

**Factors in Support Groups that Promote Positive  
Self-concept Development of Young Disabled Women**

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DISSERTATION

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## SUMMARY

A positive self-concept is vital to a person's physical and mental wellbeing. However, women with disabilities face many barriers to achieving and maintaining a positive self-concept and have difficulty making important transitions into adult life. These challenges include living independently and participating in gainful employment. Additionally, women with disabilities must negotiate harmful stereotypes regarding attractiveness and their ability to have intimate relationships and have children. This can be particularly detrimental to their overall self-concept. A few studies have shown that participation in support groups for women with disabilities is valuable in helping them to achieve a positive sense of self as well as a sense of belonging to others. However, past research has revealed few details about *how* the group process helps in the development of self-concept. This information is especially relevant for women navigating a critical developmental period: the transition into adulthood. Although some previous literature sheds light on how support groups help women cope with the onset of disability or illness, little is known regarding the specific aspects of the support group process that help women transitioning into adult life gain an affirmative sense of self. Additionally, few studies have examined which transitional milestones are subjectively important for young women with disabilities.

This research investigates both the transitional milestones that matter to women with disabilities and the specific factors within groups for women with disabilities that help them achieve a positive self-concept. These questions were investigated through qualitative semi-structured individual interviews with 12 women who are members of various online and in-person disability empowerment support groups. Qualitative

## **SUMMARY (continued)**

interviews with 11 group coordinators of in-person support groups for women with disabilities were also conducted.

The results revealed that the women encountered discrimination and inaccurate perceptions of disability from their family, medical professionals, and society at large. The women often internalized the negative perceptions of others. This resulted in a distorted self-perception about their value and capabilities as disabled women and made it difficult for them to become comfortable with who they are. The support group process helped the women recognize the falseness of what they had come to believe and helped them gain a more complete and accurate self-perception. This new vision of themselves encompassed a sense of comfort, confidence and disability pride, as well as the ability to see themselves as part of a larger collective of disabled women. Critical instances within the support group process that appeared to influence this newfound sense of self included a relational dynamic within the group that was distinctive and supportive, engagement in an attentive sharing process with similar others, and the power of community membership and the message and platform associated with it.

In regard to transitioning to adulthood, the women valued subjectively important markers, such as making their own decisions and being respected by others. The women reported their support groups provided them with both tangible resources and emotional support on their journey to adulthood. Group participation prompted some women to shift their focus from societal approved milestones of adulthood to transitional goals that were subjectively important to them.

## **SUMMARY (continued)**

Although there were pros and cons reported to both in-person and online group formats, a majority of the group members interviewed preferred the online format. It appeared younger women do not frequent in-person support. Both group members and group coordinators recounted a variety of barriers to younger women taking part in face to face support, such as lack of transportation, scheduling conflicts, and groups often being composed of older members. Thus, it was difficult for group coordinators to start and maintain successful in-person groups for young women with disabilities. However, according to the participants who did take part in in-person groups, the format appeared to yield similar results to the online support groups. These findings are valuable in the creation of support programs that help women with disabilities gain a positive sense of self and flourish within their own communities.

## I. INTRODUCTION

This chapter will first discuss the rationale for this dissertation and the specific research questions that were investigated. Next, the theoretical influences underpinning this research will be outlined followed by a discussion of my background as it relates to the topic of this research. Finally, the overall organization of this dissertation will be outlined for the reader.

### A. Summary of Research Problem and Research Questions

Research has shown that most people thrive during emerging adulthood (Arnett, 2007); this is not the case for most people with disabilities, as they tend to encounter adversity with regard to transitioning to adult life and experience a decline in their mental well-being during this time period (Ferro & Boyle, 2013; Galambos, Magill-Evans, & Darrah, 2008; Holmbeck & Devine, 2010). This has negative implications for the development of a positive sense of self, since emerging adulthood has been identified as a crucial period in the development of one's self-concept (Arnett, 2001). Moreover, women with disabilities often face particular challenges during this time in their development (Achterberg, Wind, de Boer, & Frings-Dresen, 2009; Powers, Hogansen, Greenen, & Gil-Kashiwabara, 2008). Their gender and disability status interact in complex and dynamic ways, making it difficult for them to obtain employment and meet other transitional milestones in the social and romantic realms, which are commonly associated with entering into adulthood.

Past research has established that support groups are indeed beneficial in helping women with disabilities and women with health conditions manage some of the challenges they face (Hughes, Robinson-Whelen, Taylor, Swedlung, & Nosek, 2004;



Jalovcic, 2008; Kriegsman & Celotta, 1981; Mundell, Visser, Makin, Forsyth, & Sikkema, 2012; Steihaug, Ahlsen, & Malterud, 2002). However, the factors within support groups that nurture positive changes in the self-concepts of young adult women with disabilities have been relatively unexplored.

Specifically, this research aimed to address the following gaps in the literature. First, some studies have explored the aspects of the support group process that are most advantageous to participants with health conditions, such as creating a safe space to share emotions, information, and personal stories, providing opportunities to be around others in similar situations, and fostering mutually beneficial relationships in which the helper gains as much as those helped (Ahlberg & Nordner, 2006; Cawyer & Smith-Dupre, 1995; Steihaug et al., 2002). However, these studies focus primarily on the coping process as it relates to people with chronic illnesses and do not delve into the process through which support groups facilitate a change in the self-concept of its members. Second, many of the support groups used in past studies have included only individuals with chronic illness, such as cancer, chronic pain, or HIV/AIDS, which are often mutable and are not present throughout the life course. Thus, these studies shed little light on crucial components of the support group process that influence positively the way people with long-term disabilities view themselves. Third, most of the support group research does not focus on groups that are composed solely of women. Since women with disabilities often face unique issues, such as those particularly related to gender, it is important that research begins to tap into the factors within women-only support groups that might help women with disabilities combat the complex interactions of disability and gender oppression. Last and perhaps most importantly, past studies have focused primarily on

mature adult women, not women navigating the critical period of young adulthood.

Further exploration addressing these research gaps is critical to the development of more support groups that help women with disabilities foster and maintain a positive sense of self and make a successful transition into adulthood.

Throughout the recruitment process for this research, it was discovered that a majority of younger women do not regularly take part in face-to-face support groups for women with disabilities. This research explored the reasons behind this. In addition, the study was amended to include online support group users in order to determine whether this is a viable avenue to support for young women with disabilities.

The present research explored participation in both online and in-person support groups with the goal of discovering key components that women with disabilities perceive as helpful in improving their self-concept. Specifically, the primary research questions were as follows:

- What factors within the group process lead to a positive change in the self-concept of young women with disabilities?
- How, if at all, does participation in the group help them meet transitional milestones of adulthood that are important to them?

Some secondary questions were also explored:

- What life goals and transitional milestones are important to them as women?
- What is the mission/philosophy being conveyed by the group, and how, if at all, does this mission/philosophy affect the women's self-concept?
- In the process of attempting to recruit participants, it was discovered that some in-person groups for disabled women had been discontinued for various

reasons. This finding was explored further through interviews with past group coordinators. In addition to the original research questions, these past group coordinator interviews focused on the challenges organizations face in maintaining a support group, and what resources may be/would have been helpful in overcoming these challenges.

- Where are younger women getting their support if not through in-person peer support groups? Online groups seem to be a viable option, so elements of those groups became relevant to this research as well. To that end, the benefits and drawbacks of online vs. in-person support groups were also explored.

All research questions were investigated using qualitative research methods. Qualitative interviews were conducted with disabled women who were members of online and/or in-person support groups and with group coordinators of in-person groups for women with disabilities.

## B. Theoretical Influences

There are several theoretical frameworks that inform the present research. One theory that significantly factors into the impetus for this study is Social Identity Theory (Tajfel & Turner, 1979). This theory suggests that group membership is an important part of a person's self-concept. A few studies have demonstrated that participation in a support group for women with disabilities is valuable in helping them obtain a positive self-concept and sense of belonging to others (Hughes et al., 2004; Jalovcic, 2008; Kriegsman & Celotta, 1981; Mejias, Gill, & Shpigelman, 2014; Steihaug et al., 2002). These findings are conceptually rooted in and are confirmatory of Social Identity Theory.

This framework highlights the importance of group membership to one's self-concept and is a valuable tool for conducting this type of empirical research.

The social model of disability also underpins this research. This model separates impairment, a person's bodily or functional limitation that results directly from a medical condition, from disability, which is a socially constructed disadvantage (Oliver, 1996). This disadvantage arises from a multitude of factors including environmental, attitudinal, structural, and economic barriers. The social model places less emphasis on impairment and focuses on social barriers, which are shared aspects of the disability experience, regardless of the type of impairment a person is living with. Thus, this model provides fertile ground for people with disabilities to come together across diagnostic categories and resist disability oppression. The tenets of the social model influence this research on many levels. These include selection of the research topic to research questions and the methods through which these questions are explored.

Finally, this research has roots in feminist theory (Hartsock, 1998). As such the perspectives of women are privileged and their right to tell their own stories from their socially situated vantage point is acknowledged. Furthermore, this study in part aims to illuminate gender-based oppression and its intersections with disability.

### C. **Investigator Background and Positionality**

My interest in this research topic sprang from my own life experience of growing up as a woman with a physical disability. Throughout my childhood and young adult life, I encountered many barriers including outright discrimination and low expectations from teachers and medical professionals. Unfortunately, I have never had the opportunity to take part in a disability support group of any kind, leaving my family and me to

navigate the challenges I faced alone. It was not until I entered graduate school to pursue disability studies that I began to truly understand the nature and power of disability community and the culture and pride that stems from it.

While pursuing my master's degree in disability studies I was introduced to a Chicago-based disability empowerment group for young women with disabilities. As part of a project for a qualitative methods class, I had the opportunity to interview a woman who was a member of the empowerment group. During the interview, the young women poignantly recounted her close-knit relationship with the other group members and that she had gained a new understanding of herself and her disability. Her story really resonated with me. My curiosity was sparked. Would participation in a disability support group lead to an increase in self-worth, disability pride, and sense of belonging for others, as it did for this young woman? I wanted to investigate further and perhaps one day create more empowerment-oriented support groups.

