficulty with scheduling	5 (7%)	12 (15%)
Feeling nervous/scared	6 (9%)	8 (10%)
Too tired/low energy	2 (3%)	5 (6%)
I forget to do this	4 (6%)	0 (0%)
Need help from others to do this	0 (0%)	5 (6%)
No one to do this with	5 (7%)	4 (5%)
Others do it for me	4 (6%)	2 (3%)
Difficulty remembering	3 (4%)	1 (1%)

*Note.* Before *n* = 67; After *n* = 80.

Results of the Wilcoxon signed-rank test showed no statistically significant difference in the total number of activities subjects reported participating in before and after the intervention, and specifically in the domains of leisure and social activities. The total number of activities subjects engaged in prior to the intervention was not significantly more than the total number they engaged in after the intervention,  $z = -.55$ ,  $p = .58$ ,  $r = -.19$ . The test statistic is based on positive ranks, indicating there were more positive than negative ranks in the calculation, indicating that there was a decrease in the total number of activities participants engaged in before and after the intervention. Participants did not *participate* in significantly more leisure activities after the intervention than before the intervention,  $z = -1.34$ ,  $p = .18$ ,  $r = -.47$ . The test statistic is based on negative ranks, indicating that the majority of ranks in the calculation were positive. Although not statistically significant, participants identified participating in more leisure activities after the intervention ( $M = 7.75$ ) than before the intervention ( $M = 7$ ).

Participants did not report significantly more *participation plus interest* in leisure activities after the intervention than before the intervention,  $z = -1.29$ ,  $p = .19$ ,  $r = -.45$ . The test statistic is based on negative ranks, indicating that the majority of ranks in the calculation were positive. Although not statistically significant, participants identified participating in and having interest in an average of 12 leisure activities after the intervention and an average of 10 before the intervention. Similarly, participants did not *participate* in significantly more social activities after the intervention than before the intervention,  $z = -1.09$ ,  $p = .28$ ,  $r = -.3$ . The test statistic is based on negative ranks, indicating that the majority of ranks in the calculation were positive. Although not statistically significant, participants identified participating in an average of 5.5 social activities after the intervention, as opposed to 4.75 social activities before the intervention. Participants did not report significantly more *participation plus interest* in social activities after the intervention than before the intervention,  $z = 0$ ,  $p = 1.00$ ,  $r = 0$ . The test statistic indicates that the sum of negative ranks was equal to the sum of positive ranks, therefore no difference in participation and interest in participation in social activities before and after the intervention.

Subjects were also asked to answer questions about their experience of the intervention to assess viability of the intervention. The responses of the four subjects who answered the questions are shown in Table 3.

Table 3

*Questions and Answers About the Intervention*

Researcher Questions	Participants' Answers
Tell me something that happened in the group or that you learned that was helpful to you.	<p>“She made me want to learn and do more activities in the summer”</p> <p>“What kind of communities there are. How to become a part of a community”</p> <p>“Learned to make choices with flashcards. It has helped me make good choices”</p> <p>“What is a community”</p>
What was the best part about the groups?	<p>“Learning about things I want to do more”</p> <p>“Learning about what communities people like. How people have different interests”</p> <p>“Meeting new people”</p> <p>“Community is a group of people- learning more- great OT”</p>
What made it hard to participate in the group?	<p>“Too tired”</p> <p>“Nothing. Maybe people not showing up”</p> <p>“Hard to stay focused”</p> <p>“People on their phones, its distracting”</p>

### Discussion

This study explored the impact of a pilot community participation intervention on community participation in young adults with IDD. Secondary goals of this study were to explore the ability to carry out the assessment and pilot intervention with this population. Results from this small pilot study indicate there was no statistically significant difference in the number of activities subjects reported as participating in before and after the intervention, although the numbers of activities mentioned after the intervention were trending in the hypothesized direction. There was also no statistically significant difference in the *participation plus interest* in leisure and social activities, although the number of leisure activities increased after the intervention. Subjects were able to complete the intervention and the assessment



process, although recruitment and retention were challenges. The low number of participants that completed the program may have affected the results, but this is difficult to ascertain because of lack of statistical power.

### **Effect of the Pilot Intervention**

Results indicate that no statistically significant changes in *participation* and *participation plus interest* occurred. Although not statistically significant, frequency counts of *participation* in domains of work, education, health, and chores were noted to decrease after the intervention; and frequency counts in domains of social and leisure participation increased after the intervention. This change may represent shifting priorities within the sample, to focus more on leisure and social activities. Also, there may be other variables that affected this including time of year. With regard to the *participation plus interest* variable, an increase was noted in frequency counts for leisure activities after the intervention, and no change in frequency counts for social activities were noted. Although not statistically significant, there was a trend toward increased participation in leisure and interest in leisure after the intervention.

These findings may reflect flaws in the research design including small sample size, leading to insufficient statistical power to detect change. Additionally, limited time between pre and post intervention measures and the ability of the AYA-ACS to detect changes may have impacted the results. The small sample size and the limited number of participants who completed the whole intervention resulted in limited data to analyze. The AYA-ACS was given within a 6-week time frame which resulted in limited time for participants to enact behavioral changes and increase their actual participation. Additionally, the outcome measure may not have been sensitive to changes within the sample, especially given the short time frame. The assessment was chosen partially because of the focus on both participation and interest in

participation, constructs represented in the community participation model proposed in Chapter II. These two concepts do not represent all the components in the model, indicating there are other components of community participation that can be studied. Currently there are not readily available tools for measuring other constructs related to community participation, for example, sense of belonging, in young adults with IDD.

Additionally, there are shortcomings with using self-report tools that lead to questions of reliability. For example, one participant indicated that he or she participated in driving within the past 6 months prior to the intervention. After the intervention, the same participant indicated that he or she had not driven in the past 6 months but was interested, raising questions about the validity of the participants' responses because they were only 5 weeks apart. Previous research about the ability of people with IDD to respond to interview questions indicates that most, but not all, can answer yes/no questions about their daily life (Stancliffe, Ticha, Larson, Hewitt, & Nord, 2015). While the reliability of answers may be questionable, there is evidence to support asking the individuals directly about their participation levels and interest.

Frequency counts also indicated that the profile of participation, interest, and barriers to activities changed after the intervention. This may reflect the subject becoming more aware of the concept of community participation, the opportunities available, and more critically considering the barriers to participation. The changes in the profile may also reflect changes in the temporal context, with students preparing to leave campus for the summer shortly after the conclusion of the intervention.

### **Viability of Intervention and Assessment**

The pilot intervention was a novel group approach to increasing meaningful community participation in young adults with IDD. Areas of strength included the participants' positive

responses to participating in the intervention displayed in Table 3. Also, the intervention was delivered in a group setting, providing an efficient format of intervention. The intervention was delivered without disrupting the essential elements of participants' daily routines (school, internships) and with minimal impact to the existing programming. The outcomes measure, the AYA-ACS, was administered without difficulty, although the reliability of responses was questionable. Previous research on use of the AYA-ACS on young adults with autism also supports participants' ability to complete the assessment. McCollum et al. (2015) used the AYA-ACS with a group of young adults with mild to moderate autistic spectrum disorder (ASD) per the Social Responsiveness Scale–version 2. Researchers found that there was congruence in answers about participation between the self-report from the young adults with ASD and other caring individuals who answered the same set of questions about the young adult with ASD. The sample in this study differed from that of McCollum and colleagues, but this study also demonstrates that the AYA-ACS can be administered with the population of young adults with IDD, which may include ASD.

Recruitment was a challenge to completing this study. The challenges that this researcher experienced reflect similar experiences other researchers have found with the population of adults with IDD. That is, previous researchers have identified that the consent process is often a barrier to recruitment for adults with IDD (Lennox et al., 2005). To address barriers to recruitment, Lennox and colleagues suggested engaging senior leadership and key personnel within organizations where the research occurs.

In this study the PI engaged program leadership and direct service providers in the planning, recruitment, and intervention stages of the research. Leadership within the post-secondary educational program expressed support of the project and assisted to coordinate

parental consent of the young adult participants. Program leadership acted as the primary contact for parents/guardians and the PI was available for additional questions from the parent/guardian, although none of the parents/guardians requested additional information from the PI. The key on-site direct service providers of the program were also supportive throughout the recruitment process by informing potential subjects about the project, hanging recruitment flyers, inviting the PI to attend dormitory meetings to recruit participants, and encouraging participation individually with potential subjects.

Another recruitment strategy that is recommended when a researcher is working with this population is to hold “insider” status within the group being recruited (Lennox et al., 2005). The PI and research assistants were previously known to the majority of the sample population. Prior to the recruitment phase, the PI and two members of the research team spent time with several members of the sample population on a different project. Additionally, the PI made several recruiting visits to the dormitory to develop relationships and possibly increase interest in the study. The research also occurred in the evenings, so as to not interfere with previously scheduled responsibilities (school, internships) and occurred at the participants’ dormitory. This attempt to work around the constraints of the participants is also supported by Lennox and colleagues.

Despite efforts to incorporate suggestions from previous researchers about recruitment of this population, recruitment did not proceed as anticipated. The recruitment time frame was extended by 3 weeks and additional strategies were implemented, including offering candy and gift cards to participants for completing aspects of the study. Participants were provided a \$10 gift card for participating in all four group sessions, and a \$10 gift card for completing the pre and post intervention assessment sessions. The PI obtained an amendment to the IRB approval

in order to offer the gift cards because this was not part of the initial strategy. Still, these efforts results in only 20% of the potential subjects enrolling in the study.

An additional challenge to the study was retention. One participant left the post-secondary program during the intervention phase due to leaving campus early related to an issue unrelated to the pilot intervention. Other participants did not attend all four sessions of the intervention because of competing priorities including visits to their parental home or spending time with a significant other. The strategic offering of gift cards for completion of all sessions appeared to be a motivator for at least one of the participants who asked about it frequently. Temporal aspects of the study may also have impacted recruitment and retention. The intervention groups occurred toward the end of the academic year, at a time when students may have been focused on completing their academic experience and moving out of the dormitory/graduating from the program. Also, the intervention groups occurred from 8–9 p.m. and participants reported feeling tired at times. Strategies suggested by Lennox et al. (2005) were helpful in planning for recruitment, but researchers still encountered challenges to engaging this population in research activities.

### **Limitations**

There were several limitations to this research study, as indicated earlier. The small sample size, lack of control group, and a sample derived from one specific program impact results and generalizability of the study. Participants in this study represent a small portion of the population of young adults with IDD and even a small proportion of eligible participants in the source program.

There is not a specific measure of community participation for young adults with IDD. The AYA-ACS was chosen because, in addition to a measure of participation frequency, the

assessment also includes measures of desired participation. Also, successful use of the tool was found in a previous study with a sample of young adults with similar characteristics to this sample (McCollum et al., 2015). The review of literature about community participation indicates that community participation is a complex concept that is difficult to measure in this population (Bogenschutz et al., 2015; Mahar, Cobigo, & Stuart, 2014; Milner & Kelly, 2009). The AYA-ACS may not have captured improvements in other aspects of community participation including sense of belonging within communities.

### **Future Research**

Future research about the viability of the pilot intervention can include a broader sample population with individuals from similar post-secondary programs, or young adults not enrolled in post-secondary programs. Additionally, changes to the research design would include changes in the timing, setting, and parental consent procedures to increase the numbers of participants who might accept the invitation to participate. It might also be easier to detect meaningful changes if longer term follow-up measures were employed, and a control group can provide increased data for consideration. Outcome measures that consider other aspects of community participation constructs also can be used to investigate the effects of the intervention.

### **Conclusion**

Young adults with IDD express the desire to be active members of their communities. This pilot study identified that it is possible for young adults with IDD to engage in a self-report assessment tool such as the AYA-ACS, and it is possible for them to engage in a group based intervention based on Cole's (2012) group process. Although not statistically significant, participants verbalized positive responses to the intervention experience. It is recommended that researchers employ special consideration in order to achieve research design requirements, with

a special emphasis on recruitment and retention. This study contributes information to the literature about the impact of interventions focused on individuals, not only contextual issues. Future research should continue to explore the effectiveness of these types of interventions.

## **CHAPTER IV**

### **THE EXPERIENCE OF COMMUNITY PARTICIPATION AMONG YOUNG ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES**

#### **Introduction**

Involvement in community-based leisure and social activities has been shown to improve quality of life and physical health for people with IDD (Channon, 2014; Garcia-Villamizar & Dattilo, 2010). The benefits are known, but research has shown that adults with IDD are more socially isolated and not as involved in their communities compared to other disabled and non-disabled peers (Bigby, 2008; Dusseljee et al., 2011; Milner & Kelly, 2009; Verdonschot et al., 2009). Although improvements in inclusion of people with IDD within communities have occurred, full participation in communities has not been realized.

#### **Community Participation Defined**

Recent descriptions of community participation among people with disabilities emphasize the individual's perceptions of community participation including his or her values, motivation, and perception that he or she is part of a community (Amado et al., 2013). Based on a review of the literature regarding community integration of people with disabilities, Cummins and Lau (2003) concluded that community integration of people with disabilities should not be viewed simply as being present within communities, but should involve an individual's subjective "sense of community" and feeling part of a social structure (p. 154). Delree (2011) identified that community is not just a physical location, it is also "the experience of sharing one's life with other people" (p. 47). As a result of conducting focus groups with individuals with diverse disabilities, Hammel et al. (2008) identified the themes, "being a part of" and



“enfranchisement” (feeling of being a part of) as core participation values. In a literature review of measures of belonging, Mahar et al. (2014) described the concept of belonging as intrinsic to social inclusion. They defined the sense of belonging as “a subjective feeling of value and respect derived from a reciprocal relationship to an external referent that is built on a foundation of shared experiences, beliefs or personal characteristics” (p. 1026). These findings demonstrate the importance of considering individualized meaning of community participation in defining, measuring, and promoting community participation.

Another important aspect of understanding community participation is recognizing that community participation is often defined in terms of the dominant culture. This can result in judgments about the individual’s ability to achieve the norms of the dominant culture and measurement of achievement based on the dominant culture’s values, not the individual’s sense of belonging (Cobigo et al., 2012). In a participatory action study of the perceptions of adults with IDD regarding community participation and inclusion, Milner and Kelly (2009) gathered data from focus groups, interviews, and self-authored narratives of adults with IDD. The authors found that a sense of participatory belonging emerged from opportunities that included engaging in activities that were self-chosen, occurred in places and with people they felt “known” by, and included opportunities for reciprocity in interactions. Milner and Kelly also found that it is important to consider the individual’s perspective, including acknowledging the risks an individual may associate with community participation, as defined by dominant culture, when promoting community participation for individuals with disabilities. Efforts to measure and facilitate community participation with people with IDD should consider the individual’s subjective experiences of participation and use measurements based on the individual’s perspective, not the culturally defined expectations of participation.

## **Transition to Adulthood**

The transition from adolescence to adulthood can be particularly challenging for young adults with IDD. When individuals with IDD reach adulthood, they no longer have access to the range of support services, including transition services, to which they were entitled under the Individuals with Disabilities Education Improvement Act (IDEA; Frink, Whitmire, & Bogdan, 2015; U.S. Congress, 2004). Although policy and legislative changes such as the Americans with Disabilities Act (1990) and the Olmstead Supreme Court Decision (1999) support the right of people with disabilities, including adults, to be integrated within their communities, research shows that individuals with IDD continue to be more isolated than non-disabled peers (Verdonschot et al., 2009).

Opportunities for adolescents and adults with IDD to enter post-secondary education programs in the U.S. have increased, but many programs continue to utilize non-inclusive practices, despite their statements that they value inclusion (Jones et al., 2015). Facilitating transition to the multiple roles and responsibilities of adulthood is a complex process due to challenges in the contexts and personal characteristics of individuals with IDD that require supports (Alverson, Lindstrom, & Hirano, 2015; Cheak-Zamora, Teti, & First, 2015).

## **Community Participation in Young Adults**

There are few studies examining the experience of community participation in young adults using qualitative methods. Van Asselt et al. (2015) explored enablers and barriers to social inclusion specific to young adults with intellectual disabilities using qualitative analysis of interviews of four young adults and their families. These authors identified themes impacting social inclusion that included self-determination, naturally occurring friendships, participant engagement and interactions, organizational process factors, and social acceptance; but the

authors recommended increasing the sample size for future research, and including more probing questions. Authors of another study of young adults with intellectual disabilities and their caretakers found that the 253 young adults in the sample endorsed the item “increased community activities” as one of the top items participants believed would improve their lives (Kampert & Goreczny, 2007). This study utilized pre-existing data from the Independent Monitoring for Quality, which included open-ended questions, but authors did not analyze participants’ responses to these questions. These two studies provided some insights into the unique experience of young adults with IDD, but an extensive understanding has not been achieved.

Despite advances in understanding and measuring community participation for individuals with IDD, gaps in the literature still exist, specifically related to the experience of young adults with IDD. Research evaluating community participation in adults with IDD often explores the presence of individuals with IDD within communities as a measure of participation or explores the type of participation activities people are engaged in (Crowe & Sedillo, 2015; Gray et al., 2014). Other studies have considered the environment and contextual influences on participation (Amado et al., 2012), gathered the perspectives of caregivers related to participation (Rossetti, Lehr, Lederer, Pelerin, & Huang, 2015), and explored the theoretical concepts related to community participation (Channon, 2014; Craig & Bigby, 2015; Cummins & Lau, 2003). What seems to be missing is information about the essential subjective experience of participation with a focus on young adults with IDD. Some studies have examined the lived experience of people with disabilities in general, including people with physical disabilities, related to community participation (Hammel et al., 2008), but generalizing the results to young adults with IDD is a challenge. Other qualitative research about the experience of people with

IDD and community participation does not focus on the unique experiences of young adults and either includes a sample of only middle to older adults (Craig & Bigby, 2015), or includes young adults as a small part of the sample and does not look specifically at data related to young adults (Qian et al., 2015). The purpose of the current study was to understand the subjective lived experience of community participation in young adults with IDD. The research question was: What is the lived experience of young adults with IDD related to community participation?

## **Methods**

### **Research Design**

This study was conducted using a phenomenological research design to understand the community participation experiences of young adults with IDD. Phenomenology-based research results in the description of an experience that is shared by a group of individuals, which can lead to a deeper understanding of the phenomena (Creswell, 2013). Phenomenology captures the experiences of a group of people, appreciating each individual's subjective experience while recognizing the more objective experience of the phenomenon that is shared by others. The description of the experience is formulated through gathering data (often through interviews) from individuals who have had the experience, reviewing the data with as little bias as possible, identifying significant statements in the data, describing clusters of statements that emerge into themes, and the providing a composite description of the essence of the phenomena. The research design in this study followed Creswell's (2013) approach to phenomenological analysis. Creswell's approach provides a structure for approaching and completing research and takes an inductive approach to the data. It is based on psychological phenomenology in which the analysis is focused less on the researcher's interpretations and more on the participant's descriptions. The six step process included:

1. Each research assistant described his or her own experience with people with IDD and community participation, in an attempt to set aside personal biases;
2. The researcher assistant and primary researcher reviewed the written transcripts and developed a list of significant statements, writing each statement on a notecard;
3. Significant statements were grouped into larger units of information or themes;
4. The primary assistant wrote a “textural description,” which is what the participants experienced related to the phenomenon, and included examples;
5. The primary researcher wrote a “structural description,” which is how the experience happened;
6. The primary researcher wrote a composite description of the phenomenon incorporating both the textural and structural descriptions.

Each participant participated in an individual semi-structured interview about his or her community participation experiences. The research team consisted of the principal investigator (PI) and four research assistants who are working toward their graduate degree (Master of Science) in occupational therapy at an urban private Midwestern university.

### **Sample**

The sample for this study was a convenience sample of young adults with IDD recruited from a post-secondary residential education program located in a large Midwestern city. The inclusion criteria for participation were (1) being enrolled in the post-secondary educational program, and (2) residing in the dormitory of the post-secondary program. Criteria for enrollment in the post-secondary education program included being a young adult (18–28) with a learning, or developmental disability who, if enrolled in a standard college curriculum, would have a high probability of difficulty, even with accommodations. To enroll in the post-secondary

education program, the young adult must have the capability to manage medication with limited support, be able to live in a residential setting safely with minimal adult supervision, have family members who are actively involved, and be interested and able to participate in group learning. The program does not use standardized test scores such as Intelligence Quotient (IQ) to categorize students. The program views students' functioning holistically and bases admission off of multiple factors. All 24 students enrolled in the post-secondary program were invited to participate in the study.

### **Recruitment**

Potential subjects and their legal guardians were recruited through flyers in the dormitory area, personal invitations by the research team, and invitations from program residential staff. Consent for this study was obtained along with consent for participation in the pilot intervention study discussed in Chapter III. In response to their interest, the young adult and his or her guardian were invited to an individual meeting for further explanation of the study and to complete the informed consent. All participants had a legal guardian; therefore none of the participants was able to give consent independently. Program staff assisted in gaining guardian consent because guardians were off site. All participants provided assent and their legal guardians provided consent to participate in the study. Participants were compensated with \$10 Target gift cards for completing the interview. Recruitment, enrollment, and methods for this study were approved by Rush University's Institutional Review Board and Western Michigan University's Human Subjects Institutional Review Board.

### **Interview Protocol**

The PI developed a semi-structured interview protocol that included seven main questions with several follow-up questions. The protocol included a combination of open-ended

and yes/no questions about community participation experiences. The main questions are included in Table 4; the full interview protocol, including the scripted introduction, can be found in Appendix D. The interview questions asked about general concepts of the proposed community participation model proposed in Chapter II, but because the research was designed to be inductive, specific language and directed questions at each of the model components were not included. The interview protocol was developed by the PI with input from two occupational therapists with expertise in qualitative research and a speech-language pathologist who has expertise in the communication needs of people with IDD. The interview questions were also evaluated for readability, to ensure participants could understand the questions. The Flesch-Kincaid readability scores for each of the main interview questions were obtained from a free, online source (<https://readability-score.com/text/>). The readability analysis indicated that questions ranged in Flesch-Kincaid grade levels between .5 (Kindergarten) and 8.5 (Eighth grade). The interview protocol directed participants to consider communities other than the post-secondary education program they were enrolled in because the post-secondary program provides students with an enriched residential community and structured leisure activities. Researchers felt that excluding this community from responses would facilitate discussion of other types of naturally occurring communities. Full interview protocol can be found in Appendix D.

Table 4

*Interview Protocol Questions*

Question	Relationship to Model
1. What other communities do feel you are a part of? Of all the communities you are a part of, which one is the most important to you?	Community Context Self-Assessment
2. Do you feel relaxed when you are involved in activities in _____ community? What helps you feel relaxed? Do you feel safe when you are involved in activities in _____ community? What helps you feel safe?	Facilitators of Participation
3. What are the things that make it hard to be a part of _____? What things make you feel unsafe in _____ community?	Barriers to Participation
4. What other communities do you want to be a part of but are not? Why do you think it is that you are not a part of _____ community?	Self-Assessment
5. Do you make your own decisions about what communities you are a part of? How do you feel about making/not making your own choices?	Self-Assessment Feedback
6. How do you give back to your communities?	Feedback, Opportunities
7. Is there anything else you want to tell me about your participation in communities outside of [Educational Program]?	

**Data Collection Procedures**

The PI completed an individual interview with each participant using the interview protocol to guide each interview session. The interviews lasted between 20 and 35 minutes and were recorded. The interviews occurred in a quiet, private space at the program dormitory. The PI followed the interview protocol and added probing questions to further explore responses. The interviews were transcribed into Microsoft Word by the PI for analysis by the research team. Research assistants were not aware of the community participation conceptual model proposed in Chapter II, although they completed a review of the literature related to community participation



in young adults with IDD. The PI did not inform research assistants of the model in an attempt to maintain an inductive approach to the data analysis.

### **Analysis Procedures**

For analysis, the research team followed Creswell's (2013) approach to phenomenological data analysis and representation as described earlier. All members of the research team completed step one by describing their experience of people with IDD and their own experiences of community participation in an attempt to bracket personal experiences during data analysis. Research assistants completed a 2-credit-hour course on qualitative research prior to engaging in this research project. The PI provided specific instructions to the research assistants prior to data analysis procedures commencing.

The PI and two teams of two research assistants each reviewed transcripts independently. During this phase, the PI and each team of research assistants identified significant statements in the transcripts by highlighting the transcript, and then wrote each statement on an individual index card. Next, the PI and the two research assistant teams independently grouped significant statements into units that represented themes. During a 3-hour meeting of the research team, the two research assistant teams presented the themes and significant statements they discovered to each other. The two research assistant teams then worked together to re-organize significant statements into new themes that were created by collapsing the two lists of themes together. During the research assistant team data analysis, the PI served as a resource on the process of data analysis, provided information on the experience of the individual interviews, and facilitated discussions of conflicting views on the data and themes. The next 2-hour meeting continued the iterative process in which the research assistants and the PI reviewed the themes identified in the last meeting, and then reviewed the themes identified independently by the PI. The research

team worked together to re-organize and group significant statements into themes. During this meeting the research team attempted to refine the previous list of themes and collapse themes where appropriate. Another 3-hour meeting occurred and the research team continued to refine themes and attempt to collapse the data. Research assistants also identified 1–2 significant statements they believed best represented each theme identified.

The PI completed the textural and structural descriptions for each theme. The textural descriptions included a description of what the participants experienced and significant statements from the analysis that support the description. The structural descriptions included a description of context or setting that influenced how the participants experienced the phenomenon. Statements from the analysis were also included to support this description. The PI compiled these two descriptions to develop a statement of essence. The research assistants reviewed the essence statements and provided feedback to the PI, which was incorporated.

## **Results**

Five subjects were recruited, three females and two males, with an age range of 20 years to 26 years. Three of the participants were enrolled in their first year of the post-secondary educational program and two were enrolled in their second year. One of the female participants left the residential program and did not complete the interview, resulting in a sample of 4 participants (see Table 5).

Table 5

*Sample Characteristics*

Participant	Gender	Year in Program	Most important communities
1	Male	2	Family, Hometown
2	Male	1	Family, Sports (special recreation)
3	Female	1	Nature Center, Horseback riding
4	Female	2	Family, Gymnastics

From the four verbatim transcripts, 116 unique significant statements were identified. Research teams identified 8 themes during the first collaborative process of research teams working together. At the conclusion of this first session in which themes were identified, there were several significant statements that research assistants were unable to classify and these statements did not fit together into an independent theme. The next iteration of data analysis occurred between the research assistants and the PI and the research team identified 15 themes, but continued to have a few significant statements that were not included in themes. Researchers reviewed and discussed the 15 themes and collapsed the list of themes from 15 to 9 during a subsequent meeting and were able to categorize all significant statements. The evolving themes from each iteration are listed in Table 6.

Table 6

*Themes at Each Stage of Analysis*

First Iteration – Two teams of two research assistants	Second Iteration – Research assistants and PI	Third Iteration – Research assistants and PI
1) Family as community	1) Family as a community	1) Family as a community
2) Support from family and others	2) Support from family	2) Support
3) Physical safety is a concern	3) Support from others	3) Physical safety
4) Scheduling as a barrier	4) Physical safety	4) Logistics
5) Identifying with old communities	5) Logistics	5) Identifying with old communities
6) Communities would like to join	6) Identifying with old communities	6) Desired futures
7) Actively engaged in communities	7) Desired future	7) Presence of an activity
8) Good feelings	8) Presence of an activity	8) Understanding context
	9) Positive self feelings as an outcome	9) Positive outcomes
	10) Helping others	
	11) Knowing the environment – Physical	
	12) Knowing the environment – Roles, society	
	13) Leads to independence	
	14) Avoidance of negative experiences	
	15) Autonomy	

### **Theme 1: The Need for Physical Safety**

All participants discussed a need for physical safety during community participation outside their home/residence. Much of the discussion about physical safety stemmed from the interview questions about what helped participants feel safe and unsafe in their communities. The presence of equipment to maintain safety during activities in the community was discussed several times and included references to items such as helmets for baseball and gloves for planting. Participant 4 discussed how perceived neighborhood safety enabled her to go to the park and play with other children past dark when she was younger. Also in relation to physical safety, the presence of individuals in the community to ensure safety was also described by participants. Participant 3 described her experience of participating in her horseback riding community and stated she feels unsafe “whenever there is not a person next to me at the horse, just in case something happens.” Participants also discussed feeling unsafe in communities if they anticipated physical injury. Participant 4 broke her leg while doing gymnastics in high school. She described a fear of breaking her leg again doing gymnastics and reported she quit her gymnastics team as a result, even though the doctor said she could still participate and she identified her gymnastics team as a valued community. Participant 2 also identified that he feels unsafe in his community of special recreation sometimes because of the potential to get hurt. The theme of physical safety came up outside of the specific questions about safety as well. When she was describing the challenges to being a part of her extended family, participant 4 stated that when she argues with her family members “it’s scary cuz we get into each other’s faces.” All participants discussed the theme of physical safety, indicating it is something they consider as a part of community participation.

## **Theme 2: The Need for Support**

Participants discussed the presence of supportive people facilitating their involvement in community activities. Participants discussed this most often in response to questions about what helps them feel safe in their communities. Supportive individuals were recognized both within the family context, but in other community contexts as well. All participants expressed strong ties to family members and expressed a feeling of being protected and safe with their families. Participant 2 stated, “I know my family’s always there for me,” and “just talkin’ to my, um, family. When I do helps me relax, and yeah. About good days and bad days” when discussing what helps him feel comfortable with his family. In response to the question, *What helps you feel safe in your family community?* Participant 1 stated, “That they are next to me,” referring to his parents. Participant 3 shared how her mother encourages her to participate in activities by stating, “At first I’m afraid I’m not good. I’m, I’m like scared at first. But I think about it and we talk about it and, and I, um, say ‘yes I want to do this.’” Participants discussed how others outside their family are emotionally supportive including coaches, friends, and bosses. Participant 4 stated, “The coaches, you know, love me. I, they don’t love me, but they know that like I can be their support and team mate.” Participant 4 also talked about her old gymnastics team mates hugging her and asking how she was when she attended a gymnastics meet for her sister after injury. Participants each discussed supportive people being present and encouraging them in community participation pursuits.

## **Theme 3: Presence of Activity**

When participants discussed participating in their communities, they frequently discussed the activities they performed within the community. Participants expressed feeling a part of communities based on the activities they participated in. Participant 2 stated that he participates

in his family community by “doing like chores around the house.” Participant 1 indicated that he contributes to his community by utilizing the library and “reading their books.” Other activities participants discussed included sporting activities, volunteering, going to museums, and bowling. Participant 3 defined her involvement with her community of friends by stating that they “see movies or go to lunch or hangout.” For three of the participants, one of the communities they identified as most important is a community based around a specific activity (horseback riding, gymnastics, and special recreation sports). As much as participation in activities helps participants engage in communities, participants expressed a sense of loss of community when the activity was no long available or they could no longer participate. Participant 4 stated, “I was devastated when I couldn’t be with my friends,” referring to her gymnastics injury that led her to quitting the team. Their descriptions of the experience extended beyond the activity to relationships with team mates and friends, but the participants’ connections to the communities were described through an activity.

#### **Theme 4: Logistical Challenges**

Participants expressed frustrations with logistical aspects of community participation related to schedules, routines, and locations of community participation. These were expressed mainly in response to the question about what made it hard to participate in communities. Adapting sleep habits and routines in response to community participation opportunities was identified as a challenge by participants 1 and 4. Participant 1 identified going to bed and waking up earlier made it hard to be a part of his family community. Participant 4 described how getting everything ready the night before her sister’s gymnastics meet, staying in a hotel, and waking up early made it difficult to be a part of the gymnastics community. Participants also reported that competing priorities in their schedules made participation in valued communities

challenging. Participant 3 stated, “It feels like I only get to [contribute to my community through volunteering] once in a summer” and clarified that this was because of her school schedule. She also stated that she is unable participate in her horseback riding community any more (one of her valued communities) because she is away at school can’t be present at the riding center on regular basis. Another logistical challenge a participant identified was getting to the communities the individual wished to engage in. Participant 1 stated that when he is in his hometown community attempting to go places like the library is difficult because “all the major landmarks are far away” and “I can’t walk to it, I don’t have a car, so I take the bus.” Although participants are interested in community participation, they are challenged to adapt their routines, schedules and transportation mode to be able to participate.