With this in mind, my master's thesis explored the sense of belonging that emerged among members of a support group for disabled women. Results of this research revealed that a sense of belonging did flourish among group members in a variety of ways (Mejias et al., 2014). In addition, many of the members reported developing a positive self-concept from their participation in the group. This finding was particularly intriguing. I wondered what critical instances within the support group process were responsible for this apparent change in group members' self-concepts. Thus, the impetus for this research was created.

My worldview is informed by my status as a physically disabled Hispanic woman in her mid-30s from an upper-middle class background. A disability studies perspective,

particularly the social model of disability, also influences me. Finally, my undergraduate studies sparked my interest in social psychology and how other people influence our thoughts, feeling, and action. These are the lenses through which I collected the data and interpreted the results.

**D. Organization of the Dissertation**

This dissertation is organized in the following manner: first, the literature review will provide background for the research questions and highlight existing gaps in the literature which this research is designed to address; second, the theoretical framework which helps guide this study will be further explored; next, the methodological approach used for this research will be systematically outlined and justified. The research results will be presented, along with examples from the interview responses of the study's participants. This will be followed by a discussion of how the results address the study's research questions and fit with the current body of literature. Study limitations and directions for future research will also be explored. Finally, the implications of the research findings will be examined and recommendations for future support groups will be presented.

## II. LITERATURE REVIEW

This literature review is composed of several sections. First, the multi-dimensional and often nebulous nature of the self will be discussed. Second, the importance of emerging adulthood and its connection with identity formation will be outlined. Third, the specific barriers faced by women with disabilities as they transition into adulthood and attempt to form a positive self-concept will be examined. Last, both in-person support and online groups are explored as a possible means to help women with disabilities progress into adulthood with a positive self-concept.

### A. **Background on Self-Concept**

Over the past several decades there has been much debate regarding how to define self-concept. In the most general terms, self-concept may be best defined as images or beliefs we have about ourselves (Jordan, 1994). Baumeister (1999), a noted scholar in the area of social psychology, asserts that there are three major experiences that form the basis of selfhood: executive function, interpersonal being, and reflective consciousness. Executive function entails making choices, initiating actions, and exerting control over self in the world. The second major experience related to the basis of selfhood is interpersonal being. Baumeister sees the self as neither created nor discovered in social isolation. Rather, people connect and interact with others and alter their behavior when others are watching. Interpersonal interactions have the capacity to alter self-perceptions. Third, reflective consciousness refers to the idea that the human intellect is able to turn its attention back towards the self in order to seek the self. Humans are self-aware but the self is not known directly; rather, it is observed in action or inferred in social events. Self-awareness includes self-knowledge. People acquire self-knowledge in a variety of ways such as engaging in

social interactions. The environment and significant others also heavily influence self-concept (Bong & Skaalvik, 2003). These three experiences begin to illuminate the multi-faceted nature of self-concept, and how those around us influence it.

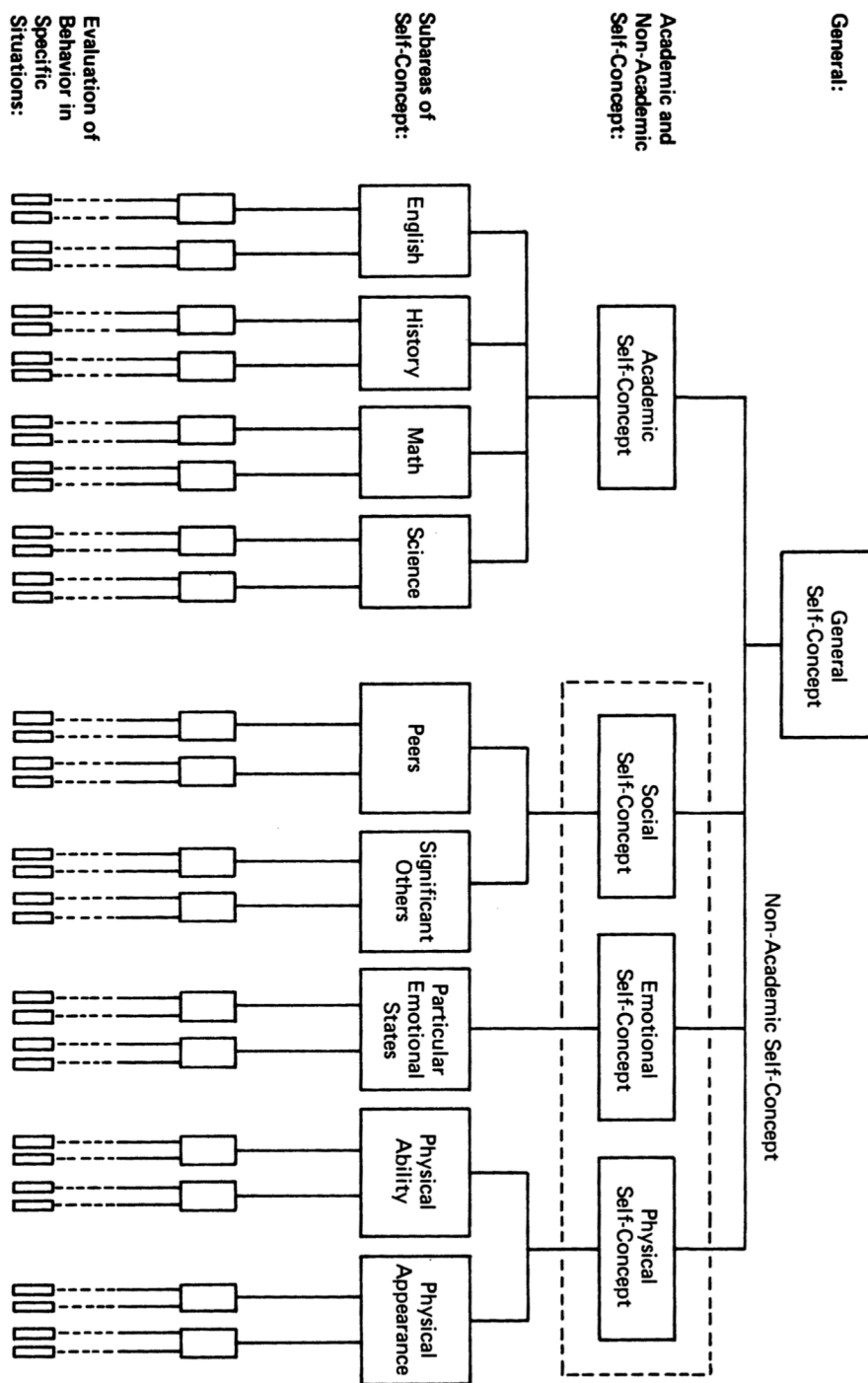
In fact, most scholars refute the notion of a singular all encompassing self-concept and now advocate for the multi-dimensional nature of the self (Baumeister, 1999; Bong & Skaalvik, 2003; Demo, 1992; Shavelson, Hubner, & Stanton, 1976). This is mainly because examining the self-concept as one distinct construct diminishes its power to explain behavior (Bong & Skaalvik, 2003). In the past few decades researchers have defined the dimensions of self-concept in different ways; however, most of these dimensions lack clarity (Demo, 1992).

Shavelson et al. (1976) created what appears to be one of the more thorough examples of the multi-dimensional self (Figure 1). They focused on students and saw self-concept as a hierarchy in which the general self-concept is at the apex of the model. The next levels are comprised of the academic and non-academic self-concept. The academic portion is divided into several subject areas including English, history, math, and science. On the other hand, the non-academic portion is comprised of the social self-concept (peers, significant others), emotional self-concept (particular emotional states), and physical self-concept (physical ability and physical appearance). Although this model is focused on students, it provides a clear example of how the self-concept is indeed compartmentalized into many dimensions. It is the non-academic portion of self-concept that is the primary focus of this research.



**FIGURE 1**

A representation of the hierarchic organization of self-concept



One representation of the hierarchic organization of self-concept (Shavelson et al., 1976).

Reprinted with permission (Appendix A).

Some relatively recent research provided empirical support for Shavelson et al.'s (1976) notion that self-concept has domain specificity. Leung, Marsh, Craven, Yeung, and Abduljabbar (2013) conducted two studies in which adolescents aged 12 to 14 received peer support interventions that were intended either to increase academic verbal skills or to increase interpersonal skills. Results revealed that in both instances, when compared to a control group, participants experienced an increase in self-concept only in the domains in which they had received the intervention. An overall increase in self-concept was not found. Thus, self-concept appears to be compartmentalized and consists of multiple components rather than being one all-encompassing construct.

The multiple components of the self-concept are not completely stable and are susceptible to change over time (Demo, 1992; Oyserman, Elmore, & Smith, 2012; Shavelson et al., 1976; Polkinghorne, 1991). Shavelson et al. note that although the top of their hierarchical model (general self-concept) is relatively resistant to change the lower components (academic self-concept and social self-concept), are changeable. Furthermore, self-concept fluctuates across the lifespan as biological development and social processes take place (Demo, 1992 Oyserman et al., 2012 ). Polkinghorne offers a useful way to conceptualize the ever-changing nature of self-concept as viewed within a narrative structure. The stories that comprise the self-narrative are heavily ensconced within and built out of a person's particular cultural environment, consisting of patterns of belief and values. This self-narrative is constantly under revision as a result of social interactions occurring throughout one's life history. This notion has positive implications for interventions that aim to provide opportunities for people to cultivate strong peer relationships. Strong peer relationships, in turn, will help develop a healthy sense-of-self.

B. **Emerging Adulthood and the Development of Self**

Emerging adulthood is a crucial time in which one's self-concept undergoes major revisions. This period typically takes place between the ages of 18 and 25 (Arnett, 2000). Arnett asserts that this period is not merely a time of transition, but is also a distinct developmental period within the life course. According to Arnett, most emerging adults in Westernized countries are not restricted by role expectations such as those associated with being a parent or spouse. Thus, independent exploration in the areas of love, work, and world-views characterizes this time in a person's life.

The high rate of change in residential status helps put in perspective the exploration that takes place in emerging adulthood. Goldscheider and Goldscheider (1994) examined multiple cohorts of different ages and found that those entering young adulthood experienced the highest degree of residential change with 40% moving back into their parents' home and then out again as they explored academic, vocational, and romantic options. Surprisingly, Goldscheider, Goldscheider, St. Clair, and Hodges (1999) found that social status and ethnicity did not affect the rate at which young people transition out of their parents' home or the rate at which they return home.

For many young people, however, it is not demographic transition that signifies the passage into adulthood, but rather subjective individualistic criteria. For instance, Arnett (2001) found that emerging adults, as well as adolescents and mid-life adults, all identified individualistic criteria as among the most important aspects of transitioning into adulthood. These criteria include accepting responsibility for one's actions, deciding one's beliefs and values, independent decision-making, and becoming financially independent. Similarly, Sharon (2015) surveyed 1,133 emerging adults, regarding the milestones of adulthood that

were important to them. Results revealed that several individualistic, non-traditional markers of adulthood were among the most important for their participants. Over 94% of participants in their research said that making independent decisions were an important hallmark of adulthood. In contrast, traditional objective milestones such as getting married and having full time employment were seen as a less important part of adulthood. Reaching these hallmarks of transition helps to revise and shape who we are as people.

Research supports the notion that most people positively experience the period of emerging adulthood. In fact, psychological well-being appears to increase during emerging adulthood (Arnett, 2007; Galambos, Barker, & Krahn, 2006). For example, using a community-based sample of 920 people ages 18 to 25, Galambos and colleagues (2006) conducted a five-year longitudinal study examining the trajectories of depressive symptoms, self-esteem, and expressed anger during the period of young adulthood. They found that depressive symptoms and expressed anger decreased while self-esteem increased during this five-year span. Thus the identity exploration and absence of role restraints in emerging adulthood appear to be psychologically invigorating when there is no adversity to overcome (Arnett, 2007).

Unfortunately, young people with disabilities who are navigating through emerging adulthood appear to be at significantly greater risk than their non-disabled counterparts for experiencing diminished psychological well-being (Ferro & Boyle, 2013; Galambos, Magill-Evans, & Darrah, 2008; Holmbeck & Devine, 2010; Janus, 2009; Klein, Glenn, Kosty, & Seeley, 2013; Rohde & Lewinsohn, 2012). As a result, incidents of depression are particularly high among young people with disabilities during this time. For instance, Galambos et al. (2008) surveyed 74 young people with motor disabilities aged 20 to 30 and

74 young people without disabilities within the same age range. They found that those with motor disabilities (43%) were twice as likely to experience depressive symptoms as those without motor disabilities (21%). Likewise, Klein et al. (2013) found that among their sample of 502 young adults aged 19 to 31, experiencing physical health problems was a significant predictor of the onset of major depressive disorder. The increased risk of experiencing psychological health problems is not limited to those with physical disabilities. People with intellectual disabilities are at a four times greater risk of experiencing affective conditions such as depression and anxiety than their counterparts without disabilities (Richards, Maughan, Hardy, Hall, Strydom, & Wadsworth, 2001).

This diminished psychological well-being may be in part due to difficulty completing important milestones and transitions that are hallmarks of adult life. In order to explore the completion of milestones, Janus (2009) analyzed data from the National Education Longitudinal Study of 1988, which followed 9,345 young people from 8<sup>th</sup> grade until age 26. Those participants who reported having a visual, hearing, speech, or other physical impairment were significantly more likely not to have completed any transitional milestones as compared to those participants without disabilities. These milestones included acquiring full-time employment, establishing independent residency, getting married, and having children. These findings were further supported in a meta-analysis examining the accomplishments of traditional developmental milestones of those with disabilities and without disabilities. Pinquart (2014) conducted a meta-analysis of 165 studies comparing attainment of adult milestones of people ages 18 to 30 with and without chronic pediatric illnesses. He found that when compared to their nondisabled counterparts, those with chronic illnesses had lower rates of completing higher education, having children, finding

employment, leaving their parents' home and getting married. It is important to note that these milestones reflect Western dominant values. Thus, this research sheds little light on transitional milestones that do not adhere to dominant values but may be important to some young people.

Relatedly, Holmbeck and Devine (2010) found that emerging adults with spina bifida were at risk for delayed completion of milestones related to vocational and educational attainment. These individuals also encountered barriers in independent functioning and social adjustment. Blum (2005) notes that the difficulty young people with disabilities face during transition to adult life can be in part attributed to the fact that many services that are available during childhood, such as those provided in special education, are terminated following their twenty-first birthday or after they receive their high school diploma.

Given the difficulty in completing these transitions, young people with disabilities may have fewer opportunities to engage in identity exploration, which is characteristic of emerging adulthood, than their non-disabled counterparts. Luyckx, Seiffge-Krenke, Schwartz, Goossens, Weets, Hendrieckx, and Groven (2008) found that 18-30 year olds with Type 1 Diabetes scored significantly lower on identity exploration in terms of both depth and breadth than their counterparts without diabetes. These results are particularly disturbing given that identity exploration has been theorized as imperative for forming a strong sense of self in adult life (Arnett, 2001).

Young people with disabilities or chronic health conditions are indeed more likely to have a less positive self-concept than their non-disabled counterparts. In their analysis of data from the Canadian National Longitudinal Survey of Children and Youth (ages 10-19),

Ferro and Boyle (2013) found that those with chronic illnesses or developmental disabilities had a significantly less positive global self-concept than those without disabilities. These results have also been duplicated in a sample that included individuals navigating through emerging adulthood. Luyckx et al. (2008) found that individuals with diabetes, aged 18 to 30, were less likely to have a strong sense of self than those without diabetes. Participants who did manage to form a strong sense of self experienced a multitude of beneficial outcomes including less depressive symptoms and better coping skills. Although this study only included individuals with a chronic health condition and not necessarily a physical or cognitive impairment, it does vividly illustrate the importance of obtaining a strong sense of self during emerging adulthood for those who encounter health-related challenges.

Psychological well-being is considered a central component of one's self-concept (Craven & Marsh, 2008). Recent research has indicated that viewing disability in a positive light is related to an increase in emotional well-being for emerging adults with disabilities. In their sample of 521 emerging adults with disabilities Chalk, Barlett, and Barlett (2019) found that maintaining a positive perception of disability was significantly associated with increased life satisfaction. This highlights the importance of disabled people gaining and maintaining favorable perceptions of their disability experience. However, as discussed in the next section, sustaining a positive view of disability and one's self in general can be fraught with challenges, especially for women with disabilities.

C. **Barriers Encountered By Women in the Transition to Adulthood and Implications for Self-concept**

Both women and men with disabilities face obstacles when attempting to complete important transitions of young adulthood. However, there is ample evidence to suggest that

young women with disabilities face unique challenges that young men with disabilities do not encounter (Achterberg, Wind de Boer, & Fringe-Dresen, 2009; Hogansen, Powers, Geenen, Gil-Kashiwabara & Powers, 2008; Powers, Hogansen, Geenen, Powers, & Gil-Kashiwabara, 2008). The transition into employment is one important transition of young adulthood that appears to reflect significant gender disparities. Women with disabilities are less likely to be employed than women without disabilities and also less likely to be employed than their male counterparts with disabilities (Erickson, Lee, & Von Schraeder, 2012; Kim, 2019). Using the U.S. Bureau of Labor Statistics, Kim (2019) calculated that only 28% of women with disabilities were employed in 2018. This is compared to 68.6% of women without disabilities. Men with disabilities appear to fare a bit better in the labor market with 31.7% of them being employed in 2018. Furthermore, in a comprehensive literature review of 1,268 studies which explored the promoting and inhibiting factors of employment for people with disabilities, Achterberg et al. (2009) found that being female was one of the biggest inhibitors to being gainfully employed. These findings illuminate the multiple or intersecting vectors of discrimination that women with disabilities encounter when attempting to enter the labor market.

Although there are likely multiple factors that account for the data presented above, low self-esteem and low self-confidence appear to be a significant barrier to employment for young women with disabilities (Lindstron, Harwick, Poppen, & Doren, 2012). Lindstron et al. (2012) surveyed high school girls with disabilities, college women with disabilities, high school and special education teachers, school administrators and employees regarding the transition and development needs for young women with disabilities. All participants identified low self-esteem and low self-confidence as major barriers in the transition to



employment. It is important to note that the low self-esteem and low self-confidence reported by Lindstron et al.'s respondents may have been the result of the young women internalizing others negative views and low expectations of them. College women and high school girls also identified a lack of transition services as being a barrier with regard to moving from school to work. Those who do make the transition from school to work often have limited options that are constrained by gender stereotypes. For instance, young women are more likely to be employed in occupations revolving around domestic life, such as house cleaning and caregiving, than men (Powers et al. 2008; Wagner, Cadwallader, & Marder, 2003). Furthermore, Lindsay, Cagliostro, Albarico, Srikanthan and Mortaji (2018) conducted a recent systematic review of 48 studies examining the role of gender in gaining and maintaining employment among disabled people under the age of 30. They found that gendered expectations such as women being expected to spend more time with family and overprotective parents were barriers to disabled women securing and maintaining paid work.

Many college women and high school girls do not have a firm understanding of their disabilities and the types of support and strategies they might need to succeed in employment or post-secondary training. Powers et al. (2008) surveyed female youth with disabilities and their parents. Results revealed that young people did not frequently express feelings of pride related to differences associated with their disabilities accommodations.

Disability awareness training as well as assertiveness and self-advocacy training has been suggested to remedy these barriers (Lindstron et al., 2012). Unfortunately, these types of programs are scarcely available to youth and young adults with disabilities and almost none are tailored to the unique needs of young women with disabilities.