#### **Theme 5: Understanding the Community Participation Context**

Participants expressed that understanding the community context and what is expected within the context helped them feel comfortable and safe in their communities. Confidence was expressed in relation to knowing the context. Participant 1 stated, “I feel safe in a familiar setting,” and in response to a question about feeling unsafe in his hometown community he stated, “I know the routes,” referring to the bus routes to get to the library, implying that he did feel safe because he knew where he was going. Participant 4 discussed playing volleyball, an activity she stated she wants to engage in, but she indicated she doesn’t like to play outside of her own home because of a prior experience when she accidentally hit her uncle in the head with the ball. She stated, “If I do it at home I’ll be like, ‘I’m not afraid, I can do this.’” In response to a question about what is challenging about being part of his sports community, participant 2 stated that doing a new sport can be a challenge because “like getting to know the rules.”



Information helpful in understanding the context emerges from others providing the information about expectations and from observations and assumptions the participant makes. Participant 2 stated, “If they yell too much it might make you feel like, you know, I’ve done something wrong and maybe I should think it over and do it the right way next time.” Two participants identified expectations related to their context and discussed a desire to meet expectations. Participant 3 discussed her volunteer position at a nature center and stated, “Normally a lot of people talk there and I’m kinda out because I’m shy and I want to get more involved in talking to people.” Identifying the disconnect between abilities and expectations served as a motivator to participant 3, but other participants viewed it as a barrier to engaging in activities outside of familiar contexts. In response to the interviewer’s question about the possibility of her joining an intermural team on the larger college campus where the dormitory is located, she stated, “I figure, the [larger college campus community] people don’t really like us [students in the specialized post-secondary program]” and then stated “I do sports at home when I can be like, proud of who I am, around my family. If I do it at [college where program is located], I’ll be like ‘I’m not gonna do sports.’”

Frustrations related to the family context and expectations were expressed by one participant. Participant 4 discussed her experience of the conflict between the cultural context of being a young adult and the cultural context of her parents’ home. She stated that when she returns home in the summer between school sessions she has conflicts with her parents about how and where she spends her time. She stated, “My dad understands I’m 21 now, so when I get home for the summer, you, know, sometimes I’m not gonna be like calling my mom and dad. I’m just gonna be like going ahead.” But, she also stated she feels like her parents “are

controlling my life” and talked about how her mom asks many questions about where she is going and wants to receive text messages and pictures of where she is.

### **Theme 6: Family as a Distinct Community**

Family is experienced as an important and unique community to participants. Family communities included immediate family, but also extended family members such as aunts, uncles, and cousins. Three of the four participants identified that their family community was one of the most important communities to them. Participant 2 stated, “I am really happy to have a family,” and Participant 4 stated, “My family comes first.” Participants experienced family communities as supportive and encouraging. Participant 3 stated family was the most important community to him and indicated this is because “You wouldn’t be able to do the things that you do now” and “you wouldn’t be able to learn how to live on your own.”

Participants identified distinct features and expectations within their families. Participant 4 indicated that her family context has a distinct culture and rituals they engage in. She stated that when she is with her extended family “It just be so fun because everybody get together and we all, you know, laugh, we talk, and then we say prayers and we eat.” As noted earlier in comments from participant 1 about logistical challenges, being part of family community includes a routine and expectations that are different than the dorm/school community.

### **Theme 7: Identifying with Previous Communities**

Several participants discussed communities they are no longer a part of as valuable communities to them. Despite not actively participating in some communities, participants identified as being a part of those communities. Participant 4 stated “gymnastics is my life” and “even though I can’t do gymnastics anymore, I still can, I still can go and support my sister.” For some participants, loss of the community is eased by engaging in a modified way, including

as a spectator. Participant 3 identified horseback riding as one of the two most important communities to her. She also stated she doesn't do horseback riding anymore, but "I would like to go and watch my friend do it." Engaging in communities in a new way appeared to have meaning to the participants. Participant 4 stated, "I go set up, you know, uh, I will, you know, watch the girls practice. I will go with my mom and then just wait inside the place for my sister."

### **Theme 8: Positive Outcomes as a Result**

Participants expressed positive outcomes and experiences related to community participation. Some of the outcomes were related to the individual and others were related to helping others in their communities. Participant 2 stated that he likes being a part of his sports community "because I feel like I'm actually accomplishing something in life. I'm actually getting physical in my life." Participants expressed the experience of positive feelings such as feeling relaxed, calm, good, and having fun. Participant 2 spoke about horseback riding and stated, "Whenever I'm on the horse and I can feel the wind going through my face and I feel um calm." Participant 2 also spoke about how her involvement at the nature center helps her meet new people, which she is happy about.

Participant 4 discussed volunteering at a homeless shelter with her mom and sister and stated, "it felt good. I feel like I'm a give back person." This was in response to the question about how she gives back to her communities. Other times, unprompted to speak about her contributions to her communities, she spoke about how important supporting her sister's gymnastics career is: "That's what I'm here for, I'm here for her." Participant 3 also mentioned helping her community as a result of her volunteer work at the nature center: "And I get to plant flowers and cut weeds and cut old trees and plant new ones to help the environment."

Two of the participants did not appear to understand the direct question about how they give back or contribute to their communities. Participant 1 indicated that he gives back to his home town community by using the library; he stated “I read their books.” Participant 3 did not appear to understand the question and in response to the interviewer’s prompt about “sharing” with her community, she stated she tells her uncle about what she is doing. Although she did not directly answer the question, themes of contributing emerged in response to other questions, as noted above in her response about helping the environment through volunteering.

### **Theme 9: Desired Future Participation**

Participants envision futures that include community participation in old and new communities. Participants expressed a desire to be involved in their communities and viewed community participation as important to meeting other life goals. Participant 2 stated, “You want to help your community and be a part of working because you need work experience for the future.” Participants also expressed hope around future community participation and have visions for their futures. In response to the question about communities they would like to be a part of but are not, three of the participants answered without prompting, and one was able to identify an activity with prompts.

Participant 1 needed prompting to identify a community and indicated he liked bowling when he was in high school and isn’t sure why he stopped doing it. Participant 2 stated he wanted to be involved in the cooking community and “learn how to like, prepare food and uh, make it from scratch.” Participant 3 indicated she wanted to do more volunteer work with children at the nature center. Participant 4 stated she wanted to be on a volleyball team. Participant 4 also discussed, during other portions of the interview, getting married and having a family someday. Participants discussed community participation as a means to more

independence including through job acquisition, learning new skills, and establishing a family community of their own.

## **Discussion**

This study explored the experience of young adults with IDD related to community participation. The analysis of interview transcripts indicated that participants recognized distinct communities that they feel they are a part of, and expressed the desire to participate in communities now and in their future. The data analysis produced nine themes that categorized the responses to interview questions. Several of the themes reflect factors that influence community participation. Other themes reflected where and how participants experience communities.

### **Factors that Affect Community Participation**

Several factors that can impact community participation were identified in the analysis. These included *physical safety, support, understanding the community context, and engaging in an activity*. Several of these factors have been recognized in other research focused on people with disabilities in general and people with intellectual disabilities specifically. In their review of literature, Bray and Gates (2003) identified that safety in communities was a concern expressed by many. McClimens et al. (2014) interviewed adults with IDD about their community experiences and found that they identified safety as one of the two main concerns they expressed. Along with physical safety, another theme that emerged in this review was the presence of support, which has also been noted in other studies as well (Bray & Gates, 2013; Qian et al., 2014).

The theme of *understanding community context* relates to an individual's understanding and ability to meet the expectations in his or her communities. Subjects in this study expressed

the desire to meet those expectations, but also identified ways they avoid certain communities when they worry about meeting the expectations. Gaining an understanding of expectations either through education or experiences and checking in about perceptions of expectations may facilitate increased involvement in communities.

Presence of an *activity* was noted as a factor impacting community participation in this study. This finding is similar to findings from a 5-year observational study of moderately impaired adults with IDD. Craig and Bigby (2015) identified that the presence of an integrating activity facilitated active participation in communities. The factors impacting community participation noted in this study have been noted in other studies of community participation, indicating that the experience of young adults with IDD is similar to the broader population of adults with IDD.

### **Challenges in Young Adulthood**

Other themes align with the general experience of young adults during transitional years. The experience of transition into adulthood for young adults with IDD is similar to young adults without disabilities. In the theme, *understanding the context*, one participant discussed conflicts about her autonomy as a young adult. This participant's description of reconciling her family context and expectations, with her expectations of autonomy in young adulthood may be similar to non-disabled young adults' experiences. Although not specific to the theme of understanding the context, issues of creating new identities that challenge the transitional norms in families around the young adults' autonomy were noted. Consideration of a developmental perspective is important to understanding the challenges young adults with IDD face.

## **General Experiences of Community Participation**

The theme of family as a community is important to supporting community participation. The majority of participants in this study identified family as most their important community. Interventions for community participation should include consideration of the family as a primary community. Community participation is often conceptualized as occurring outside the home environment or with others aside from family members, but this finding demonstrates the need for interventions that value the family context as a community in itself.

Lastly, participants in this study expressed a desire to engage in communities. Participants were able to identify positive outcomes they experienced as members of communities and expressed the eagerness to continue to participate. Addressing the facilitators of participation can enable young adults with IDD to continue to engage.

## **Relationship to Community Participation Model**

The community participation model presented in Chapter II includes several components that may be supported by this study. A primary component of the model is *activity*, which serves as a link between the community and the individual in the model. Participants in this study discussed community participation through activity involvement. When participants talked about communities, they often referred to the activities they performed within communities. The model also includes a *self-assessment* process in which individuals assess their skills in comparison to the activities available within the community context in an attempt to *match* them. This process is captured within the *understanding context* theme above, as participants discussed how they evaluate the safety of the context and the expectations related to the activity. Individuals in this study talked about knowing the expectations of contexts and activities and comparing those things to their own abilities.

One finding that is not included in the proposed conceptual model is the presence of *support* within the context. The participants in this study and others discussed that support from people around them helped them become involved in their communities. Participants discussed support people helping them make decisions, pointing out opportunities in their communities, and helping them feel safe. The presence of supportive individuals has been noted in previous research (Craig & Bigby, 2015; McClimens et al., 2014). This important component should be included in the conceptual model based on these findings and previous findings.

### **Limitations**

There were several limitations to this study. The small sample included subjects enrolled in a specific post-secondary program, limiting generalizability. Admission criteria for the post-secondary program require that family members are actively involved in the students' educational experience. The sample likely includes a bias toward young adults with ample family supports, and is not representative of the diverse population of young adults with IDD. Additionally, the PI was known to the participants and this may have influenced the participants to view the PI as a staff member of the program which may have biased the responses. This is the first qualitative interview project completed by the PI and the interview protocol may have been too structured and not provided enough opportunity to explore topics more deeply.

### **Implications for Practice**

The findings of this study suggest that young adults with IDD want to be involved in their communities and view community participation as a positive experience and a tool to meeting other life goals. The experience of and engagement in community participation is impacted by physical safety, logistical issues, support from others, the presence of an activity, and individuals



understanding the community context of their valued communities. These factors can be addressed through direct intervention with individuals and adapting the community context.

## **CHAPTER V**

### **SUMMARY OF RESULTS**

This dissertation explores community participation in young adults with intellectual and developmental disabilities (IDD), in which I examined the topic in a series of three papers. In the first, I propose a conceptual model for community participation; in the second, I reported on a pilot study of the feasibility of an intervention to increase community participation; and, in the third, I examined the experience of community participation through qualitative inquiry.

The first of these component papers (Chapter II) was a review of the concepts of community participation for young adults with IDD. In my review of literature about community participation, I noted that community participation is an area of concern for people with IDD because individuals with IDD express the desire to be more involved in communities and research indicates their participation rates are lower than peers. I also discussed the complexity of the concept of community participation due to the number of related concepts, and the fact that a single distinct definition of community participation does not exist. In the literature review, I also noted that several models of community participation and community inclusion for people with disabilities exist. One important concept, the presence of an activity, was noted to not be a prominent component in existing models of community participation. A new conceptual model was proposed that included activity as a primary concept in the model, along with other well studied concepts including the community context, individual characteristics, and opportunities within the community.

Additionally, the proposed conceptual model incorporated process components consisting of *assessment*, *match*, and *feedback*. My review of the literature did not yield any community participation models that include process components. Including process components can aid in planning interventions. The proposed model included an assessment process with a self-assessment of individual abilities, values, motivations, and experiences. The assessment process within the proposed model also included an assessment of the opportunities and activities within the community context. The process included that individuals compare their self-assessment to the assessment of the opportunities and activities available. This process leads to the *match* component of the model, which provides the link between the individual, the activity, and the community context. The proposed model was also based on the system theory, indicating that feedback from the community engagement impacts the individual, context, and opportunities.

In the second paper (Chapter III), I presented the findings and discussed the viability of a pilot intervention focused on community participation for young adults with IDD. I presented the process and concepts that I used to develop the pilot intervention and selection of outcome measures. After I delivered the intervention, I completed a statistical analysis of the results and considered the feasibility of the intervention. The results indicated that there was not a statistically significant difference in activity participation before and after the intervention for these four participants. Participants were able to complete the outcome measure, the Adolescent and Young Adult Activity Card Sort (Berg et al., 2015) with slight modifications. The participants were also able to engage in the 4-week pilot study with support and incentives. I presented recommendations for completing research with this population and indicated that future research on interventions to impact community participation at the individual level is needed.

In the third component paper (Chapter IV), I used phenomenological inquiry to explore the lived experience of community participation in young adults with IDD. Four participants were interviewed and a research team analyzed the transcripts. Nine themes are identified from the interviews: *The need for physical safety, the presence of support, logistical challenges, understanding the context, the presence of an activity, experience of positive outcomes, identifying with old communities, family as a community, and a desired future.* The results identified several factors that influence community participation. Many of these themes were identified in other studies of people with disabilities participating in communities, while others are more specific to the young adult population. This study was one of few that consider the perspective of young adults with IDD related to community participation.

### **Discussion**

Beyond the purpose of comprehensively summarizing the findings of the three component papers of this dissertation project, a secondary purpose of this chapter is to identify how the results of the pilot study of a community participation intervention presented in component paper two and the results of a qualitative inquiry presented in component paper three contribute to revisions of the model presented in paper one.

#### **Application of Results to Contribute to the Model of Community Participation**

The results of the phenomenological inquiry support including activity as a primary component of the model. The presence of an activity was noted as a facilitator of participation in this study and others (Craig & Bigby, 2015; Mahoney et al., 2013). In the phenomenological study, participants spoke about engaging in their communities through activities. The proposed model in Chapter II includes the activity as the link between the individual and the opportunities

within the community context. Therefore, the results of Chapter III support including an *activity* component in the model.

Another concept in the model that was supported by results from the qualitative study was the *assessment* process an individual engages in to identify a match between the activities available in his or her community and his or her abilities, motivations, values and experiences. This component in the model can be aligned with the theme of *understanding the context*. In this theme, participants discussed the importance of understanding the context to facilitate or diminish their participation. One participant discussed being aware of the expectation of social skills in a specific community context, and compared it to her desire to participate in the community, which resulted in her acknowledgement that she needed to work on her social skills. Another participant discussed being aware of contextual expectations of college intermural volleyball and identified that she would choose not to participate in volleyball in that community context and would instead choose a different context. These two examples demonstrate the self-assessment and match process displayed in the model. During the pilot intervention, it was noted that participants were able to complete the intervention activities in week one and week three that focused on identifying the qualities of communities and identifying personal strengths, interests, and values. These findings support incorporating a self-assessment process into the model when individuals have the cognitive skills to do so.

The model does not include two important aspects of community participation that were noted during the qualitative study. The two themes, *physical safety* and *the presence of support*, emerged from the analysis. A somewhat surprising finding to this author was that all participants discussed concerns about their physical safety during community participation activities. One participant discussed fear of injury preventing her from participating in her gymnastics

community. Others indicated they felt most comfortable when they had the right equipment to maintain safety or someone was present in the environment to help them if they were to get hurt. The importance of safety has been noted in other studies as well (Bray & Gates, 2015; McClimens et al., 2014), indicating it is an important concept to include in community participation models. A less surprising finding is the need for support to engage in community participation. Participants discussed how individuals, including family members and other important people, provided support, encouragement, and guidance to help them engage in community participation. Neither of these concepts were part of the original conceptual model, but I believe they should be integrated.