Numerous studies have indicated that chronic unemployment is associated with decreased levels of psychological well-being and deflated sense of self (Daly & Delaney, 2013; Pietromonaco, Manis, & Markus, 1987; Wanberg, 2012). For instance, Daly and Delaney (2013) found that among their sample of 6,253 British adults, a lifetime of unemployment was a significant predictor of psychological distress at age 50. These results were obtained even after controlling for other socio-demographic factors that are known predictors of psychological distress. The psychological impact of unemployment has also been demonstrated in studies solely comprised of women. Pietromonaco et al. (1987) surveyed both employed and non-employed women; they found that career-driven women who were employed full-time were happier in their lives than career-driven women who were unemployed or employed part-time.

Studies have also shown that employment status has significant implications on the self-concept of young people. Patton and Noller (1990) conducted a longitudinal study in which they investigated the effect of unemployment on adolescent self-concept. They found that those adolescents who had been unemployed for two or more years scored significantly lower on a multi-dimensional measure of self-concept than those who were employed. Given the psychological implications of engaging in consistent gainful employment, it is imperative that disabled young women are given the support they need to close the gender gap in this regard.

Women with disabilities not only have difficulty transitioning into the labor market, but they also face a myriad of other challenges in reaching milestones which are hallmarks of young adulthood. For instance, young women with disabilities are less likely to live on their own after graduating from high school than are young men with disabilities (Powers et

al., 2008). They are also more likely to have their activities restricted due to safety concerns (Lindsay et al., 2018; Powers et al., 2008). Powers et al. (2008) found that 42% of parents of females with disabilities indicated that they were likely to discourage their daughters from doing something because of safety concerns, while only 35% of parents of males with disabilities reported this. These findings are particularly worrisome given that living independently and freedom to explore one's own identity is crucial to successful transition into emerging adulthood (Arnett, 2007).

Taking part in romantic relationships is another rite of passage that often takes place during emerging adulthood. However, women with disabilities yet again face obstacles within this realm. Rintala, Howland, Nosek, Bennett, Yong, Foley, and Chanpong (1997) vividly captured some of these obstacles. They surveyed 250 single women with physical disabilities and 180 women without disabilities regarding the dating issues they faced. Results revealed that women with disabilities were significantly more likely to report perceived societal barriers (e.g., negative attitudes, environmental constraints), perceived personal barriers (e.g., pressure from family members not to date), and perceived more constraints on attracting partners than women without disabilities. Given these findings, it is not surprising that women with disabilities reported significantly less satisfaction with their dating life than women without disabilities.

Similarly, Kinne, Patrick, and Doyle (2004) surveyed both people with and without disabilities and found that 14.9% of people with disabilities experienced a lack of romantic relationships compared to only 6.3% of respondents without disabilities. Women with disabilities also report greater fear when it comes to engaging in activities that often lead to the establishment of romantic relationships. For example, Lysack, Neufield, and Dillaway

(2014) found that women with spinal cord injuries reported significantly greater risk associated with revealing personal information to others, going on a blind date, or a roll/walk after dark than their male counterparts.

The difficulty establishing dating relationships often leads to trouble in establishing serious, romantic or marital relationships. In 2018 the marriage rate for people without disabilities ages 18-49 was estimated as 71.8 per 1000 people. However, for people with disabilities this statistic drops to approximately 41.1 per 1000 people (PensandNeedles.org, 2018). Women with disabilities are susceptible to unique challenges in the romantic realm. Nosek, Howland, Rintala, Young, and Champong (2001) surveyed 475 women with physical disabilities and 406 able-bodied women. They found that 64% of the women without disabilities were married or involved in a serious relationship compared to 52% of women with physical disabilities. Furthermore, among women with physical disabilities who were not married or in a serious relationship, 42% of them said it was because no one had asked them. Only 27% of women without a disability cited this as a reason for not being in a serious relationship. Although women with intellectual disabilities may be more likely to marry than women with physical disabilities, they often lack access to sex education and are less likely to have interactive sexual experience than their counterparts without disabilities (Dotson, Stinson, & Christian, 2003; Szollos & McCabe, 1995).

Trouble in the romantic realm for women with disabilities appears to extend beyond the borders of the United States. Wiegerink, Stam, Gorter, Cohen-Kettenis, and Roebroek (2010) conducted a four-year longitudinal survey of 61 Dutch men and 42 women with cerebral palsy (ages 16 to 20) regarding their sexual activity and romantic relationships. It was found that young adults with cerebral palsy participated less in romantic relationships

and sexual activities when compared with an age-appropriate Dutch reference group. However, an equivalent level of sexual interest was expressed for the duration of the four-year study.

The barriers women face in their romantic lives have been associated with negative implications for their self-concept as well as increased vulnerability across the globe (Gartrell, Baesel, & Becker, 2017; McCabe & Taleporos, 2003; Rousso, 1996). In a recent study Gartrell et al. (2017) interviewed 33 disabled Cambodian women concerning their sexual and reproductive health experiences. They found over half of the women were single and did not have children. The women who had never been married, did not have children and lacked social support reported experiencing the greatest vulnerability with regards to social discrimination, violence and poverty. It is important to note that recent research has found that being connected to service organizations is central to improving both social relationships and intimate relationships for people with disabilities (Friedman, 2019). This bodes well for the potential value of support groups in this regard.

Issues encountered in the romantic realm are further compounded by body image concerns and low sexual self-esteem (Appleton, Elis, Minchom, Lawson, Boll, & Jones, 1996; Moin, Devdevany, & Mazor, 2009; Taleporos & McCabe, 2001). Taleporos and McCabe (2001) used focus groups and survey data to investigate how physical disability impacts body esteem. In their sample of 35 people with physical disabilities between the ages of 19 and 60, it was discovered that having a physical disability commonly affected body image. For instance, 24 participants either strongly agreed or agreed with the statement, “I would look much better if I didn’t have a disability.” Furthermore, participants seemed to covet normal bodies: 22 participants either strongly agreed or agreed

with the statements, “I envy people with normal bodies” and “I would do a body swap with an able-bodied person if I could.” During the focus groups, some women discussed at length how they only took pleasure at looking at the reflections of their non-impaired body parts and how they would go to great lengths to hide the parts of their bodies that were impaired. Additionally, Taleporos and McCabe (2005) found that except for the face, people with physical disabilities devalued all aspects of their bodies more than able-bodied people. They also found that those with more severe impairments had lower body esteem than those with milder impairments or able-bodied people.

Relatedly, Moin et al. (2009) surveyed 70 women with a physical disability and 64 women without a physical disability concerning their body image and life satisfaction. Women with physical disabilities were found to have the same sexual needs and desires when compared to their non-disabled counterparts. However, they had significantly lower body image, sexual self-esteem (self-perception of being a good or bad sexual partner), sexual satisfaction and overall life satisfaction when compared to women without disabilities. Importantly, these differences were stronger among young adult women (aged 21 to 30) than among more mature women. This demonstrates the need to tailor interventions aimed at helping emerging adult women with disabilities develop a more positive sense of self.

Studies focusing on the body image of women with disabilities have almost exclusively focused on women with physical disabilities. However, Eden and Randle-Phillips (2017) recently surveyed 48 individuals with intellectual disabilities and found that they generally had a positive perception of their body. That said, there is evidence to suggest that people with intellectual disabilities struggle with body image issues. For

instance, Gravestock (2000) notes that people with intellectual disabilities are at increased risk for a variety of eating disorders, which have been linked to body image issues and low self-worth. This is particularly pertinent given that there is a longstanding established link between one's body image and self-concept, especially for women.

Lerner and Karabenick (1974) empirically demonstrated this link when they surveyed 70 men and 119 women college students regarding their self-perceived attractiveness and how physically attractive they assumed each of their own body parts were. Participants also completed a self-concept scale. Results revealed that physical attractiveness ratings were significantly related to self-concept for women but not for men. Furthermore, a large number of the attractiveness ratings for individual body parts were related to self-concept for females, but not for males. For instance, shape of legs, profile, thighs, waist and ankles were all highly correlated to self-concept for women only. In a slightly later study, Lerner and Brackney (1978) found that more external body features (e.g., general outward appearance and height) than internal body features (e.g., brain and heart) were significant predictors of female self-concept. These results have negative implications for young women with physical disabilities as their bodies often fall outside the socially constructed norm, thus making it more difficult for them to build and maintain a positive sense of self.

The problems women with disabilities face when gaining and maintaining a positive sense of self do not occur in a social vacuum. Cultural stereotypes and oppressive beliefs about these women are pervasive in our society. Women with disabilities often receive societal messages that they are not important, that they are not full human beings or valued members of the women's community (Nario-Redmond, 2010). They are widely viewed as

incompetent, child-like, asexual, and incapable of sexual expression. As a young woman with cerebral palsy interviewed by Dune (2014) poignantly recounted:

The messages we are getting is that you're not sexually attractive; you're not going to get anyone to do that [have sex with you]. You're not going to have someone who is going to love you outside of your family. ... It's going to affect your social development. (p. 9)

Furthermore, the outside world often perceives women with disabilities as not being able to partake in traditional gender role activities, such as dating, marrying, and childbearing. Nario-Redmond (2010) empirically demonstrated the societal stereotypes that women with disabilities must combat. She found that women with disabilities were never described as feminine, were hardly ever described as nurturing, and were commonly labeled as “unfit parents” when participants were asked to list stereotypical beliefs about women with disabilities.