The concept of feeling safe can be noted in the model components of *community context*, *opportunity*, and *activity*. As part of the assessment process, individuals evaluate the safety risks in community contexts, opportunities, and activities. This can be recognized as part of the *match* process between the individual and the activity. As noted in the results of the qualitative inquiry (Chapter IV) the evaluation of safety may not be accurate and it can be helpful to assist the individual in evaluating safety risks. The presence of support from others can help with this process. The support can include recognizing opportunities in the environment, assisting in assessing the characteristics of activities, understanding the community context, and providing emotional support.

The community participation model presented in Chapter II is revised to reflect the findings from the pilot intervention (Chapter III) and qualitative (Chapter IV) studies (see Figure 5). The presence of support is represented in the model as a half circle around the person. The support does not impact other aspects of the model directly. For the young adult population it is important to support self-advocacy and autonomy; therefore, the support is focused on the

individual, not the context or activities. By remaining focused on the individual only, the support person provides support the individual and does not enacting changes in other areas of the model.

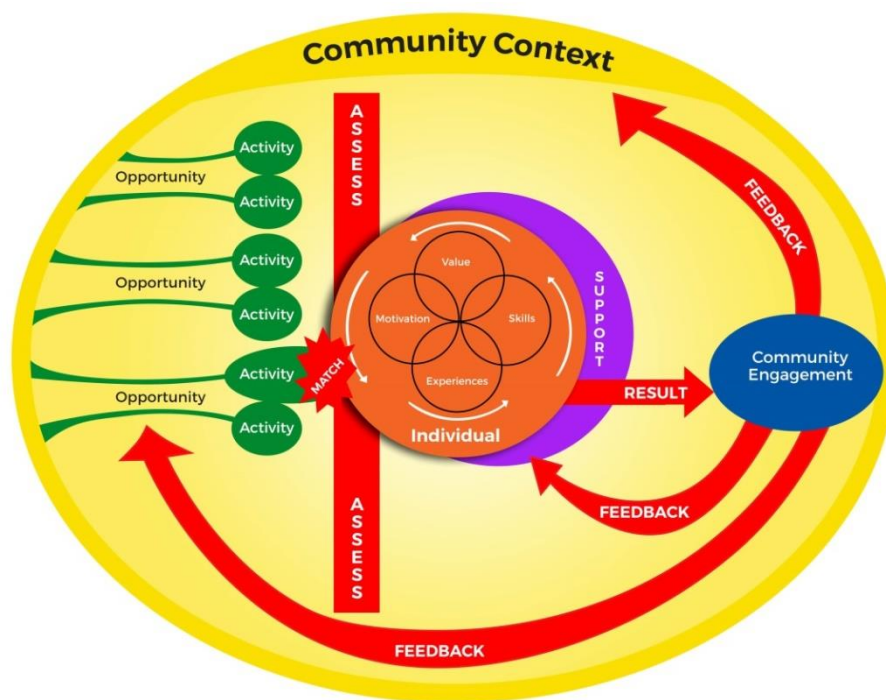


Figure 5. Revised Model of Community Participation

### Limitations

There were several limitations to this dissertation project. The small four-person sample for the qualitative and pilot intervention studies was the same sample in both studies; therefore, results are difficult to generalize. Additionally, the PI in these studies was known to the participants who may have biased their responses to questions during the qualitative interviews. The time frame did not allow for follow up or continued studies to increase the sample size. Future research should include a larger sample, from other locations, with varying cognitive abilities.

## **Implications for Practice**

Community participation in young adults is an important focus of research because a disparity in participation, and related health benefits, exists for people with IDD. In addition, few studies have considered the unique perspective of young adults with IDD. Results of this project and previous research indicate that young adults with IDD want to participate in their communities, indicating a need for continued facilitators and supports of that involvement. This project supports existing literature about the factors that influence community participation, but also expands that knowledge by focusing on young adults with IDD. For example, although many aspects of community participation were similar to that of the general IDD population, young adults with IDD may also benefit from a developmental perspective in addressing community participation. The pilot intervention indicated that the young adults with IDD in this sample were capable of engaging in assessment and intervention specific to community participation. The pilot intervention is perhaps one of the first studies of a community participation intervention specifically aimed at the individual, within the complex community participation process. Many studies have explored other interventions that are aimed at support staff or barriers. This study supports the exploration of interventions targeted at individuals with IDD.



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**Appendix A**  
**Group Protocols**

## Community Participation Intervention Week #1

**Name of Activity:** Individual Abilities

**Description of Activity/Rationale:** Through active participation, discussion, and group interactions, participants will increase awareness of their skills and abilities as they relate to various community participation activities. Participants will also begin to identify interests and values that guide their decision making

**Goals:**

- Participants will identify their abilities and challenges as related to community activities
- Participants will identify preferences and values as related to community activities

**Environmental Requirements/Considerations:** The group will take place in one of the Program study rooms in the dorm building.

**Materials:** Table, chairs, pens/pencils

**Directions & Presentation to the Group:**

*Introduction:* The group leader will welcome everyone to the group and introduce herself. The comprehensive six week group plan will be reviewed, briefly highlighting the goals and activities for each of the weeks. The goals for Week One and an overview of the Week 1 group will be provided. *5 minutes*

Because it is the first session, expectations will be presented. The group leader will ask each participant to introduce him/herself and identify one way that other people in the group can show respect to him/her. The group leader will write the responses on the dry erase board. The group leader will add (if not presented already): Listen when others are talking, Don't interrupt, Put cell phone away during group, use school appropriate language, and don't insult others. These items will be reviewed at the beginning of each of the group sessions and will be referred to throughout the group if participants are disrupting the group process. *10 minutes*

*Warm-up:* Participants will each go take a turn identifying one thing in the community outside of the educational program they enjoy doing. *2 minutes*

*Overview of Activity:* The activity will focus on the skills and abilities of each participant and identifying how they relate to different community participation activities. Emphasis will be placed on the abilities that participants have and helping participants self identify what those are.



*Activity:* Participants will be seated at a table in a circle. *15 minutes*

- 1) Each participant will be handed a piece of paper with a picture of a community activity at the top.
- 2) Participants will verbally identify the activity and the group will decide what community participation activity is represented in each picture (Walking on the lakefront, a community or campus group, religious participation, hanging out in a coffee shop, volunteer activities).
- 3) Each participant will identify the skills required to engage in the activity represented in the photo. A list of skills will be provided and participants can add to the list.
- 4) Participants will identify what interests someone participating in the activity should have. A list will be provided and participants can add to the list.
- 5) After the participant has identified the required skills and interests, the participant will then identify if they possess the skills by adding a check mark to the “I have the skills” box. Participants will do the same thing for the “I have the interests” box.
- 6) Participants will pass their paper to the right and when they receive the new paper, they will complete steps 3-5.

The activity will be stopped after 15 minutes if the participants have not completed it within that time.

*Processing:* The group leader will hold up each picture and ask the group to talk about what skills and interests were identified. Each participant will then be asked to share 3 skills they identified as having. Next the group leader will ask each member to share 3 interests they identified as having. Lastly, the group leader will ask each member to share 1 activity they identified as having the skills to complete and 1 activity they identified as having the interest in doing. *10 minutes*

*Generalizing:* The group leader will lead a discussion about why it is helpful to know one’s own strengths and interests. The group leader will emphasize that knowing these things help people make decisions about what to do, and to participate in activities that “fit” and we can be successful at. The group leader will also ask why it is important to know what skills and interests we don’t have. Emphasis will be placed on individuality and their being no “right” combination of skills. In addition to the same answers as above, the leader will emphasize that individuals can work to improve skills so they can do things they have an interest in. The group leader will ask participants to identify if there is something they have an interest in but don’t have the skills to complete. *5 minutes*

*Application:* The group leader will ask participants about how this can apply to their lives outside of the group. Questions including: what did you learn during this group (about

yourself, about someone else, about your community?). The group leader will ask students to identify one thing they will do this week to use their skills. *3 minutes*

*Summary:* The group leader will thank everyone for coming to the group and participating. The participants will be assigned “homework” for week 2. The homework assignment will be to identify one activity outside of the educational program that is available to them- examples include campus activities, library events, clubs, Park District events/opportunities.

## Community Participation Intervention Week #2

**Name of Activity:** Community Context

**Description of Activity/Rationale:** Through active participation, discussion, and group interactions, participants will increase awareness of the communities around them.

**Goals:**

- Participants will define community
- Participants will identify what communities they are already a part of
- Participants will identify additional communities that are available to them
- Participants will classify communities based on their level of comfort and acceptance

**Environmental Requirements/Considerations:** The group will take place in one of the educational program study rooms in the dorm building.

**Materials:** Table, chairs, pens/pencils/colored pencils/markers, large paper

**Directions & Presentation to the Group:**

*Introduction:* The group leader will welcome everyone to the group and introduce herself. The goals for Week Two and an overview of the Week 2 group will be provided. The leader will review group expectations that were discussed during the first group. 5 minutes

*Warm-up:* Participants will each go take a turn identifying one thing in the community outside of the educational program they enjoy doing. 2 minutes

*Overview of Activity:* The activity will focus on awareness of the communities around the participants and feelings of safety associated with the communities. This will be achieved through brainstorming, discussion, and individual community maps

*Activity:* Participants will be seated at a table in a circle. 20 minutes

1) Group leader will guide a discussion about communities and ask participants to identify communities they are a part of first- family, friend group, educational program group, religious group, work group, clubs/campus groups, city community. Answers will be written on the whiteboard.

2) Group leader will next ask for other types of communities that exist that participants are not a part of. Answers will be written on the whiteboard.

- 2) Participants will receive a handout with a blank community map. Participants will place names or drawings of their communities onto the handout according to how close they feel to that particular community.
- 3) Group leader will give suggestions of other communities that participants may add to their map.
- 4) Participants will color code their communities according to how safe they feel and how accepted they feel in each of the communities.

The activity will be stopped after 10 minutes if the participants have not completed it within that time.

*Processing:* Participants will take turns sharing their community map and talking about what was included. Group leader will ask the following questions/probes:

- What communities did you include?
- What communities do you feel most connected to?
- What communities do you feel least connected to?
- What communities do you feel safest in?
- What communities do you feel less safe in? Why?
- What communities do you feel most accepted in? What about that community makes you feel accepted?
- What communities do you feel least accepted in? Why?

*10 minutes*

*Generalizing:* The group leader will lead a discussion about what things were similar between group members and what things were different, focusing on the themes of connection, safety and acceptance.

- What communities did everyone have in common?
- What are some communities that you heard today that you haven't thought of before?
- Are there any communities that other people talked about that reminded you of a community you have been involved in? or want to be involved in?
- Were there any communities that you know you have no interest in?

*5 minutes*

*Application:* The group leader will lead a discussion on the importance of being aware of communities and opportunities within them. The leader will focus the discussion on highlighting the benefits of new opportunities for leisure, support, work, friendship, and civic engagement.

The group leader will also lead a discussion on the importance of safety awareness in communities, focused both on physical safety and emotional safety. Leader will also

focus on strategies to manage safety issues by soliciting answers from the group and providing input as needed.

*Summary:* The group leader will thank everyone for coming to the group and participating. The participants will be assigned “homework” for week 3. The homework assignment will be to identify one activity outside of educational program that is available to them- examples include campus activities, library events, clubs, Park District events/opportunities.

## Community Participation Intervention Week #3

**Name of Activity:** Activity

**Description of Activity/Rationale:** Through active participation, discussion, and group interactions, participants will increase awareness of how activities are embedded in communities.

**Goals:**

- Participants will categorize the nature of activities (being present vs. being active)
- Participants will identify match activities to contexts
- Participants will identify preferences for activities and communities
- Participants will set one goal for community participation

**Environmental Requirements/Considerations:** The group will take place in one of the educational program study rooms in the dorm building.

**Materials:** Table, chairs, pens/pencils/colored pencils/markers, large paper

**Directions & Presentation to the Group:**

*Introduction:* The group leader will welcome everyone to the group and introduce herself. The goals for Week Three and an overview of the Week Three group will be provided. The leader will review group expectations that were discussed during the first group. *5 minutes*

*Warm-up:* Participants will each introduce one other member of the group and say something that person does well. *2 minutes*

*Overview of Activity:* The first activity will focus on awareness of the nature of activities that occur within communities. Participants will actively categorize activities based on active or passive participation, next they will identify the contexts those activities can occur in, focusing on how the activity may change based on the context. The second activity will include writing a community participation goal.

*Activity:* Participants will be seated at a table in a circle. *20 minutes*

1) A stack of cards, each with a different activity will be provided to group members. The group leader will review the two categories (Being Present vs. Interacting) and participants will place their activities under one of the categories.

2) Group leader will review the placement of activities and ask participants to explain why they placed it in that location. Any differences in opinion will be discussed.

3) Next, each participant will be assigned an activity and asked to identify a community in which the activity can occur. Group leader will lead a discussion about each of their choices and will encourage them to think of their home communities and where the activities can occur.

4) Finally, the group leader will provide a worksheet to aid participants in setting a community participation goal. Each participant will read their goal

*Processing:* Participants will take turns sharing their community participation goal and talking about what was included. Group leader will ask the following questions/probes:

*Was it hard to think categorize the activities?*

*Was it difficult to set your goal?*

*10 minutes*

*Generalizing:* The group leader will lead a discussion about what things were similar between group members and what things were different, focusing on how some activities can be at the level of Being Present and some are at the level of Interacting and this can change based on the community. Group leader will emphasize that individuals may start with being present in a community and build to interacting within the community, or being present may be enough for individuals and communities.

*What activities did we all agree were more Being Present and more Interacting?*

*What communities did we all agree certain activities can take place in?*

*What are some activities you heard today that you haven't thought of doing before?*

*What are some communities that you heard today that you haven't thought of before?*

*What was similar about the goals each of you set?*

*5 minutes*

*Application:* The group leader will lead a discussion about how this activity can be applied to their lives outside of group. The general discussion will be about how choosing activities that you are interested in and are able to do can help with choosing communities to be a part of. Also, that adjustments to the activity might be made depending on where the activity occurs. The group leader will ask the following questions/probes:

*Which of the activities we talked about today are things you can do?*

*Which communities are you able to participate in that we talked about today?*

*Summary:* The group leader will thank everyone for coming to the group and participating. The participants will be assigned "homework" for week 4. The homework assignment will be to think about any problems or challenges they might have when trying to achieve their goal.

## Community Participation Intervention Week #4

**Name of Activity:** Planning and Appraisal

**Description of Activity/Rationale:** Through active participation, discussion, and group interactions, participants will plan and learn to appraise their community participation experiences

**Goals:**

- Participants will identify a plan for community participation
- Participants will identify potential outcomes of community participation, including their appraisal of the experience
- Participants will identify potential barriers and challenges to community participation
- Participants will identify at least one strategy to address challenges
- 

**Environmental Requirements/Considerations:** The group will take place in one of the educational program study rooms in the dorm building.

**Materials:** Table, chairs, pens/pencils/colored pencils/markers, large paper

**Directions & Presentation to the Group:**

*Introduction:* The group leader will welcome everyone to the group and introduce self, the goals for Week Four, and an overview of the Week Four group will be provided. The leader will review group expectations that were discussed during the first group. 5 minutes

*Warm-up:* Participants will introduce self and state one activity they participated in during the past week. 2 minutes

*Activity:* Participants will be seated at a table in a circle. 20 minutes

- 1) Participants will review their community participation goal set last week. (3 minutes)
- 2) Participants will draw a picture of what they would look like engaging in that activity (7 minutes)
- 3) Participants will discuss their picture and be asked to identify emotions they might feel while engaging in the activity (list of emotions will be reviewed and provided)
- 4) Participants will each provide feedback to each other about strategies to address the emotions they might feel during the activity.
- 5) Participants will be asked to identify at least one barrier to participation
- 6) Each group member will provide feedback to each other about strategies to address the barriers they might feel during the activity



*Processing:* Participants will take turns sharing their community participation goal and talking about what was included. Group leader will ask the following questions/probes:

*Did you like drawing the picture?*

*Was it hard to think about emotions? Barriers? Ways to overcome?*

*Did you like hearing suggestions from others?*

*Was it hard to give suggestions?*

*10 minutes*

*Generalizing:* The group leader will lead a discussion about what things were similar between group members and what things were different. Similarities in emotions and barriers identified will be presented. Leader will emphasize that everyone has strategies that work for them and sharing and talking about them can help. Also strategies suggested by others that were similar will be identified. Specific questions will include:

*What were some of the same feelings you identified about meeting your goals?*

*What were some of the same barriers you identified about meeting your goals?*

*What were some of the same suggestions people had?*

*5 minutes*

*Application:* The group leader will lead a discussion about how this activity can be applied to their lives outside of group. The general discussion will be about how being aware of feelings during participation can help with managing them. Also, anticipating what feelings and barriers might occur can help with planning strategies to manage them. The group leader will ask the following questions/probes:

*Which of the strategies we talked about today are things you can do?*

*How will you apply the activity we did today to life outside of PACE?*

*Summary:* The group leader will thank everyone for coming to the group and participating.