The significance of this problem is illuminated in a conversation that occurred at a 1982 conference between Letty Cottin Pogrebin, then-editor of *Ms. Magazine*, and Judy Heumann, a highly noted disability rights activist (reported by Fine & Asch, 1988):

Pogrebin proclaimed that “The concerns about sexual harassment affect all women” Heumann retorted with “You know, I use a wheelchair, and when I go down the street, I do not get to be sexually harassed. I hear non-disabled women complaining about it, but I don't ever get treated as a sexual object,” to which Pogrebin replied, “You would hate it.” (p. 29)

Mejias, Gill, and Shpiegelman (2014) recounted and discussed the significance of this exchange:

The point of Heumann's statement, however, was that many women with disabilities never get a chance to hate sexual objectification because the public's view of them as non-sexual and degendered excludes them as women. Thus they are not subjected to some forms of gendered oppression but they are excluded from the experiences, relationships and triumphs that women share as a community. Given this, most women with disabilities do not find it empowering or liberating to be spared from gender expectations. In order to compensate for the exclusion from being a valued



member of the women's community, some women with disabilities may be more apt to tolerate sexism and conventionally restricted roles in order to claim their "normalcy" and similarity to non-disabled women. (p. 209 ©2014, American Psychological Association, reproduced with permission, Appendix B)

The stereotype that women with disabilities are non-sexual is so pervasive that it appears to extend into cyberspace. Lee (2012) conducted a comprehensive Google image search using the search terms "girls," "disabled girls" and "girls and disability." Using the search term "girls," Lee found that the majority of the images produced were highly sexualized, e.g., gazing directly into the camera, kissing and embracing. In contrast, the search term "disabled girls" produced only a few sexualized images. Instead, the images primarily were of disabled girls who had been victimized, those whose bodies were the objects of public scrutiny/debate, and those who were receiving care or in need of help from charitable organizations. The search term "girls and disability" produced images that resisted traditional stereotypes of disabled women to some degree. However, only one of the 68 images analyzed in connection with this search was portrayed as sexualized. These results clearly demonstrate that one form of objectification is simply being traded for another. Disabled girls and women are spared sexual objectification but must endure being considered objects of charity and pity instead. Both types of objectification can have devastating consequences on one's sense of self. These types of negative media images can readily become assimilated into the women's self-concept (Simon & Hoyt, 2013).

Societal stereotypes about women and girls with disabilities often are manifested in the form of lowered expectations, especially expectations pertaining to the social and sexual aspects of their lives. For example, Rousso (1988) conducted a unique retrospective study of 43 adult women with physical and sensory disabilities. Twelve of these women's disabilities occurred after adolescence (the control group). Participants were asked to reflect

on their own social and sexual expectations during adolescence as well as the expectations their parents had for them. Results of the study indicated that parents of girls who were disabled before adolescence tended to have lower expectations for their daughters in the social and sexual arenas and higher expectations for them in the educational and vocational arena when compared to the girls in the control group. Most of the girls with a pre-adolescent disability reported that they felt their parents' high academic expectations were based on their parents' belief that they would not have a successful social life.

These results have been replicated in later studies. For instance, Hogansen et al. (2008) conducted 24 focus groups with 146 high school and college-aged young women with disabilities, their parents and educational professionals regarding transition expectations. They found that the majority of young women desired future families in addition to productive careers. Although their parents were in agreement regarding career goals, their expectations and desires concerning their daughter's future family conflicted. Parents often voiced concern about their daughters' ability to raise a child, as one parent commented, "She's always wanted to be a mom. And there's no way. She doesn't even have the patience for us grown-up people. She's not – you know, it scares me to death that she's going to have a child, and I'm going to raise it. I don't want to do that" (Hogansen et al., p. 221).

Gender and disability appear to compound the lowered expectations women with disabilities face. Powers et al. (2008) found that one in five women with a disability reported that people expected less of them because of their gender, while only one in ten males reported this to be the case. Additionally, females with disabilities were twice as

likely as their male counterparts to report that people expected less of them because of their disability.

Recent research has shown that attitudes regarding disability remain stable over time. Charlesworth and Banaji (2019) analyzed data from over four million explicit and implicit attitude tests regarding six social categories: sexual orientation, race, skin tone, attitudes, disability, age, and body weight. Data were collected from people over the age of 13 from 2007 to 2016. Taking measures to address and control for several confounding variables they found that all explicit attitudes regarding the categories measured showed at least some trend towards neutrality. In most cases the implicit attitudes regarding the social categories improved over time. However, implicit attitudes remained stable over time for age and disability, while implicit attitudes for body weight showed a trend away from neutrality. The results from this study illuminate just how ensconced and resistant to change the attitudes about disability are in our society.

Women and girls with disabilities are often given little access to information to help them counter the negative stereotypes and lowered expectations they endure. Rousso (1988) also found that girls with pre-adolescent disabilities were less likely to talk to their mothers about topics such as dating, marriage, or having children. A more recent study discovered similar results: Lafferty, McConkey, and Simpson (2012) conducted focus groups and individual interviews with 100 family caregivers, frontline staff, and professional staff, who work with individuals with intellectual disabilities. Results revealed that family members of adolescents and young adults with intellectual disabilities were often reluctant to have conversations regarding sexual health with their relative who had intellectual disabilities. These findings are particularly disturbing because having these types of conversations with

daughters furthers their awareness of their sexuality and helps them make good choices (Malhotra, 2016; Rousso, 1981). Furthermore, these types of conversations can help dispel the myth that women with disabilities are asexual.

In addition to the lack of informal conversations with parents regarding sexual health, there seems to be a paucity of formal sexuality and relationship education programs available for people with disabilities. Although all stakeholder groups interviewed by Lafferty et al. (2012) agreed that relationship and sexuality education was needed for young adults with intellectual disabilities, they noted that there were few resources or programs available to accomplish this. The sparse training that is available only deals with the physical aspects of relationships, and neglects the social and emotional aspects (Lafferty et al., 2012; Stinson, Christian, & Dotson, 2002).

Healthcare providers also bear some responsibility for the lack of sexuality information available to young people with disabilities. Nosek et al. (2001) found that 30 percent of women with disabilities who participated in their survey reported that they believed they had received inaccurate information regarding birth control options, while only nine percent of women without a disability reported this. Women with intellectual disabilities may face even greater barriers when working with healthcare professionals than do their counterparts with physical disabilities. Parchomiuk (2012) surveyed 98 specialists, including healthcare workers, nurses, and physical therapists, regarding their attitudes toward the sexuality of people with disabilities. The results indicated that respondents were more accepting of the sexuality of people with physical disabilities than those with intellectual disabilities. They were also more accepting of sterilization of individuals with intellectual disabilities. It is not surprising that doctors hold prejudicial attitudes and do not

communicate appropriate information regarding sexuality to their patients with disabilities, given that material regarding sexuality and disability is not uniformly taught within medical schools. Solursh, Ernst, Lewis, Prisant, Mills, Solursh, Jarvis, and Salazar (2003) surveyed 93 medical schools in North America regarding the content of their curriculum, and found that only 69.3% of them included at least some information on disability, illness, and sexuality in their course content. The lack of uniform education provided to healthcare professionals about disability, illness, and sexuality only compounds the lack of information available to help women with disabilities counter demoralizing stereotypes.

In the face of countless negative stereotypes pertaining to disability and gender, and with little information to counter these stereotypes, many young women end up internalizing these ideas. This phenomenon is well documented in the literature and is generally referred to as “internalized oppression” (Charlton, 1998; David, 2014; Gibson, Teachman, Wright, Fehlings, Young, & McKeever, 2011; Reeve, 2002). Theoretically, the concept of internalized oppression was first captured through Cooley’s (1902) concept of the looking glass self in which the views of other people are largely responsible for molding one’s personal definition of self. David (2014) explicitly defines this phenomenon as “a set of self-defeating cognitions, attitudes, and behaviors that were developed as one consistently experiences an oppressive environment” (p. 14). This destructive process results in a grossly inaccurate perception of oneself and others. The experience of internalized oppression is a common occurrence among historically marginalized groups.

Gibson et al. (2011) illuminated this phenomenon in a study, which explored the attitudes and values about walking held by children with cerebral palsy (ages 9 to 18) and their parents. It was found that children adopted their family’s and society’s dominant

perception that a non-disabled body and identity is preferred. Adoption of these notions had deleterious consequences for the self-concept of some of the children, especially in regard to their perceived ability to be an active and valued member of their community. As one 18 year old participant noted,

I've come to the conclusion that my inability to walk makes me at various levels a parasite on society. I'm rather upset about my inability to walk ... I believe that sometimes, in my most upset moments, that death or an end to my life would be for the greater good of society. (p. 66)

Galvin (2005) found similar results when she analyzed telephone dialogues and autobiographical material from 92 participants with acquired disabilities from the United States, United Kingdom, New Zealand, and Australia. All participants who had visible impairments spoke at length about the disconcerting reactions they received from others, such as being patronized, pitied, singled out, ignored, stared at and reviled, and how this affected their self-view. As one woman vividly recounts, "as a fairly high functioning individual I felt like a total waste and I internalized the devalued attitude I continually encountered in others, in the media and even in myself" (Galvin, 2005, p. 397).

Galvin (2005) also noted that the constant exposure to stereotypes of what is physically desirable had a markedly negative impact on many participants' self-perceptions of themselves as sexual beings. Individuals with cerebral palsy interviewed about their perceptions of how the media and society perceives people with disabilities corroborate these views (Dune 2014). They saw the media and society in general as considering them unlikely sexual partners because of their inability to conform to normative expectations. They also believed that others' perceptions of disability and sexuality were detrimental to their socio-sexual development.

Evidence of internalized oppression has also been reported in studies whose sole focus was on women with disabilities. The young women interviewed by Hogansen et al. (2008) reported that other's negative perceptions of their disability took a toll on them and contributed to a negative self-image. As one participant lamented, "I don't remember a lot of positive stuff people say because so many people have said negative stuff that, that's like all I think about and all I know" (Hogansen et al., 2008, p. 225).