## **Appendix B**

### **Pre and Post Intervention Assessment Protocol**

Protocol for Introducing and Administering the Pre and Post Intervention Assessment:

The Adolescent and Young Adult Activity Card Sort (Berg, 2015)

Thanks for meeting with me today. My name is \_\_\_\_\_. I am an occupational therapy student at \_\_\_\_\_ University. Today we are going to do an activity and talk about the activities that you participate in. There are no right or wrong answers and you can take as much time as you want. If you have questions or something is confusing, you can stop to ask me.

I am going to show you a group of cards with activities on them and ask you to sort them into piles based on whether or not you have participated in them during the last 6 months. Here is the first card, what do you see happening in this card?

*If they don't read it, say: Can you tell me what this says? (pointing to the text)*

*If they can't read it, hand them the cards individually and read the activity to them*

*If they correctly read the card, hand them each sub-section of cards independently, but begin with the first item below:*

Do you grocery or clothes shop? Place the card in either the Yes or No pile here.

*If they ask for clarification, read the text at the bottom of the card*

**Appendix C**  
**Post Intervention Questions**

Participant Name: \_\_\_\_\_

After completing the AYA-ACS, please ask the participant the following questions and  
write down their answers:

Tell me something that happened in the group or that you learned that was helpful to you:

What was the best part about the groups? What did you like best?

What made it hard to participate in the groups?

**Appendix D**  
**Qualitative Interview Protocol**

### Community Participation Interview

*A community is a group of people who have things in common. They might be interested in the same things, they might have experienced something together, or they might live near each other. Most times, communities are a small part of a bigger group of people. People can feel like they belong to many different communities.*

*For example, PACE is a community. PACE students are like each other in some ways. PACE students have similar experiences of living in dorms, going to school and working. PACE students are a small part of the bigger community of National Louis University.*

*I'm going to ask you questions about your participation in communities other than PACE.*

*There are no right or wrong answers. I'm interested in your feelings about your communities.*

Question	Category
<p>1- <i>What other communities do feel you are a part of? Think about here in Chicago. Think about your hometown.</i></p> <p><i>(Student needs to name at least 2 communities in question #1. If not prompt with: Where do you go, outside of [Educational Program], where you are with other people? Do you do things with other people who have the same interests as you? What other groups of people do you like to be around? )</i></p> <p><i>If the subject provides more than 2 responses: Of all the communities you are a part of, which 1 is the most important to you?</i></p>	
<p>2- <i>Do you feel relaxed when you are involved in activities in (Fill in with one of the communities the subject identified above) community?</i></p> <p><i>What helps you feel relaxed?</i></p> <p><i>Do you feel safe when you are involved in activities in (Fill in with one of the communities the subject identified above) community?</i></p> <p><i>What helps you feel safe?</i></p> <p><i>Ask about 2 communities named above</i></p>	<p>Comfort within communities</p>

<p>4-What are the things that make it hard to be a part of (Fill in with one of the communities above)?</p> <p>What things make you feel unsafe in (Fill in one of the communities above)?</p> <p>Prompts: <i>Unsafe feelings are when you feel scared of something or even worried something might happen to you. This could be something hurting you physically, or even hurting your feelings.</i></p> <p>Ask about both communities</p>	<p>Barriers to community participation</p>
<p>5-What other communities do you want to be a part of but are not?</p> <p>Why do you think it is that you are not a part of _____ community?</p>	<p>Choice in participation</p>
<p>7-Do you make your own decisions about what communities you are a part of?</p> <p>Prompts: Do you get to choose what groups you are a part of? Does someone else tell you what groups to get involved in?</p> <p>How do you feel about making/not making your own choices</p>	<p>Choice in participation</p>
<p>8-How do you give back to your communities?</p> <p>If prompts are needed: <i>Giving back means adding something, contributing, even sharing something.</i></p>	<p>Contributions to communities</p>
<p>9- Is there anything else you want to tell me about your participation in communities outside of [Educational Program]?</p>	

Thank you for answering all of my questions. You did a great job.



**Appendix E**  
**Recruitment Flyer**

## **Community Participation Study**

### ***An Invitation to Young Adults and Information for Family Members***

#### **Who?**

- Young adults enrolled in the P.A.C.E program

#### **What will young adults be asked to do?**

- Young adults will be asked to spend about 30 minutes with a researcher twice to:
  - Completing the Adolescent and Young Adult Activity Cart Sort, a self-report assessment of participation in daily activities.
  - Receive a \$10 Target Gift Card for completing this
- Young adults may be asked to participate in a 30 minute interview with a researcher to discuss experiences and feelings about participating in communities.
  - Receive a \$10 Target Gift Card for completing this
- Young adults may be asked to participate in an evening group for one hour a week for 5 weeks. The group will occur in the P.A.C.E. dorms.
  - During the group, young adults may be asked to think and talk about experiences in the community and to participate in one activity outside of P.A.C.E.
  - Receive a \$10 Target Gift Card for completing all sessions

- 

#### **What will the benefits of participation in this study be?**

- Target Gift Cards for participation in each portion of the study
- The benefit to young adults who participate is the potential for increased self-awareness and abilities related to community participation.
- By participating, young adults are also contributing to what is known about community participation and the results may influence future programming, policies, and resources.

#### **Interested in participating?**

- Sign up with PACE dorm staff and you will be contacted by study staff to set up a time for completing the initial assessment.
- Or, contact the Principal Investigator, Molly Bathje, at [Molly\\_M\\_Bathje@rush.edu](mailto:Molly_M_Bathje@rush.edu) or (312)942-2262.

**Appendix F**  
**Informed Consent**

**Investigator: Molly Bathje**

**Contact Information: (312)942-2262**

**Title of Study: *Community Participation in Young Adults with Intellectual and Developmental Disabilities***

**Sponsor: *Departmental, Rush University***



## **Subject Information Sheet and Consent Form**

### **Introduction**

*Note: If you are the guardian, or legal representative of a person who is not able to consent for themselves the terms “you” or “your” refer to you and/or the person being asked to participate in this research.*

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the information in this form carefully, as it may contain words you do not understand. You may wish to discuss it with your doctor, counselor, family, and/or friends. If there is anything that you do not understand or if you would like more information, please ask questions and the study staff will try their best to answer them. Once the study has been explained and you have had all your questions answered to your satisfaction, you will be asked to sign this form if you wish to participate. Before anything is done for this study, you must sign this form. A copy of this signed form will be given to you.

You do not have to take part in this study. You are free to withdraw from this study at any time you choose without giving a reason. This will not affect your participation in the P.A.C.E. program. No promises can be made about the outcome of this as far as your current condition, either positive or negative. People who take part in research are called “subjects” instead of “students.”

### **Why are you being invited to participate in this study?**

You are being asked to take part in this study because you are enrolled in the P.A.C.E. program at National Lewis University and you are a young adult with an intellectual and/or developmental disability.

### **What is the purpose of this study?**

The purpose of this study is to describe the experience, satisfaction, and engagement in community participation activities in young adults with intellectual and developmental disabilities. Another purpose of this study is to identify if a program designed to increase community participation and interest is effective.

### **How many study subjects are expected to take part in the study?**

All students enrolled in the p.a.c.e. dorm program are being invited to participate in this study. Researchers expect to enroll 20 participants from the p.a.c.e program. No other individuals are being invited to take part in this study.

### **What will you be asked to do?**

\*You will be asked to meet with a research assistant for 45 minutes twice (once in March or April, Once in May or June).

\* During the meeting you will be asked to complete an assessment called the Adolescent and Young Adult Activity Card Sort. For this part, you will look at 70 pictures of everyday activities and sort the cards to indicate if you participate in the activity shown on the card or not. You will be asked a few more questions about the activities you don't participate in. This will take you about 30 minutes.

\*You will be asked to participate in a one hour evening group once a week for six weeks.

\* During the group you may be asked to think and talk about your experiences in the community around you.

\*You may also be asked to set a goal to do one new thing outside of P.A.C.E., make plans to meet that goal, do the activity, and talk about your experience.

\*You may also be asked to meet with the Principle Investigator individually for 30 minutes

\*If you are asked to meet with the Principle Investigator you will be asked questions about your feelings about community participation.

Researchers will be collecting information on the number and types of activities you participate in, the things that prevent you from participating, and your feelings about participating in community activities outside of the P.A.C.E program.

The Adolescent and Young Adult Activity Card Sort and interview will occur in March or April. The group activities will occur in April and May. The Adolescent and Young Adult Activity Card Sort will occur again in May. The interview with the Principle Investigator will occur between April and June.

### **How long will you be in the study?**

You will be in the study for up to 7 weeks. Two of the weeks will be doing the Adult and Adolescent Activity Card Sort and the interview. Five weeks will be participating in the group sessions.

### **What are the possible risks of the study?**

The risks to participating in this study include the risks associated with participating in any PACE group activity. There are not physical dangers. You will potentially share feelings and personal information with others, or hear about other's feelings which may cause emotional discomfort.

### **Are there benefits to taking part in the study?**

Participants will receive \$10 Target gift cards upon completing of each of the following 3 items: 1) both of the Adolescent and Young Adult Activity Card Sort sessions, 2) the interview with a researcher, and 3) the weekly groups.

Other benefits to participating in the study are that you will be contributing to research about community participation for adults with intellectual and developmental disabilities, which may have potential to influence programming, resources, and support services.

You may also benefit directly from participating by increasing your self-awareness and abilities.

### **What other options are there?**

If you chose not to participate in this study, there are no other options available. You will continue in the PACE program as usual.

### **What about confidentiality of your information?**

Records of participation in this research study will be maintained and kept confidential as required by law. Your name will not be used, you will be assigned an identification number. All information collected will be stored in a locked file cabinet in a locked office at Rush University and only the Study Investigator will have a key. Any electronic information will be stored on a password protected external drive that only study staff will have the password for and it will be kept in same locked file cabinet in a locked office at Rush University when not in use.

If you withdraw from this study, the data already collected may not be removed from the study records. The study team may ask you whether they can continue to collect follow-up data on you. If follow-up information will be requested, you will be asked to sign a separate consent form before this information can be collected.

Your identity will not be revealed on any report, publication, or at scientific meetings. Audio tapes will be kept in a locked file cabinet within a locked office. Once the study is complete, the audiotapes will be destroyed.

In order to conduct the study, the Principle Investigator, Molly Bathje, will use personal information about you. This includes information already in your school record, as well as information created or collected during the study. Examples of the information that may be shared include your age, diagnosis, results of the Adolescent and Young Adult Activity Card Sort, information you share during interviews, and if you participated in the group sessions. The study investigator will use this information about you to complete this research.

Confidentiality and disclosure of your personal information is further described in the attachment to this form. The attachment is titled HIPAA Authorization to Share Personal Health Information in Research (2 pages).

**The Rush Institutional Review Board (IRB) will have access to your files as they pertain to this research study. The IRB is a special committee that reviews new and ongoing human research studies to check that the rules and regulations are followed regarding the protection of the rights and welfare of human subjects.**

### **What are the costs of your participation in this study?**

There are no direct costs to you for participating.

**Will you be compensated or paid?**

You will be compensated with a \$10 target gift card for completing each of the following 3 things associated with this study: 1) the adolescent and young adult activity card sort twice 2) interview with a researcher 3) participation in groups.

Rush University Medical Center has no program for financial compensation or other forms of compensation for injuries which you may incur as a result of participation in this study.

**Whom do you call if you have questions or problems?**

Questions are encouraged. If there are any questions about this research study or if you experience a research related injury, please contact: Molly Bathje, (312)942-2262. Questions about the rights of research subjects may be addressed to the Rush Research & Clinical Trials Administration Office at 1-800-876-0772.

By signing below, you are consenting to participate in this research study. You have read the information given or someone has read it to you. You have had the opportunity to ask questions, which have been answered satisfactorily to you by the study staff. You do not waive any of your legal rights by signing this consent form.

**SIGNATURE BY THE SUBJECT OR THE SUBJECT'S LEGAL REPRESENTATIVE:**

\_\_\_\_\_  
Name of Subject

\_\_\_\_\_  
Signature of Subject

\_\_\_\_\_  
Date of Signature

\_\_\_\_\_  
Subject Assent

\_\_\_\_\_  
Date of Signature

\_\_\_\_\_  
Parent, Guardian or Legal Representative's Signature

\_\_\_\_\_  
Date of Signature



**SIGNATURE BY THE INVESTIGATOR/INDIVIDUAL OBTAINING CONSENT:**

I attest that all the elements of informed consent described in this consent document have been discussed fully in non-technical terms with the subject or the subject's legally authorized representative. I further attest that all questions asked by the subject or the subject's legal representative were answered to the best of my knowledge. .

---

 Signature of Individual Obtaining Consent

---

 Date of Signature

- Check here if the Individual Obtaining Consent observed the signing of this consent document and can attest, to the best of their knowledge, the person signing the consent form is the subject or the subject's legally authorized representative and the person signing the form has done so voluntarily. By checking this box, the Individual Obtaining Consent does not need to sign on the Witness signature line (below).*

**SIGNATURE BY WITNESS/TRANSLATOR**

**(for use if this consent is being used as a written summary of the research along with a short form consent OR when the person obtaining consent is not the witness):**

I observed the signing of this consent document and attest that, to the best of my knowledge, the person signing the consent form is the subject or the subject's legally authorized representative and the person signing the form has done so voluntarily.

---

 Signature of Witness/Translator

---

 Date of Signature

- Check here if a separate witness signature is not necessary.

**SIGNATURE OF THE PRINCIPAL INVESTIGATOR**

I attest that I am aware of the enrollment of this subject in the study discussed in this consent document.

---

 Signature of the Principal Investigator

---

 Date of Signature

- Check here if Principal Investigator obtained consent and a separate signature is not required.

**Appendix G**  
**Pre and Post Intervention Data**

### Initial AYA-ACS Data

Initial ACS Assessment												
Participant	Chores Y	Chores N	Leisure Y	Leisure N	Social Y	Social N	Health Y	Health N	Education Y	Education N	Work Y	Work N
1	10	1	5	9	4	6	6	4	7	1	5	5
2	6	5	9	5	3	7	6	6	5	3	5	5
3	8	3	7	7	5	5	9	1	8		8	3
5	8	3	13	1	9	1	10		6	2	9	1
4	7	4	7	7	7	3	6	4	4	4	6	5
	7.8		8.2		5.6		7.4		6		6.6	
Not participating but want to												
Participant	Chores	Barriers	Leisure	Barriers	Social	Barriers	Health	Barriers	Education	Barriers	Work	Barriers
1	0		8	42,30,35,38,37,42,42,42	6	41,39,42,40,17,7	1	8	1	30	5	26,40,39,21,17,7,5
2	3	33,24,18	1	18	5	18,13,24,24,41	1	12	1	17	4	26,26,33,19
3	2	39,1,9,34,40	3	24,36,Want to be alone	2	39,41,32	1	40			1	1,5
5	3	12,42,42,42	1	42	1	10,30			2	42,15,2	1	42
4	3	9,24,24	2	12,39	2	41,42	3	17,16,20	2	9,10	4	10,42,41,42
		15		15		18		6		7		18

### Follow up AYA –ACS Data

Second ACS Assessment													
Participant	Chores Y	Chores N	Leisure Y	Leisure N	Social Y	Social N	Health Y	Health N	Education	Education	Work Y	Work N	
1	8	3	5	9	3	7	4	6	6	2	4	6	
2	6	5	9	4	3	7	5	5	2	6	2	9	
3	8	3	9	5	7	3	10	0	8	0	8	1	
5													
4	8	3	8	6	9	1	4	6	5	3	4	6	
Not participating but want to													
Participant	Chores	Barriers	Leisure	Barriers	Social	Barriers	Health	Barriers	Education	Barriers	Work	Barriers	
1	2	7,4,42	5	24,29,35,3,8,41	5	7,30,35,3,9,40,42	4	3	5,42,42,43,4	1	43	5	5,7,26,40,41,42,43
2	5	41,42,42,42,43	2	36,39	5	18,23,24,24,25	1	12	3	10,13,24	8	16,23,24,24,26,37,42,43	
3	3	1,5,39,39,40,41	1	1	2	15,18,21,41,41	0	0	0	0	0	0	
5													
4	2	24,24	4	5,41,41,42	0	0	6	5,5,39,41,41,41	0	0	3	9,41,41	
	3	16	3	13	3	17	2.75	12	1	4	5	18	

## Data about Leisure Interests

Participant	Pre				Post			
	Yes	No	No-I	Y+No-I	Yes	No	No-I	Y+N-I
1	5	9	0	5	5	9	5	10
2	9	5	3	12	9	4	2	11
3	7	7	2	9	9	5	1	10
5	13	1	3	16				
4	7	7	3	10	8	6	4	12

**Appendix H**  
**Interview Transcripts**

## Participant 1- Transcript

M: OK, so, I'm gonna ask you some questions.