It's important to note that although harmful stereotypes, disparaging treatment, and cultural assumptions do have an impact on one's self perception, people can and do resist these negative social images, and manage to achieve a positive sense of self (Bogart, Lund, & Rottenstein, 2018; Guldin, 2000; Hogansen et al., 2008). As a poignant illustration of this Bograt, Lund, and Rottenstein (2018) surveyed 710 disabled people to determine the personal and environmental factors that influence disability pride. They also examined whether disability pride mediates the relationship between stigma and self-esteem. The results indicated that perceived stigma, social support and being a person of color predicted disability pride. Furthermore, disability pride moderately mediated the relationship between stigma and self-esteem. Thus, experiencing greater levels of stigma predicted an increase in disability pride, which in turn predicted an increase in self-esteem. Their findings demonstrate that in some cases encountering stigma paradoxically motivates individuals to reject negative societal assumptions about disability and cultivates a sense of pride toward their disabled identity.

#### **D. The Importance of Peer and Social Support in the Development of Self**

Positive interactions and support from friends and peers is one of the best ways to abate or prevent the effects of internalized oppression. In fact, the college women in

Hogansen et al.'s (2008) focus groups noted that they were able to overcome many of the ramifications of internalized oppression and meet their transition goals because of the support from their friends. As one young woman stated,

After my freshman year, from my sophomore to senior, I started to figure out my goals ... and my friends helping me out with socialization ... [they] just encourage me, say, "It's going to be okay. If you do it, you'll pass." They encourage me to do stuff that I was afraid to do. (Hogansen et al., 2008, p. 222)

The positive effects of peer relationships have also been documented quantitatively. Antle (2004) found a significant correlation between global self-worth and support from friends among a sample of 85 young people, aged 8 to 23, with spina bifida. These findings do not just apply to people with physical disabilities. Shany, Wiener, and Assido (2013) found similar results when they examined the self-concepts and global self-worth of 102 university students with and without learning disabilities. The students with learning disabilities scored significantly lower on global measures of self-worth and social acceptance. This difference was particularly prominent for women; however, those who reported more stable friendships scored significantly higher on both measures than students with learning disabilities who did not report having stable friendships. These results demonstrate compelling evidence for the need to provide opportunities to develop enduring peer relations for people with disabilities. This is particularly so for women, who appear to be at a greater disadvantage than their male counterparts when it comes to gaining social acceptance and cultivating self-worth (Shany et al., 2013).

In addition to having a beneficial impact on the way people think and feel about themselves, peer relationships have many other related advantages. Mazurek (2014) found that the number of friends reported by young people with autism independently predicted levels of self-esteem, depression, and anxiety. Individuals who reported more friends also



reported a decrease in depression and anxiety, and an increase in self-esteem. The existence or absence of friendship networks can also impact physical health. Jetten, Haslam, Haslam, and Branscomb (2009) reported that adolescents with few friends get tension headaches, the flu, and colds more often than their counterparts with vast networks of friends (as cited in Zambo, 2010). Developing a stable friendship network can also help foster romantic relationships. Participating in peer group activities has been found to be a catalyst for the development of dating relationships among young adults with disabilities (Wiegerink et al., 2010). Thus, developing positive peer relationships has the potential to aid in many areas of personal development.

Social acceptance and peer relationships appear to play a larger role in the formation of the female self-concept than for the male self-concept. Rosenberg and Simmons (1975) surveyed 2,000 children and adolescents in a landmark study in which they examined sex differences in regards to the self-concepts of adolescents and children. It was found that girls are more people-oriented (concerned with others' attitudes towards them) while boys stress achievement and confidence. These differences appear to increase among older adolescents. Thus, perceived social acceptance is likely to play a critical role in the development of self-esteem and overall self-concept, especially for young women and girls. Frey, Tobin, and Beesley (2004) examined psychological distress and relationship patterns in college-aged men and women. They discovered that for women, strong peer relationships and connections to their community predicted lower levels of psychological distress, whereas for men, peer relationships were not a significant predictor of this. The opportunity to develop strong peer relationships is particularly important for women.

Relatedly, social support also appears to be particularly important to the development of a positive self-concept for women, especially those who face barriers to participation in important arenas of adult life. For instance, Waters and Moore (2002) surveyed 201 unemployed men and women to determine predictors of self-esteem (the evaluative component of self-concept). They found that social support had a stronger positive relationship to self-esteem for women than for men. This finding has markedly detrimental implications for women with disabilities since, as noted above; they often face profound barriers to participation in the labor market as well as other areas of adult life.

#### E. **The Implications of Social Identity Theory for the Development of Self-concept**

The development of social support and social acceptance is often fostered through one's group membership. This can provide a fruitful avenue to cultivate one's self-concept and self-esteem. This notion is consistent with social identity theory, which posits that group membership is an important part of a person's self-concept (Tajfel, & Turner, 1979). People are often motivated to view their own group in a positive light and salient group membership provides a potent source of self-esteem. Marmarosh and Corazzini (1997) experimentally tested the tenets underlying social identity theory. They randomly assigned 41 members of a psychotherapy group to either a control condition (received pamphlets regarding the benefits of psychotherapy) or an experimental condition in which participants "put the group in their pocket" (received pamphlets about how to use group identity to deal with stressful events that may occur outside of the group). Consistent with social identity theory, results revealed that collective self-esteem was positively correlated with personal self-esteem. In addition, participants in the experimental condition reported a greater overall gain in their perception of the value of the group than those in the control condition.

These results provide a striking testament to group membership's ability to influence one's self-concept in a positive manner.

The principles of social identity theory have been documented within the disability community as well. In one study, Nario-Redmond, Noel, and Fern (2013) surveyed adults with both non-apparent and readily visible disabilities to determine whether the degree to which individuals define themselves as members of the disability community affects their self-esteem. The coping strategies they used were also explored. Results indicated that identification with a disability community predicted greater use of collective strategies to minimize stigma, such as redefining stigmatized traits as a prideful part of identity. Identification with a disability community also predicted higher levels of personal self-esteem (global evaluation of one's self as an individual), as well as collective self-esteem (positive views of one's self as a member of a group). These findings held true after controlling for the degree visibility of disability and time of disability onset.

It appears that emerging adults with disabilities are very motivated to take on political advocacy and group identity when they have the opportunity. Nario-Redmond and Oleson (2015) found that disabled emerging adults demonstrated more political conviction and were twice as likely as similarly aged non-disabled individuals to be involved in disability rights advocacy. Emerging disabled adults were also found to have stronger perception of solidarity and personal and group discrimination than their non-disabled peers.

Interestingly, experiences of group discrimination may have different consequences than experiences of personal discrimination. In their sample of 288 Spanish people with physical disabilities Molero, Recio, García-Ael, and Pérez-Garín (2019) found empirical support for their notion that perceived experiences of group discrimination and personal

discrimination influence self-esteem through two different pathways. Results of their quantitative measures revealed perceived personal discrimination acts through internalized stigma, thus lowering self-esteem. On the other hand, perceived group discrimination acts through group identification and promotes intent to take part in collective action, thus indirectly raising self-esteem.

In addition to the psychological benefits of group membership, positive identification with a group has been noted to have physiological benefits. For example, individuals with a strong sense of social identity with a group display significantly lower levels of cortisol (hormone which indicates stress) during stressful situations than those who do not have a strong social identity (Haslam, Jetten, Postmes, & Haslam, 2009). Individuals navigating through emerging adulthood are particularly likely to reap the benefits of group identification since personal and collective identities are being explored and becoming solidified (Oyserman et al., 2012; Zarrett & Eccles, 2006).

#### F. **The Benefits of Support Groups for People with Disabilities**

Given the numerous benefits underlying positive identification with a group, it is no surprise that support group membership has widespread implications for the well-being of people with disabilities (Chung, Liu, Ivey, Huang, Chung, Guo, Tseng, & Ma, 2012; Yaruss, Quesal, Reeves, Molt, Kluetz, Caruso, McClure, & Lewis, 2002). Past research has demonstrated that individuals with disabilities who attend support groups experience more positive outcomes related to their well-being than those who do not. For instance, Chung et al. (2012) conducted focus groups with people who did and did not attend a support group for people with epilepsy. The focus group data indicated that those who participated in a support group had greater knowledge about epilepsy, were more likely to engage in social

activities and had a more positive outlook on life than those that did not attend a support group.

Research has also consistently demonstrated that being involved in a support group with peers helps heighten feelings of belonging, acceptance and trust, as well as strengthens individual social networks (Badger & Royse, 2010; Jalovic, 2008; Kriegsman & Celotta, 1981; Mejias et al., 2014; Subramaniam, Stewart, & Smith, 1999). Subramaniam et al. (1999) interviewed 13 individuals who were enrolled in a chronic pain support group. Participants reported that their sense of belonging and opportunities to develop new friendships had increased since joining the group. Participants also said that the increased contact with fellow pain sufferers was very helpful and fellow group members were better able to understand their experiences and problems associated with their chronic pain than were their family members.

Some research has further indicated that involvement in a support group may also be valuable in helping individuals obtain a positive self-image and accept their disability. For example, Yaruss et al. (2002) surveyed 71 individuals who had participated in stuttering support groups. Results revealed that 93.8% of the participants reported that being part of a support group had positively affected their self-image as well as their acceptance of themselves as people who stutter. Stewart and Bhagwanjee (1999) further demonstrated that support groups can lead to an empowered consciousness and self-determination. They created an 18-month intervention in which people with physical disabilities, aged 18 to 42, took part in a multi-component peer-led support group. Components included disability rights education, guided dialogues with fellow group members, recreational activities, and opportunities for personal growth and development. A noted shift towards group

cohesiveness, members' ability and willingness to take control over the group, and empowered consciousness took place upon conclusion of the group. This is exemplified by "Chariots of Fire," the name that the members chose for the group. One participant expounds on this saying:

Just as chariots were traditional war wagons, so are wheelchairs [by], which we will fight those who discriminate against us. Our fire represents our light and strength by which we will make the public more aware of our group and increase our group members by spreading into the community. (Stewart & Bhagwanjee, 1999, p. 341)

Although the benefits of support groups in general have been well documented in the literature, studies exploring the benefits of groups solely for women with disabilities are limited. There are a few studies, however, that provide evidence that groups for women with disabilities are beneficial and produce similar results to the ones cited above. Jalovcic (2008) conducted individual interviews and focus groups with members of a telephone support group for women with spinal cord injuries. The women reported that being part of the group helped them realize that others had similar problems and heightened their sense of belonging. In another study Kriegsman and Celotta (1981) investigated a series of in-person creative coping groups. The women in the group were of different ages and had physical disabilities. The group members participated in a variety of activities aimed at relationship building among group members and enhancing their problem solving skills. The women reported improvements in several notable areas including independent living skills, socialization, and self-esteem. They also said they were better able to perceive themselves as "whole women."