That's pretty cool right [subject is looking at recording device]. Have you ever seen anything like that before?

[Kock on door]

M: Go ahead, you can answer that.

We were just trying to find a quiet spot.

Staff: its fine, I just need to grab my stuff

READ THE INTRO TEXT

M: So what other communities do you feel you're a part of? What other communities do you feel you're a part of?

1: Um, my home community

M: What is your home town?

1: [River Park]

M: [River Park] ok. You feel a part of the town of [River Park]. How bout one more?

1: [River Park]

M: OK, how about another community within that.

So think about, like, where do you go outside of [Educational Program] where you are with other people.

Do you do things with other people who have the same interests as you?

1: sometimes

M: Can you give, can you tell me about

1: I don't know

M: Um, what other groups of people do you like to be around?

1: mmmmm? (sounds like I don't know)

M: So,

1: Oh, uh, I just like to be with people that, that like the same things I like.

M: OK, Can you give me an example of what something is that you like

1: Museums

M: Ok

Alright. And of all the communities that your a part of, so you talked about being part of a [River Park]community, um, you talked about museums, and I'm also wondering if there is a a community like about the people that you live with when you are not here at [Educational Program]. Who are those people? Would you consider your family one of your, part of your communities?

1: Yes

M: Yeah, Ok

So of the communities you talked about, your family, um, [River Park], and um, people who go to museums, which are the most important to you, which one is the most important

1: My parents

M: OK, your family, OK

Um, Ok, do you feel relaxed when you are involved in activities in your community of [River Park]

1: Yes

M: What helps you feel relaxed

1: I just feel comfortable

M: What helps you feel comfortable?

1: Um That I'm with people that I know

M: OK

1: Um, do you feel safe when you are involved in activities in [River Park]?

1: Yes.

M: Ok

1: Small, Small town

M: And, what about, do you feel relaxed when you are in your family community?

1: Nods

M: And what helps you feel relaxed when you are around your family?

1: I just, uhhh, feel safe in a familiar setting

M: OK

M: So you feel relaxed in a familiar setting? And do you feel safe with your family?

1: Yes

M: And what helps you feel safe?

1: That the, they are next to me

M: OK

What are the things that make it hard to be a part of

1: Having to wake up early in the morning

M: So, being a part of your family community, what makes it hard to be a part of that

1: Uhhh, having, having to go to ah, bed earlier

M: OK, and um, what things make you feel unsafe to be a part of your family community?

1: There is nothing unsafe

M: OK

And, what are the things that make it hard to be a part of the [River Park] community, the bigger community of [River Park]

1: Umm, not, uhh, everything, everything, all the major landmarks are far away, are far away.

M: OK, can you tell me a little bit more about what you mean by that.

1: Like I can't, I cant walk to, walk to it. Um, I don't have a car so I take bus

M: OK, Do they have busses in [River Park]?

1:Nods

M: OK, but things are far away for you.

And when you say landmarks, what do you mean by that?

1: Like libraries

M: OK, alright, um, so its hard for you to get to some of the things. OK

Is there anything that makes you feel unsafe in [River Park]?

1: I know the routes

M: Ok, alright

Are there any communities that you wanna be a part of but your not

1: I can't think of any right now

M: OK

Um, do you get to make your own decisions about what communities you are a part of ?

1: Well, uh, yeah,

M: OK

1: How much longer?

M: Just a couple more minutes, were almost done, your doing good

So does someone else tell you what groups you have to be involved in?

1: No

M: OK, you get to choose that?

M: Um, And how do you feel about being able to make your own choices about what communities you're a part of?

1: Good

M: Um, here is another question, a little bit different. How do you give back to your communities? Do you know what that means?

1: Um hum, I give back by going to the library.

M: OK, Can you tell me a little bit more about that?

1: I just go to the library

M: So giving back can mean like adding something, sharing something, contributing, volunteering

1: I just go to the library and read their books

M: OK

Um, and is there anything else you want to tell me about your participation in communities outside of [Educational Program]

1: No

M Ok, alright, thanks [Andy] that's all, you did a great job

1: Thank you, There is not much to tell, tell about [River Park]

M: Um hmm

1: Its like very small and Most of the interesting things is located in like in a small area

M: Um hum

Have you lived there all your life?

1: No I only moved to [River Park] in 2000

M: OK, And where were you before that?

1: [River Oaks]

M: Um hum, Oh, that's not too far from right? Those are kinda close to each other?

1: [River Park] and [River Oaks] yes. In fact its like a half hours walk from my house

M: Did you go to high school in [River Park]?

1: Yes, [River Park High School]

M: OK, Were you involved in any activities in high school?

1: Bowling on Tuesday nights.

M: Oh, OK, Do you ever bowl any more?

1: [Shakes head no]

M: How come?

1: I just, uh, I don't know

M: Is that something you'd be interested in doing again?

1: Maybe

M: OK, we can talk more about that in group

1: Can I please have my gift card?

M: OK, thanks



## Participant 2-Transcript

M: OK, Um So hows it going today?

2: Good

M: Yeah, having a good day?

2:Yep

M: Alright, So, uh, were gonna just talk a little today about your communities. We've been talking a little about that in group a little bit.

Script for interview read

Besides [Educational Program], what communities do you feel like you're a part of?

2: uum, I feel like I'm a part of the um, uhh, my uh, sport community

M: OK, can you tell me a little more about that?

2: Um, I'm , involved in SLARC special rec

M: Oh, OK, awesome

Is that in your home town?

2: uh, Yea. And I've done basketball, uh, softball, um and I've done gymnastics too

M: OK

2: so, yeah

M: All right , so yea, that sports community?

2: yea

M: So, are there other communities that you feel like you are a part of?

2: Um, I'm in, I feel like , I feel like I'm a part of 12..., well I'm, um I'm a part of the Chicago community

M: Sure

2: So, yeah

M: Can you tell me a little bit about that? How you feel like you are a part of that?

2: Well basically I live in Chicago and I, Ya know, feel like I'm involved in the whole community here.

M: OK, alright

2: Yep

M: Um, How about other communities? So if you think about, like, where you go to do things with other people who have the same interests as you, other groups of people you like to be around. Some people mention their family as on of their communities. Would you say that family is a communities?

2: Sometimes, yea, yea

M: Ok, can you tell me a little bit more about your family community?

2: Um, my family is very good to me. They, they, they, We do, we do stuff together,

M: Umm hmm

2: and I, I'm really happy to have a family.

M: Whose in your family?

2: My mom, my dad and my brother

M: Ok,

2: Yea

M: Alright, So, of the communities that you named, which community is most important to you.

2: Um, I think that family is the most important

M: Ok, can you tell me why?

2: Cuz family, you wouldn't be able to uh, um, you wouldn't be able to do the things that you do now.

M: Um hum

2: You wouldn't be able to learn how to live on your own

M: Ok

2: And everything

M: Ok,

Um, alright, so the next few questions are going to be about. Um

Can you tell me the second community that you feel is most important to you? So you said family...

2: Um, I think my sports community

M: Your sports community, ok, alright

Um, So, do you feel relaxed when you are involved in activities in your sports community?

2: Yes I do

M: Can you tell me a little about that and what helps you feel relaxed?

2: What helps me feel relaxed in, in my sports community is, like, if you get stressed you can like always go outside and shoot some hoops and hopefully calm down a little bit. And

M: Ok

2: Yea

M: Do you mean that like if your, um, feeling stressed in a different, doing something else, you always have a sport to go out and..

2: Yea

M: The sport itself helps you relax?

2: Yea

M: OK, Um, how about when you are actually participating in the sport, do you feel relaxed?

2: Sometimes yeah

M: OK, um, is there something that helps you feel relaxed when you are doing the sports activity?

2: Just , uh, you know, thinking about, you know, um just just uh, doing the sports in general makes me feel relaxed, and helps me to relax and yea

M: OK

And how about, do you feel safe when you are involved in activities within your sports community?

2: Not really, but

M: OK is there anything that helps you feel safe?

2: Umm, Like a helmet when playing softball

M: Umm hmm

2: like a helmet, Yea, like yea

M: And what are the unsafe things about being in your sports community?

2: You could get hurt

M: Ok, the physical part?

2: Yeah, physical

M: Is there anything else you feel kind of unsafe about?

2: Uh, No

M: Ok, alright and then do you feel relaxed when your doing activities within your family community?

2: Yes

M: OK, and can you tell me a little bit about that and what helps you feel relaxed?

2: Um, just, you know talking to my family about, you know, um, just talkin to my um family. When I do helps me relax and yea. About good days and bad days. So, But yeah

M: OK

Is there anything. Uhhh, what helps you feel safe when you are involved in activities with your family?

2: Um, my mom and dad make me feel safe, and my brother. Like, my bro, my family's always, like I know my family's always there for me.

M: Umm hmm

2: And they would do anything to protect me. So I feel safe around them

M: Ok

2: Yea

M: Alright

Um, are there things that make it hard to be a part of your family community?

2: Ummm, Not really. Like if you, if they yell at you too much, or,

M: Ok

2: Yea

M: So if they yell at you too much, what, tell me more about that

2: If they yell too much it might make you feel like, You know, I've done something wrong and maybe I should think it over and do it the right way next time

M: OK

Um, are there things that make it hard to be part of your sports community?

2: Um No

But uh, probably, but probably, umm. Try, like doing a new sport, like tryin a new sport, might get a little challenging

M: OK, like which ways would it be challenging

2: Like getting to know the rules

M: OK

2: And yeah

M: OK

Is there anything else that makes it hard to be a part of the sports community?

2: Uh uh

M: OK

Um, and we kind of already talked about what makes you feel unsafe in the sports community, you talked about getting physically hurt

2: Yea

M: Um, is there anything else that makes you feel unsafe?

2: Uhh, no

M: And is there anything that makes you feel unsafe in your family? In your family community?

2: Just uh, just uh, well, no I don't think so

M: OK

Alright

Um, are there other communities that you wanna be a part of and your not.

2: I want to be a part of a cooking community

M: OK, um, tell me more about that

2: Um, I wanna, I wanna learn how to like prepare food, and uh, uh make it from scratch

M: OK

Um, and why do you think you are not a part of that community right now.

2: Maybe it's a part, maybe, uh, probably because of schedules. Of schedules

M: OK, can you tell me what you mean by that?

2: Uh, may, maybe its because like busy schedule or like you have too much to do

M: OK

2: Or something like that

M: Too much to do and then you can't cook, or learn the new stuff?

2: Yea

M: OK

Alright, so in general, do you get to make decisions about what communities you are a part of?

2: Yea, and I think, yea. Um, I think its good to, I think, I think you can make your own decisions, and, ummm, if you, if you wanna do that, if you like wanna cook, go for it ya know? You, you, No body can tell you what to do

M: OK, so you feel like you are, and you get to make your own decisions?

2: Yea

2: OK

Um

And, um, ok and then the last question here is um "how do you give back to your communities?" Do you feel like you give back to your communities at all?

2: I give back to the community by um, just helping them out, and, doing my fair share

M mmm hmm, can you give me some examples of what you mean by that?

2: Umm, Just, hmm, Just uh, play by the rules

M: Uh hmm

2: Annd,

M: When you are thinking about that are you thinking about like in your family, or are your thinking about your sports community?

2: My sports community

M: OK, so play by the rules. So you follow the rules of the game?

2: Yea

M: OK, so are there other ways you help out or give back?

2: I think um, I basically help my family ya know, by doing like chores around the house and everything, and yea

M: OK

2: Yea

M: OK, so is there anything else you want to tell me about your communities outside of [Educational Program]?

2: I'm happy to be a part of my community

M: mm hmm

2: Yea

M: Um Why do you feel happy about that?

2: Because I feel like I'm actually accomplishing something in my life.

M: Um hmm

2: I'm actually getting physical in my life

M: Umm hmm

2: And yea

M: OK, um, since high school has it been hard for you to be involved in communities?

2: Uh, not really

M: Ok, well, that's all I have

2: Is there anything else you want to tell me about?

M: Um, no

2: Ok, thanks so much

Participant 3

M: Ok, so thanks for meeting with me. Um, so were going to do just an interview today, there's no right or wrong answers for any of this. We are going to talk about community participation, we've been talking a lot about that in group as well.

**Read scripted opening**

So what other communities do you feel like you're a part of besides [Educational Program]

3: My, block party community

M: OK, can you tell me a little more about that?

3: I live in [Pine Forest], I grew up in [Pine Forest], uh, my family moved to [Pine Forest], we were, you know, like this a safe neighborhood, for our children to grow up in. Well my mom and dad decided that, you know that, that the four of us wanted to grow up in you know, in a neighborhood that was safe for us. Like go to the park, and you know, stay out past night time.

M: Mmm, hmm

3: And we decided that I think getting neighbors that got to know us, you know, saying "Welcome to [Pine Forest],, this is what we do and this is what we handle, and this is what happens, when it get really nice outside, we want the kids and the teenagers, we want all the, you know, adults to come outside and the dogs, and just let them." And, which I get to it by having a block party. And we get, you know, permission from all the neighbors, just saying hey, there's going to be a block party. And, we start to get into it about having parties and each of the houses and just you know, being very good like communities and you know and be having like the car by car. It was really like fun to see all my neighbors outside

M: Mmm hmm

3: at block parties

M: Mmm hmm, so you said two things, one is um, your community of [Pine Forest], like the big town of [Pine Forest].

3: Yea

M: And then specifically your block and your neighbors.

3: Right

M: Right. So its like, kind of your small community is your block, and your big community is your, uh, is [Pine Forest],

3: Right

M: Yeah, And then, are you saying your on a block party planning committee? Is that what you are saying?

3: I'm not on the community, but a lot of people in my neighborhood is on the community. So you know, they like put flyers up on our door, or like, if we aren't home.

M: Mmm hmm

3: It was, You know, ring our doorbell. And if we don't answer they say, they like ask "Hey, the [Smith's] home?", they say no the [Smiths] aren't home at the moment I keeping, I keeping an eye on their house, ummmm.

M: OK, so um, besides [Pine Forest], and the block um, that you live on, is there another, other communities that you feel like you are a part of?

3: Umm, the gymnastics community

M: Ok, gymanastics? OK, can you tell me about that?

3: Um, when I was little, by the age of three my mom put me in gymnastics cuz she thought it would be, you know, something that I can do for the rest of my life.

M: Mmm hmm

3: and it had been, you know, really good doing gymnastics. And you know, I started doing gymnastics by the age of three and you know, when my little sister saw me doing gymnastics she wanted to do

gymnastics, and now she doing gymnastics. And, its like watching her, going to her competitions, seeing her, you know. But, by the age that she and me both suffered really bad injuries

M: Oh Ok, so your not actively doing gymnastics?

3: Not any more, because I suffered a really bad injury

M: Oh, I'm sorry

3: I had broke my leg

M: Woah

3: And I was flipping on the vault and I was suffered the injury. And By the time I was in high school, this happened the days of high school. And, it kind of effected my whole career. And I just told my parents, "hey I want to quit". You know, and my mom and dad was like, "you know you got all your medicines, trophies, and you know your giving up on your dreams". "I'm just like saying I've been since I was three, I think I have to give up, you know I don't think I can go back

M:Mmm hmm

3: "I don't think I can flip any more".

M: Mmm hmm

T: But I still can flip.

M: haha

3: But, just a couple days later my little sister had an injury at gymnastics too. She shattered her right arm

M: Oh, geez

3: And got rushed to the hospital and got surgery and stitches, same for me. And my parents were saying it because they had two injured daughters, and I was like, I feel "hey, don't give up gymnastics" My doctor, The doctor like "Your leg is fractured, you can't flip anymore." So I was devastated that I couldn't be with my friends

M: Yea

3: But, after my leg healed, after I got the surgery and the cast, and you know you got it off. It moved past, and I told my parents, hey can I do another sport? Because now I'm not into gymnastics anymore but I still go to the competitions with my sister and I still watch her and I still say "you can do it little sister I believe in you", you know. But I just with, like, I could still do it, but she's like. "sorry that you hurt yourself," and "I'm sorry that we both hurt ourselves, but this is what happens when you do gymnastics. You get injured and you just move past it.

M: So did you do another activity that you liked to do?

3: Um I did cheerleading in high school

M: ok

3: You know, I was always into cheerleading because my mom did it in high school

M: Mmm hmm

3: So I was saying, I was saying to my mom "hey mom, you know, maybe I can try for cheerleading", she said "That sounds good" and I tried out and I made the team.

M: And how about now, are you involved in any activities like that now?

3: I mean no, I sit at home. I cheer for my mom and she's like "you still got it!" and I'm like "yea, I still got it".

M: hahaha

Ok, so, when I asked about other communities you feel a part of you talked about [Pine Forest],, your block, um, you talked about your um gymnastics team. Are there any other um communities that you feel like you are a part of?

3: My family community

M: Ok, can you tell me a little bit about that.

3: Yes, Um, my family, on my dad's side, we are really a huge family.

M: Mm hmm

3: My parents are married so they got four kids all together. We got a dog, he's a sweetheart, he's horrible, but he's a sweetheart. But, he's really my dog.

M: He's a what?

3: He's a sweetheart

M: Oh, a sweetheart

3: Cuddly little puppy. He don't bite nobody, but. I can't wait to see him, just can't wait to see him. I'm so excited.

Um but yea, um last year we lost somebody special in my family. That, that devastated the whole family.

M: mmm hmm

3: My older cousin, Brandon, he was 23, and he shot his girlfriend to death and then killed hisself.

And.... it was a gun.

And I was first year last year. In the same 22 unit, and it was me (Room mate), (Room mate) and (Room mate) in this unit. And, it devastated me, when I got a phone call from my mother saying Brandon committed suicide. And I couldn't sleep because I never thought of my own cousin would do something devastating

M: Sure

3: And it took my dad's mom to a whole nother level. How she lost a grandson and how her son and his wife felt about it and the other kids. Cuz they got 6 boys and one girl. And, all his brothers and his sister were devastated. Even their mother.

M: Mm hmm

3: And she took her bloody son's clothes. And then my uncles, my dad little brother said "throw the clothes away". And, it was just was devastating that we had to go through this as a family and we had to loose somebody special. And it my, it took my, it took everybody in the family to forget that what happened. And It took my grandma to a whole different level and how she sad. And she has to get all her grandkids over, and all her kids over, and celebrate his birthday. He, he was born on April 4<sup>th</sup>, I mean August 4<sup>th</sup>. And, we all were over at my grandma's apartment, my dad's mom, and she's still alive. And we had played music, there was food, then we got her in a big circle and then prayed you know for the healing and that he in a better place.

And, it just like devastated us that we had to like go through this as a family.

M: Yea

3: And my grandma said that "I don't want to go on no more seeing my grandson or my grand daughters

M: mm hmm

3: commit suicide." "We need to change our family. We don't have to be best friends, but we need to be family forever cuz family stick together".

And now I see what my dad saying to me. And what he's saying is that, I get when you are saying leave me alone or I need my space. I get that. See you 21. My dad understands that I'm 21 now, so when I get home for the summer, you know, sometimes I'm not gonna be like calling my mom and dad. I'm just gonna be like go on ahead. I'm not saying, I'm still going through my cousins death. I'm still going through it, but you know. When I go out with my auntie or uncle, to get the family together. I go see them, or they come see us. We all "Heeey". And then we don't ever forgot that hey, this person can't be here with us, he's is in a better place.

But we all doing good. We all moving past it. Everybody doing good, school and everything.

And my grandma doing good. She like seeing us. She like seeing her kids you know doing good. And she like seeing all her grandkids doing good. Well my grandmom want this for her children for her grandkids

M: So it sounds like your family community went through a pretty big tragedy, but pulled together and is doing well now.

3: yea

M: Ok, thanks for sharing that.

3: Uh huh

M: Um, so, of all the communities you talked about, you talked about your uh, community of [Pine Forest],, your block that you live on, gymnastics, and your family. Which one is the most important to you?

3: My family.

M: OK

3: Family comes first it has always come first, you know. I will never forget what family do for each other. They may fight, but family is family.

M: Ok, now um, what about a second most important one?

3: (Pause) Gymnastics

M: OK

3: You know, gymnastics is my life. I may not do it any more, but everyday, I see my sister and she just flip and she the person that stands out. I just say "Ooh, your so, I'm so proud of you, you still got it!". But I wish I can flip, because every time I flip its go back to the injury and it just effect my whole career. And my mom and dad say "All your life you wanted to do gymnastics, and you got to keep going, you can't", and like. I just. And my parents knew that I had a disability and they didn't want to say, they didn't want to push me that hard.

M:OK

3:So

M:Ok

3: Over the summer I'm working, I'm doing better, and I, you know, watching my sister compete

M: So your part of the gymnastics community but in a different way?

3: Yea, I will, you know, I'll go help set up, you know. Uh, I will, you know watch the girls practice. I will go with my mom, and then just wait inside the place for my sister.

M: Mm hmm

3: And I'm like "Oh my gosh I'm so proud of you". And all her gymnastics friends will come hug me like, "hey, we remember you. Hows your leg? We heard that you had a tragic injury" and it was, uh, "it was fine". And they like "we were so sorry, that we saw you, you were laying down"

M: Yeah

3: "and we just thought that, we thought".

I wasn't crying I was just in a lot a lot of pain,

M: Sure

3: When you like broke your leg, I heard something. And, there like They like "hey!". Coaches ran over, it took 10 guys to pick me up and put me in the ambulance

M: Wow

3: Because that leg was like in so much pain

M: Wow, sounds really bad

OK, so I have a couple of more questions. So do you feel relaxed when your involved in activities in your family community?

3: Yes

M: Ok, so can you tell me a little bit about that, what helps you feel relaxed?

3: When I, when my whole family get together on my dads side. We have a big family. And we all, you know, goof around. Its, we so funny. We all say "Cousin, Auntie, Uncle". They all say "Dang, Terri you got so tall, you should be playing basketball" It just be so funny how everybody come over my parents house. Everybody bring a dish and my dad barbque and we all be outside in the little alley and play basketball and we all. We all be "haahh"



All the girls go, you know, go in my room. We be "Haha, Oh my god". And the guys and women be in the summer talking. And then, It just be so fun because everybody get together and we all, you know, laugh, and we talk, and then we say prayers, and we eat. And my grandma, my dad's mom, she like to see this, she likes to see this she like to see all her children interacting.

M: Mm hmm

3: All the grandkids not fighting. Cuz she like, I just don't understand, soon you all gonna get married then have you family of your own. I'm like "yea, grandma, some of us wont do that ". So, you know. And she like seeing all her grandkids going to school and college. If it may effect one of us. So its good for me. But yea, you know, my grandma, my dad mom like seeing this.

M: Ok, so you feel relaxed around your family?

3: Yes

M: Ok, and do you feel safe when you are involved in activities in your family community?

3: Yea, because if I tell them something they wont be like "Oh my god, did your hear what Terri said about blah blah blah". And, They will not go to school or work tellin them "Oh, hey, Terri, my niece, blah blah, she's pregnant with this guy baby" You know, If I tell them "hey you know, my cousin" They wont be like "Hey (Whisper motion). They wont go work..

See my daddy, he own his own company, So if I tell my dad, he wont go to his job. My dad own his own business. My dad wont go to work and tell his co-workers "hey, you know what my daughter did? Blah Blah". Because I was like "Daddy! Daddy! Nooo!"

M: OK,

3: So I can trust my parents

M: Ok, so, like it feels safe because they don't talk about you behind your back?

3: They better not!

M: Hahaha

Ok, um and what helps, so, let me also ask you about your gymanastics community? Do you feel relaxed when you are involved in activities in the gymnastics community?

3: Yea, because the coaches, you know, love me. I they don't love me, but they know that like can be like their support and team mate

M: Uh huh

3: Like, when I put, when I got that cast off. And then doctor said do you want a cast on or do you want a boot on. I said a boot, so I can like walk around. And they were like "look at you, getting around!" With, you know, with the leg and everything. And this is my, look, this is the same leg, but, you know, it wasn't a fake leg, it was not my real leg. And I carried it. And it was just this part shattered.(pointing to leg)

M: Mm hmm

3: And I walked in, they was like "Oh my gosh, She's back" and everybody went to me and I was like "Hey, hey, hey, hey". I gave everybody hugs. But I don't want to ??? people.

Then my sister is like 'great, your back". And, I was just like "you don't understand". She was like, "hey, come on, the coaches want to see you". So feel safe that I'm part of the gymnastics community.

Because, even though I can't do gymnastics anymore, I still can, I still can go to gymnastics and support my sister.

M: Mm hmm, mmm hmm

3: Its what I'm here for, I'm here for her.

Its boring its slow, its like, oh my god. They have to warm up, they have to do the scratch and they have to go point by point, be like like oh my god. So, its just boring, but I j dont have a choice about it. I just have to.

I don't like gymnastics meets, my sister said "please come, come, will you please come" so I be like "Ugh, but it's so boring" So I just go, but I watch.

M: So do you feel safe?

3: Yes, I feel safe because I know that I can trust somebody that they, they wont you, know talk about my injury behind my back.

M: Any other reasons that you feel safe in the gymnastics community?

3: Because they like my second family.

M: Ok

3: We all get together over each other's houses and we spend the night and we just talk about each other.

M: OK, alright

What are things that make it hard to be a part of the gymnastics community

3: Um. You get out of school you gotta go straight to practice

M: OK

3: And... You don't get out of practice until like 9. Then you go home, eat dinner, do homework, do your chores, shower, then high school the next day.

M: And how about now, since you don't go to the practices as much you just go to the meets? Is there something that makes it hard to be a part of that community?

3: It depends. When we leave at the house, we had to be like rushin, we had be like "OK, Uh....Please pack your bags the night before." Because if we leaving as a family then its gonna be like "Ok, pack your bags the night before, cuz when we leave early in the morning, and I don't want to be forgetting things". To my mom then I say "OK, I'll help the girls pack, your help the boys pack". And my dad was like "I'll help the boys pack, you help the girls". And my mom be like, "Ok, wait,... I forgot something. Terri, you go get it. I'm forgetting something!"

It was like oh my god, its just, we be rushin because.....

Its just us and one family.

So we all pack our bags the night before because if we pack in the morning it wont work out.

M: Right

3: So, everything we had packed

M: OK, so you have to put some effort in to being able to get there

3: Yea

M: OK

Anything else that makes it hard to be a part of the gymnastics community?

3: Wakin up early in the, in the morning, and, starting to compete.

M: Umm hmm

3: Its, its really tiring me, like....

You have to put water on your face. Like my first, and, the first time my sister competed we were in a hotel and my mom had came to the bedroom and turned on the hotel lights. And I'm looking like "oh really mom?" and she goes (clapping) "light light, wakey, wakey were gonna roll!"

M: Um hmm

3: The competition, you know its like. "ugh, ok, you give me a second" and my sister is like "ugh" My moms like (claps) "we gonna be late". I'm like "just 2 more minutes" my dad was like "up, up, showers, brush teeth, get ready".

My sister had like acted like, help her get out of bed cuz she was so tired

M: Yea

3: "Mom, I just competed yesterday, I don't want compete again". We was like "You on the gymnastics" so it's really hard like get the whole family up. Cuz see, in our family, if one person wake up and it make a lot of noises, a lot of people wake up and make a lot of noises.

M: Yea

So are there things that make you feel unsafe in your gymnastics community?

3: (Pause) No.... Oh. There was this one thing. I have, I think, a 5 year old was running and fell off the vault, but she didn't hurt herself.

M:OK

3: And she, I was like "Oh my god, you ok?" she goes "I just wanted to jump" I was like "You 5, so if you, you know, did something to, you know, hurt yourself, it would be, you know, the coaches will really because they wasn't watching you."

M: Anything that makes you feel unsafe though?

3: Thinking of my injury again, you know.

M: OK

3: Going to a different gym. Imagining how to do it and not get injured

M: OK, alright

And then, what makes, what things make it hard to be a part of your family community?

3: (Pause) When we get to.... one argument, everybody jump in. Its scary because we get into each other's faces.

M: Mm hmm

3: And, we physically, like we put our hands on each other.

M: Umm hmm

3: And its scary how somebody gonna get hurt

M: Yea, that can be scary. Ok, is that a time you might feel unsafe as well?

3: Yea, because my cousin get in my face he's just saying "You!! Ugh!!" and he might punch me and I'm gonna be like..

M: Woo!

3: I don't, I don't think like that you're my cousin anymore. I don't think that, you know, punch me and you get this close to my face, then I think that you scary. You physically going to put your hands on me? With my parents and my dad watching you? You could get arrested for that and I could press charges.

M: Yea

3: So when everybody went "Oh! ha, I'll play with you". If I play with you and you physically get in my face, give me a black eye, then how my dad not gonna go crazy and you, I'm his daughter? And, the cops going to come and then someone gonna get arrested and then the cops gonna ask, do you want to press charges? And I'm gonna be like "You my cousin and I don't want you to get arrested and I'm not gonna press charges. But, if you... didn't, if you wasn't my cousin, then, if you physically hit me, then yea, I would press charges."

M: OK, Yea, that sounds like, a little scary.

Alright, are there other communities that you want to be a part of but you are not.

3: Um..... (long pause) Volleyball.

M: OK

3: I'm tall, so, I like playing volleyball.

M: Yea, And why do you think you are not a part of the volleyball community?

3: I don't know, its just when I play volley ball....

(burp) ooh, excuse me, sorry, I had wings today

M: Hahaha

3: So, um, volleyball, I said, I'm really tall, and I can like reach stuff at my house for my parents, well they tall too. But my siblings are shorties.

M: Haha

3: So, uh

M: So what do you think you aren't a part of the volleyball community? What keeps you from getting involved?

3: Um, I'm just afraid that if I hit the ball I would hit, you know, my dad in the face. Last time I played volleyball in my back yard

M: Uh huh

3: I threw the ball, hit my uncle in the back of the head.

M: OK

3: So, then, it didn't hurt him. But he was like "OK, Who did it? !". And I kinda said (raises hand) "Maybe you shouldn't play volleyball" (as in uncle's voice). I was like, "But its so fun" "but you hit people" (as in uncles voice)

"I was trying to hit the ball, but I hitted it in the opposite way"

M: umm hmm

3: It went one way, it hit you

M: Did they ever have a volleyball club or anything here at [Educational Program]? Or something though Depaul?

3: I mean, I figure that Depaul people don't really like us

M: What do you, tell me more about that.

3: We did an ice cream social

M: Yea

3: Yea, you came for Rush OT

M: Yea, last week

3: We did the ice cream social. DePaul people were really nice, you know. But, I just figured a lot came, but I just figured its [Educational Program]. But, a lot came but

I have DePaul friends, so you know, I'm not really into like DePaul sports

M: OK, sometimes they will have like an intermural team or something

3: Yea

M: But your not interested?

3: No

I do sports at home. I do sports at home where I can be like, proud of who I am. Around my family

If I do it at DePaul ,I'll be like I'm not gonna do sports

So if I do at home I'd be like "I'm not afraid! I can do this!". Everybody be like "you got it girl! You just need some more practice. " So I'm not afraid, if I do it, then, I love all my family

M: OK, alright. So do you get to make your own decisions about what communities you get to be a part of ?

3: Um, yea, If I tell my parents, if I say "hey mom and dad, you know, I want to, (pause), you know, (pause) do something in my life". And they go "What do you want to do in your life? Tell us".

I'm like, I'm just tired of my parents, cuz they got guardianship of me because my disability, they got guardianship over me.