The potential benefits of support groups for the development of a positive self-concept were further demonstrated in a more recent study. Hughes, Robinson-Whelen,

Taylor, Swedlund, and Nosek (2004) randomly assigned 102 women with physical disabilities to either a six week psycho-educational self-esteem enhancement support group or a control group that received only the traditional services provided by their local independent living centers. The self-esteem enhancement group included discussions of the impact of gender and disability, communication and assertiveness training, and activities to promote mutual social support and connectedness. At the end of the six-week program, participants who took part in the intervention showed significant improvements in self-esteem and moderate improvements in symptoms of depression when compared to the control group. Although these studies only included women with physical disabilities, they do lend support to the notion that groups for women with disabilities help their members develop a positive sense of self.

As an alternative to face-to-face support, the Internet provides a promising avenue for connecting and supporting similar others. There are an estimated 4.4 billion Internet users around the world (Miniwatts Marketing Group, 2019). Approximately 41% of the world's population is interconnected through cyber space. The United States is ranked third in the world in regard to Internet use with an estimated 312 million Internet users. A large majority of these users are young adults. Recent research found that 98% of 18-29 year olds in the United States were Internet users (Pew Research Center, 2018a). Although men are slightly more likely to use the Internet, it has been recently estimated that 88% of the female population are Internet connected (Pew Research Center, 2018b). It is also important to note that disabled people are less likely to use the Internet than able-bodied people (Anderson & Perrin, 2017; Goggin, 2015). In recent decades the increasing affordability of smart phones has begun to address the digital divide for many disadvantaged populations.

However, it still persists among those with disabilities. Web accessibility legislation and guidelines are currently being implemented in hopes of improving Internet access for disabled people (Goggin, 2015). Despite its pitfalls, the Internet allows users to instantly transcend geographical boundaries and connect similar others, making it an intriguing avenue of support for disabled people.

There is evidence that some individuals prefer to get their support online. For instance, Chung (2013) surveyed 158 users of online health-related support groups. She found that those who were dissatisfied with their support networks offline were more likely to prefer social interaction in online support groups. Also a greater preference for online support groups was found among those who reported building deeper social relationships in these groups. Individuals who received more support through their online support group reported a stronger preference for these groups.

Further illustrating preference towards an online support platform Nosek, Whelen, Hughes, Porcher, Davidson, and Nosek (2011) beta tested the feasibility of Second Life as a delivery method for an intervention aimed at increasing the self-esteem of disabled women. Second Life is an online platform where people create avatars of themselves and navigate through a virtual community while interacting with others. Three out of the four women who beta tested the intervention unequivocally said they preferred the online platform over a face-to-face platform for support. The fourth said she preferred the online platform only when significant barriers such as transportation prohibited her participation in face-to-face groups. Despite having some technical issues with the platform, all of the women perceived the intervention positively and saw it as allowing them to transcend barriers associated with face-to-face support. Data concerning the direct outcomes of the intervention were not



reported. However, these findings begin to support the notion that at least some disabled women perceive the benefit of and/or prefer an online support over a face-to-face support option.

Other research has shown disabled people appear to be directly benefiting from online support (Dolezal, Simonette, & Orr, 2017; Obst & Stafurik, 2010). For instance, Obst and Stafurik (2010) surveyed 160 members of disability-specific online support communities regarding their perceived social support, psychological well-being, and psychological sense of community. They found that members received both moral support and personal advice through their participation in these communities. A significant sense of community was sparked among the users. Additionally, a sense of community online and online social support was positively correlated with well-being in the domains of personal growth and personal relationships.

Dolezal et al. (2017) found similar results when they examined the effects of three Facebook support groups for individuals with Spinal Muscular Atrophy. Out of the 25 responses they received, approximately 67% of individuals reported an increased sense of self-worth due to their involvement in support groups. Over 91% of respondents felt that they made new social contacts and 83.34% of participants agreed that they felt less lonely because of their participation in the online support group. Although this is a very small sample, this research does begin to lend credence to the idea that online support does have a beneficial effect in the realm of self-concept for its users. It also supports the notion that Facebook is a viable platform for support communities.

Facebook is a social networking site that allows users to create a personal profile, connect with friends, and “like” and join various groups and pages within the site. Users see

updates from their friendship network and the pages they “like” and join on their personalized newsfeed when they log onto the site. Facebook has the largest number of active users and the largest global reach making it the largest social networking site on the web (Statista, 2019). As of the first half of 2019 Facebook had 2.38 billion active monthly users. Approximately 39.4% of Facebook users are between the ages of 18 to 24 and fall within the traditional definition of emerging adulthood. Furthermore, 10% of active Facebook users are women ages 18 to 24 (We Are Social, DataReportal & Hootsuite, 2019). These statistics demonstrate that Facebook has the potential to reach emerging adults and connect them with similar others.

Disabled people appear to log on and benefit from social networking sites such as Facebook regularly. Schpigelman and Gill (2014) reported that out of the 172 individuals with disabilities they surveyed, 69% visited Facebook at least once a day and 44.2% reported using the site for up to 30 minutes at a time. Quantitative data from this study indicated that respondents mainly used Facebook to connect with their non-disabled friends. But, qualitative data revealed that people got support and advice through Facebook, which in turn reduced the isolation they felt.

As illustrated in the preceding paragraphs, online support seems to be a viable option for many people with disabilities in general. However, there appears to be a paucity of research specifically focusing on the effect of online support groups for women with disabilities. The research that does exist mainly focuses on the therapeutic outcomes of support groups for women with cancer or chronic illnesses (Rodgers & Chen, 2005; Vilhauer, 2009; Winters & Sullivan, 2013). For example, in order to investigate the therapeutic factors that emerge within online support groups, Vilhauer (2009) assigned a

total of 20 women with metastatic breast cancer to one of three online support communities. Women were free to discuss whatever they liked and encouraged to talk about both negative and positive experiences. Survey and interview data revealed six therapeutic factors that appeared to be helpful within the online communities. These were: group cohesiveness, information exchange, universality, instillation of hope, catharsis, and altruism. Rogers and Chen (2005) also found that participation in an Internet-based support group for women with breast cancer produced a variety of psychological benefits. They conducted a longitudinal examination of 33,200 postings from an online breast cancer bulletin board and analyzed the life stories of 100 randomly selected women from the bulletin board. The psychological outcomes of their participation in online support included information sharing, reciprocal social support, positive affect towards the discussion board, optimism towards breast cancer, increased coping skills, improved mood, and decreased psychological distress. Women living with cancer undoubtedly face different types of challenges than women living with lifelong disabilities. That said, these studies do demonstrate that online health-related support groups for women have the potential to produce results similar to those seen in face-to-face groups.

The critical incidents within the group process that lead to a positive change in self-concept remains relatively unexplored, within both in-person and online support realms. That said, there is a body of related literature that explores the beneficial aspects of support groups connected to the coping process. Steihaug, Ahlsen, and Malterud (2002) conducted a series of five focus groups with members of a chronic muscular pain support group for women. Results revealed that the experience of being recognized within the group was

crucial to helping the women cope with their chronic pain. This recognition that emerged in the group setting included listening, understanding, acceptance, tolerance, and confirmation.

Mundell, Visser, Makin, Forsyth, and Sikkema (2012) found similar results when they used qualitative analysis to examine the key psychological processes underlying a support group for pregnant South African women with HIV. The processes the women noted as being the most beneficial included being able to identify with others in the same situation, being able to view other women in the group as role models, using group support to accept and come to terms with their HIV-positive status, and becoming empowered through having an opportunity to give and get advice from others. These helping processes operated both independently and concurrently as the women navigated towards successful adjustment to their HIV-positive status. Other beneficial aspects of the group process related to coping and self-help include having an opportunity to help others, sharing experiences with others, and creating a safe space where trust and openness can flourish (Ahlberg & Nordner, 2006; Cawyer & Smith-Dupre, 1995).

Research regarding the helping process within online support groups appears to be similar to that of in-person groups. For instance, Winters and Sullivan (2013) found that women with chronic illness who participated in a computer-mediated support group relished the connection they felt with fellow group members, sharing stories with one another, expressing words of encouragement, and exchanging jokes with their fellow members.

In sum, these studies illuminate helpful factors within the group process that likely have implications for the self-concept development of women with chronic illnesses. These include giving and receiving information, the opportunity to be recognized within the group space, having access to role models who are in similar situations and sharing stories and

words of encouragement with one another (Mundell et al., 2012; Steihaug et al., 2002; Winters & Sullivan, 2013).

However, past research on this topic has mainly included women who are middle-aged or older with chronic illnesses. The experience of living with chronic illnesses, such as cancer, chronic pain or HIV is likely different than living with a lifelong disability. Thus previous research sheds little light on the beneficial aspects of the support group process as it relates to positive changes in the self-concept of young women who are living with long-term physical, sensory or intellectual disabilities.

Mejias et al. (2014) further illuminated the need for additional research on this topic. We conducted qualitative interviews with members of one of the few empowerment support groups available in the U.S. for young women with disabilities. The interviews focused on the sense of belonging that the group cultivated among the women. An interesting finding was that the group process appeared to influence the women's self-concept. For example, one of the participants, a Hispanic woman with a physical disability proclaimed:

[After joining the group] I just got a sense that I could do anything and everything I wanted. ... I became a lot more progressive, I became a lot more liberal; I got this attitude like, "Kiss my butt! I'm gonna do what I want to do." (p. 216, ©2014, American Psychological Association, reproduced with permission, Appendix B).