And, I'm thinking, you guys babying me like I'm a two year old. And they like "we're not babying you! We love you."

"I'm sorry, I just feel like you guys are controlling my life"

They like "we your parents. What do you want us to do?"

M: Mm hmm

"We trying to keep you safe." I'm like "you can't keep me safe forever". "What happens if I just leave this floor (or world?) and never come back?"

They go, "this is why we got guardianship of you"

I'm like, "You don't understand, what happens Daddy if one day I get married and you don't have guardianship of me anymore?"

He go "Then your mother and I will walk you down the isle", well my dad will walk me down the isle

M: Mm hmm

3: Or both my parents, I haven't decided yet.

M: Haha

3: Well maybe both my parents will walk me down the isle and give me away to my husband and be like (arms outstretched). And then like....

What should I say? "Mom and Dad I think that you should let Jon Jon and me, Jon Jon, me, Nashi and Terrell, let go.

My dad like, that my job. "That's my job. My job is to protect this whole family".

Because god forbid something happen to my mom, or my brother, or me or my sis... my younger siblings. I'd be devastated. Or my Dad, Because I love my family.

I think all the time that if something happened to my mom, like if my mom gets in a car accident or my dad, if he get stabbed to death and he die....

M: So, is it sometimes an issue when you wanna make your own decsions

3: Its an issue that if I want to go to a friend's house to sleep over, I just let my mom know where I'm going, you know. She say "How you gonna get there? Is it a safe neighborhood?" you know, "How many people gonna be over the house?" I'm like "You don't need to know that !"

"I'm your mother" "I even know where your sister goes half the time!"

I'm like "She's sixteen, she's not gonna tell you everything!"

She go "Ooooh, now". I'm like "EWWWW, YOU".

"I'm your mother wanna know who you texting, who going, how many people gonna be in the car"

So it sounds like that's kinda frustrating for you

If I go to my Grandma house she says "Send pictures".

I'm like "How..... This is your mother in law! You know her dad and mom! Let me go mom, I'll be with cousins!" she go "And?". "They your nieces! They your nieces mom!" "Jesus!"

M: Now I have another kind of different question for you and its how do you give back to your communities? Do you know what I mean by that?

3: Yes

M: OK

3: We did, you know, things Thanksgiving day, me, my mom, my sister went to the homeless shelter.

M: OK

3: And we set up. And other the people did it too. And it was my mom, cuz my mom, my mom's a AKA.

M: In the AKA? What 's that?

3: It's a sorority

M: Oh, yea, yea, ok

3: So, me and my sister gonna be one. Um, but yea (Pause). We um. We did homeless thing. For the homeless people. While the boys played football. Because they boys. The boys play football, my dad says boys play football while we do something much funner.

M: Um hmm

3: Much fun to help homeless people. So my mom and I and my little sister did the homeless shelter with AKA and other people. And we gave back to the community by helping homeless and we told them it was shelter and free food

M: and how did you feel about that?

3: I felt good. I feel like I'm a give back person. So if I see a person on the street, I ...

I just, I feel sad that I don't like, I want to help them, I want to give them a place to stay. I would like to invite them here so they can like shower, and like get clean clothes. Like, like, go to the shelter But, I can't do that because its an apartment and security not gonna let them in.

M: mmm hmm

3: So, And, I can't bring them to my house because they might have bad plans and do something to my family.

M: Uh huh

3: So, I just feel like I know I'm like my time, I like, like "here is your sandwich" and "here's, you know, a water bottle"

M: Uh huh

3: and , uh, "I feel sorry that you eat out of the garbage". But um, And, "here"....if I saw a person like dig in the garbage, like I would , I go outside, at night time. And there was a person and he do this (leans toward interviewer). And I's like, drop the garbage and ran back in the house. cuz he give me this creeping look and its scary taking that garbage out at night time.

Sure

Because theres always be a homeless person looking at you like he gonna do something to you.

M: Have you ever done anything else to give back?

3: My mom and my dad, you know, they would help him to the car. But not me, I just feel bad. But my mom, you know, open her door and be like "here". And then he be like "God bless you" and my mom be like "God bless you too" and my dad, do the same thing.

M: Ok, alright. Well is there anything else you want to tell me about your participation in communities outside of [Educational Program]?

3: I mean, I love helping people. You know, I want to own my own daycare one day. Like my dad own his own business, I want to own my own business.

M: mm hmm

3: And I just want to make my parents proud of me because they know that I'm doing good in the [Educational Program]?

M: mmm hmm

3: and they know that I'm very smart with or without my disability.

And that everyone have a disability, we all do.

And.... my parents they is like, "you got 2 weeks left and your graduating". So,

And now, look at me now I'm graduating from the[Educational Program] and I'll be back next year, so I'm really excited to like meet my, meet new people and everything

M: mmm hmm

T: So

M: Great, well, thank you so much for participating in the interview

T: Uh huh

## Participant 4

M: Thanks for meeting with me today. We are just going to talk about community participation.

R: Ok

M: Read the introduction

So, what other communities do you feel like you're a part of?

R: Um, I volunteer at the [Green Tree Nature Center]

M: Ok

R: and I'm gonna do that this summer.

M: OK, great

Can you tell me a little bit about what you do there?

R: Um, we plant flowers and we pull weeds and, um, cut old trees and plant new ones.

M: Ok, and is it like a job or you said you volunteer?

R: Volunteer and its open to the community

M: OK, great

R: Yea

M: Are there other communities that you feel like you're a part of?

R: Um, I used to do horseback riding

M: Ok, can you tell me a little bit about that?

R: Um, I used to um, um, ride on the horse and trot with him, which is like running.

M: mm hmmm

R: And walk with him, and do like different stuff like with them, like courses

M: OK, great

R: They used to have and Olympics with um the horses.

M: Oh, neat.

R: Yea

M: Ok, um, other communities? That you feel like you are a part of?

R: Um, no.

M: Can you think about where you go outside of PACE where you're with other people?

R: Um, my family or my friends

M: OK, can you tell me a little bit about your family?

R: Um, I have family in Chicago so I get to see them a lot. And I have family, like my parents and my siblings.

M: mm hmm. So when you say you have family in Chicago you mean like aunts and uncles, cousins kind of thing?

R: Yea, yea

M: Um, great. And how about your friends, can you tell me a little bit about your friends?

R: Um, my friends live in [Forest Stream], so I get to see them some times. See movies or go out to lunch and or hang out at my house or their house.

M: Ok, so of the communities that you talked about, which one is the most important to you?

R: Um, volunteering at Green Tree Nature center.

M: Is it Green Tree? Is that what you are saying?

R: Yea

M: OK, Umm, And, what about a second, like number two most important community?

R: I, um, liked the horseback riding, that was really important to me.

M: OK, um, are you um currently doing horseback riding?

R: Um, no, but, um, I would like to go and watch my friend do it, cuz shes doing it this summer.

M: OK, so, um, do you feel relaxed when you are involved in activities at the Gree Tree Nature Center?

R: Yes

M: Ok, and what helps you feel relaxed there?

R: Um, like if I know what I'm doing I feel relaxed and calm. And if I have any questions I ask um the person whose is in charge of it.

M: Ok, and um, do you feel safe when you are involved in activities at the nature center.

R: Yea

M: And, what helps you feel safe?

R: Um, we wear gloves to keep us from cutting yourself. And there's thorns in the woods and that helps us a lot.

M: There's what in the woods?

R: Like thorn bushes

M: Oh, thorns, ok

R: yea

M: And..other things that help you feel safe? Besides things that help you feel physically safe, other things that help you feel like emotionally safe, like safe in a different way?

R: Um, what do you mean?

M: Like um, comfortable.... um, like, like, safe like you feel safe to ask a question. You don't feel like anyone is going to ignore your, or laugh at your, or make fun of you. That kind of thing. Do you feel safe that way?

R: Um, depends on the person.

M: Ok. So what helps you feel safe, like what about the particular people helps you feel safe?

R: If they are nice to you and respectful

M: Mm hmm

R: Like a person should treat you like you want to be treated

M: Mmm hmm

So what about your horsebackriding community? Do you feel relaxed when you are involved in activities with your horseback riding community.

R: Yea. Beause they let us, make us wear helmets in case we fall and we sit in the saddle and there's people watching you.

M: OK. So is that kinda like a safety thing

R: Yea, we wear boots too.

M: OK, um, and then how about relaxed? Do you feel relaxed?

R: Yea

M: When you're doing horseback riding?

R: Yea

M: And what helps you feel relaxed.

R: Um, whenever I'm on the horse and I can feel the wind going through my face and I feel um calm and if I know what I'm doing I feel relaxed

M: OK, great

M: Um, so what are things that make it hard to be a part of the Green Tree Nature Center community?

R: Um, I'm shy so I would like to be more social.

M: OK, so the things that you do at the nature center, um being shy makes that a little bit hard?

R: Yea

M: Ok, so can you tell me a little bit more about that?

R: Well, normally a lot of people talk there and I'm kinda out because I'm shy and I want to get more involved in talking to people.

M: Ok, um, what things make you feel unsafe at the nature center?

R: Um, the thorn bushes



M: Ok

R: Yea

M: Um, and then, is there anything that you worry about when you are at the nature center?

R: Um, Getting cut by the thorns and bleeding

M: mm hmm, OK, and then are there things that make it hard to be a part of the horseback riding community?

R: Um, just um, school gets in the way

M; OK, School as in National Lewis?

R: Yea

M: The PACE program ?

R: yea

M: Ok, So when was the last time you were able to ride?

R: Um, I think 2 years ago. I did it for a while but then school got in the way. When I graduated from high school and I went to college.

M: OK, um. And, are there anything, is the anything that makes you feel unsafe part of the horsebackriding community

R: Um, whenever there is not a person next to me at the horse just in case something happens.

M: OK. Are there other communities that you want to be a part of but your not?

R: Um, like, is mowing someone's lawn part of a community?

M: Um, mowing someone's lawn?

R: Yea

M: Ummmm, yea

R: Yea, I would like to mow someone's lawn

M: OK, Tell me about that

R: Um, Just in case in the future I need to mow a lawn and I don't know how to, I like to learn this summer by my parents or my brother.

M: OK, and is part of mowing lawns like making money?

R: Um, maybe, if they allow me.

M: OK, OK, um, any other communities that you want to be a part of but you are not?

R: Um, something to do with kids, like little kids.

M: OK, tell me more about that.

R: At the Green Tree, they um do like this thing where they teach kids and they go on activities. And um Trails, cuz there's trails there and I would like to help with that.

M: Um, so why do you think you are not a part of working with the kids at Douglas Heart?

R: Um, because I just didn't sign up for it but my mom talked to me about it so I might say want to do it

M: OK

R: But, I'm also kinda scared because I'm shy and you gotta be social to work with kids

M: Mmm hmm, mmm hmm

R: Yea

M: Um, so, in general do you get to make decisions about what communities you want to be a part of?

R: Yea

M: Do you get to make those decisions?

R: Yea, my mom helps me with it too.

M: Ok, um, and can you tell me a little bit about how your mom helps you?

R: Cuz she tells me about it and she helps me like fill out an application if I need to.

M: Ok, and how do you feel about being able to make your own decisions?

R: Um, I feel good because I make the right decisions

M: Ok, is it every scary for you to make your own decisions?

R: No

M: Ok, and the next question is a little bit different. How do you give back to your communities? Do you know what I mean by that?

R: Like by helping?

M: Mm hmm

R: Um, you help your community and if you..... Um, sorry I'm getting kinda distracted by the noise.

M: I know, what is that?

R: I think it's coming from upstairs

M: Oh, ok.

R: Yea, and you want to help your community and be a part of working because you need work experience in the future.

M: Mmm hmmm

R: So, what are ways that you feel like you contribute?

M: Um, I want to get more involved in community, cuz, um, I'm, it feels like I only get involved only once in a summer.

R: Ok, what is the way that, the once way you get involved?

M: Um, by looking, researching?

R: Ok

M: So you said, like you only get involved once a summer. What is that one thing you do in the summer?

R: Green Tree. Cuz they only do the program in the summer.

M: Oh, ok, ok

R: Yea

M: Ok, so can you think about any way you have shared something with one of your communities? And that community could even be like family or friends as well, or given back some way to them.

R: Um, yea, Like if I told any body about it?

M: Ummm, yea, or like contributed or shared something

R: Oh, yeah, I've shared with my uncles and cousins and my friends,

M: Ok

R: and my siblings too.

M: OK, shared what?

R: Um, what I did in a community

M: Ok, alright

Ok, so is there anything else you want to tell me about your participation in communities outside of PACE?

R: My presentations?

M: Your um, participation. Like, is there anything else you want to tell me about how you're a part of your communities outside of PACE?

R: Um, my mom helps me and she, um, the first time I did Green Tree she encouraged me to do it and I did

M: Ok, and is that how it usually goes for you?

R: Yea

M: She suggests something...

R: Yea

M: Ok, do you ever say no to what she suggests?

R: At first I'm afraid I'm not good, I'm, I'm, like I'm scared at first. But I think about it and we talk about it and I, um, say yes I want to do it.

M: OK. And what are the things your mom usually says to you to convince you to do something.

R: You should do it. Its gonna be good for you. Its gonna be a great experience, it will be fun, you will meet new people

M: Ok, What do you like about being part of, um, your community

R: Um, I get to meet new people and they are really nice. And I get to plant flowers and cut weeds and cut old trees and plant new ones to help the environment.

M: OK, Alright well that's all I had.

R: Ok

M: Thanks for answering all my questions.

R: Ok

M: Alright.

**Appendix I**

**Rush University Institutional Review Board Approval**

RUSH UNIVERSITY MEDICAL CENTER  
 1653 WEST CONGRESS PARKWAY, CHICAGO, ILLINOIS, 60612-3633  
 RUSH UNIVERSITY



OFFICE OF RESEARCH AFFAIRS  
 312.942.5488  
 312.942.2874 (FAX)

Institutional Review Board #1  
 FWA #: 0000462

### *Expedited Review Initial Approval Notification*

The following research activity has been reviewed and approved by the Institutional Review Board (IRB) at Rush University Medical Center. In accordance with the Federal Regulations found at 45 CFR 46.110, this review was conducted on an expedited basis:

Research on individual or group characteristics or behavior (including, but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and 49CFR46.110 social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. Category 7

Please note the date for continuing review. Although you will be notified near the time for continuing review, it is your responsibility to assure that your project receives ongoing IRB approval.

ORA Number: 16012005-IRB01

Principal Investigator: Molly Bathje

Project Title: Community Participation for Adults with Intellectual and Developmental Disabilities

Date of approval: 3/8/2016

Due for continuing/annual review: 3/8/2017

COI Management Plan Approved? Not applicable.

Waiver of informed consent: Not applicable

New Project Application

Consent Document: [Consent Document](#)

HIPAA Authorization: [HIPAA- SocioBehavioral](#)

Study Protocol: [Study Protocol](#)

Other (specify): [Recruitment Flyer: Adult and Adolescent Activity Card Sort Scoring Form\(0.01\); Interview Questions](#)

(The below is a representation of an electronic record that was signed electronically and is the manifestation of the electronic signature.)

John Cobb  
3/8/2016 4:20 PM  
Signing for Mary Jane Welch

Mary Jane Welch, DNP, APRN, BC  
Director, Human Subjects Protection  
Office of Research Affairs

**Appendix J**

**Western Michigan University Human Subjects  
Institutional Review Board Approval**

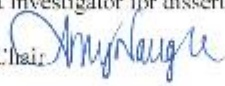
## WESTERN MICHIGAN UNIVERSITY



Human Subjects Institutional Review Board

Date: March 29, 2016

To: Nickola Nelson, Principal Investigator  
Molly Bathje, Student Investigator for dissertation

From: Amy Naugle, Ph.D., Chair 

Re: HSIRB Project Number 16-03-34

This letter will serve as confirmation that your research project titled "Community Participation for Adults with Intellectual and Developmental Disabilities" has been **approved** under the **expedited** category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note: This research may **only** be conducted exactly in the form it was approved. You must seek specific board approval for any changes in this project (e.g., ***you must request a post approval change to enroll subjects beyond the number stated in your application under "Number of subjects you want to complete the study."*** Failure to obtain approval for changes will result in a protocol deviation. In addition, if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

**Reapproval of the project is required if it extends beyond the termination date stated below.**

The Board wishes you success in the pursuit of your research goals.

**Approval Termination:**

**March 28, 2017**