Since this change in self-concept was not the focus of the study, the reasons behind it were not fully explored. Thus, it provided fertile ground for future research. Research to identify the critical instances within support groups that promote self-concept development is imperative. It will further the creation of support groups that can help women with disabilities gain and maintain a positive sense of self during the crucial developmental period of young adulthood.

### III. METHODS

I used a qualitative approach to explore my research questions. There are several advantages to using qualitative methods for this research. To begin with, qualitative methods are inherently flexible. This is particularly important when exploring an under-researched phenomenon, such as the specific developmental process of support groups for young women with disabilities, and when examining multifaceted and dynamic social phenomena such as disability and self-concept (Patton, 2002). In addition, this methodology has a unique ability to empower participants by giving them a chance to tell their story in their own words (Neisz, Koch, & Rumrill, 2008). The interview process gave participants this important opportunity. The semi-structured interview guide enabled participants to answer questions with as much detail as they liked and in a manner they thought best conveyed their thoughts and feelings. They were not limited by predetermined choices or short answers, which would have been the case if quantitative methods such as surveys were used.

Another distinct advantage of using qualitative methods is that it allows for context of the phenomenon to be brought to light and thoroughly examined (Morrow, 2005). Given the complicated nature of the disability experience, it is extremely important that the research results are framed with adequate context. The semi-structured interviews allowed for the context of participants' lived experiences within the group to be illuminated. One-on-one interviews helped capture background regarding their life stories and how their participation in the group has influenced them on an individual level.

The qualitative methods chosen for this research conform to important tenets of both feminist theory and the social model of disability. This methodological approach privileges

the perspectives of socially oppressed groups such as young women with disabilities, recognizes their right to frame their own experience, and allows for the context in which they live to be explained in their own words. Although these conceptual frameworks inform my work, I took a grounded theory approach to explore the process the women experienced in developing a more positive self-concept through group support. This means that my research is inductively driven and not based on any firm expectations or pre-determined hypothesis (Strauss & Corbin, 1994; Wuest, 1995). It is important to note, for the purposes of this investigation, that the unit of analysis is the individual participants. This unit of analysis enabled me to document in-depth the factors within group support that have influenced the individual trajectory of the participants, especially in terms of the development of their self-concept and the accomplishment of goals that are important to them in their transition to adulthood. Since each individual is likely to have a different trajectory, analyzing the group as a whole would not provide me with the in-depth insight that I sought regarding each member's unique trajectory.

#### A. **Design of Study**

The specific qualitative design of this research entailed conducting one-on-one semi-structured interviews with members of both online and in-person support groups for women with disabilities and with past and present group coordinators of in-person groups. Interviews were conducted via phone or email. This data collection strategy was chosen because individual interviews allow participants ample opportunity to expand on their experiences and express their thoughts and feelings in their own words as they see fit. Given the personal nature of each individual's journey within the support group process, individual interviews are better suited for this research than other qualitative methods. For

example, if focus groups were used it is likely some women may have been reticent to speak up about their personal experiences and/or expand on experiences that fell outside the norm of the group.

I chose to interview both group members and group coordinators because they each provide insight from different perspectives of the support group process as it relates to my research questions. The group coordinator interviews are valuable in ascertaining what works and does not work within the realm of face-to-face support for disabled women, the challenges the coordinators faced when starting and maintaining the group, and how these challenges were overcome, if they were. On the other hand, interviews with group members document in detail individual journeys through the support process and what factors within this process leads to a change in self-concept, if it does at all. Group member interviews are also helpful in determining what goals are subjectively important to young disabled women and how group support promotes the accomplishment of these goals.

I had originally planned to conduct a series of follow-up interviews with new members of in-person support groups. It was hoped these follow-up interviews would further capture the trajectory of the change in self-concept due to group involvement. However, the apparent low participation of young disabled women in face-to-face support groups made it difficult to locate new members who were eligible to take part in the follow-up interviews. Thus, follow-up interviews were not conducted.

Nonetheless, the group member interview guides (Appendix C and D) were designed to document a change in self-concept among group members. The guides included questions about their self-perception both before and after joining the group. The questions also prompted participants to discuss directly the change in self-concept or a lack thereof



gleaned from group involvement. Their responses to these questions helped highlight the trajectory of the change in their self-concept.

## B. Sample

This research took a purposeful sampling approach identified by Patton (2002). I aimed to recruit women who had information-rich stories to share about their involvement in disability support groups. Within the framework of purposeful sampling I intended to achieve maximum diversity as far as the ethnic backgrounds of the participants and the types of disabilities they had. It was hoped this research would include the perspectives of women with physical, intellectual and sensory disabilities.

I aimed to recruit a minimum of ten group members and a minimum of ten group coordinators. Even so, I was committed to continuing data collection until data saturation was reached. This occurs when repeated themes emerge across the data consistently and the data are no longer revealing new findings relevant to the research questions (Patton, 2002). Based on this definition, data saturation was achieved in the present study.

At the onset of this research I had intended to include only disabled women ages 18 to 35 who acted as their own legal guardian and who were actively involved in face-to-face support groups for disabled women. The in-person support group format provides three dimensional interactions and experiences for their group members. For example, within this support group realm people can physically interact with one another and have the opportunity to read and interpret others' body language. Thus, at the onset of this research I believed in-person support groups would spark the most vivid change in self-concept development and best equip their members to provide information on how the support process influences self-concept development.

However, I had great difficulty locating in-person groups that had a majority membership of disabled women ages 18 to 35. Most groups had a majority membership of above age 45. According to several group coordinators, they had difficulty recruiting and retaining young women with disabilities. This led to the exploration of online support groups as another possible means for young disabled women to get support. Recruitment efforts were expanded to include women who were part of online support groups. The age eligibility criterion was also extended to include women ages 18 to 45 years old with an age of onset of disability at 21 years old or younger.

This age range is higher than the commonly defined transitional phase of emerging adulthood (18-25). However, people with disabilities tend to meet transitional milestones of adulthood later than those without disabilities (Pinquart, 2014; White, 1997). Including only women who acquired their disability before the age of 21 ensured that all the participants would be able to elaborate on their transition to adulthood as a disabled woman. Women who were older than 35 were asked to discuss retrospectively how group involvement *would have* helped them transition to adulthood if they had had access to the group during their young adult years. This allowed for the exploration of the influence of the group process as it relates to young adult women even among slightly older participants. Disability status as well as the age of onset of disability was obtained by asking group members directly what type of disability they have and the age of onset of their disability. Screening questions verified that they met all the eligibility criteria prior to their enrollment in the research (Appendix E and F).

In addition to the criteria described above, online group members had to be regularly active (posting approximately twice per month) for at least two months in an online support

community for people with disabilities to be eligible for the online member interviews. These criteria were implemented to ensure that participants had knowledge of the online support group process. It also ensured participants were able to expound on how, if at all, the support group process benefitted them with regard to self-concept development and transition to adulthood. Due to the scarcity of online disability support groups for women only, eligibility for this research was open to women who were a part of online support groups for people with disabilities in general. That fact notwithstanding, 11 of the 12 group members who were interviewed for this research were involved in women only support groups.

Group coordinators who were 18 or older, their own legal guardian and who facilitate an in-person support group for women with disabilities were eligible for participation in an individual interview. Given the high proportion of disabled women's groups that have trouble maintaining an active membership, the decision was made to include both past and present group coordinators. This gave me the opportunity to explore the challenges group coordinators face in running a disabled women support group and what resources and strategies might be helpful in overcoming these challenges. Two separate conversational interview guides, one for current group coordinators and one for past/inactive group coordinators were used to conduct the interviews (Appendix G and H).

### C. **The Recruitment Process**

The recruitment process for in-person support groups for women with disabilities entailed conducting a comprehensive internet-based search (through Google search engine). Key search terms such as “young women with disabilities,” “young disabled women,” “support group,” “social support group,” and “empowerment group” were used in various

combinations with each other during web searches. In addition to the web search, referrals were taken from individuals who have knowledge of current support groups for women with disabilities. Recruitment notices were also posted on relevant listservs such as The Society for Disability Studies. Given the focus of this research, groups that primarily serve individuals with chronic illnesses that cause symptomology that is highly changeable over time, such as cancer or HIV-AIDS were excluded from potential recruitment. As discussed in the literature review, support group research on this population is already plentiful. Furthermore, it is likely support groups that primarily include individuals with highly fluctuating chronic illnesses, have a support group process geared more towards coping than self-concept development.

A list of support groups that may have met the eligibility criteria for participation was created. If an in-person support group appeared to meet the criteria for the research, facilitators or the group's hosting organization were sent the Email Recruitment for Participation in Research document (Appendix I). An additional two documents were attached:

- Research Information Sheet for Group Members (Appendix J) – This document was specifically intended for all members of the support groups who were in close enough proximity to the primary investigator to be considered for the naturalistic observation. This research activity involved observing in-person group meetings for disabled women and taking notes on the group activities and group member interactions. It was hoped this would illuminate the group process further. Unfortunately, interested groups within a reasonable travel distance that had a core membership of younger women were not identified

during recruitment efforts. Thus, the naturalistic observations did not take place over the course of the research. The document details the purpose of the study, the research activities, and the eligibility criteria.

- Recruitment Document for Individual Interviews (Appendix K). This document is specifically intended for group members who were eligible to participate in an individual interview (i.e., members ages 18 to 45 who act as their own legal guardians). The group coordinator was asked to distribute the Recruitment Document for Individual Interviews to members age 18-45.

The content of the initial recruitment email to the group coordinator included an explanation of the purpose of each of these documents. In the event that a valid email could not be located or the initial recruitment inquiry was not responded to within one week of being sent, the group coordinator was contacted by phone, informed of the study and asked if they received the recruitment email. Three attempts were made to contact a group facilitator; if all three attempts were unsuccessful, their group was removed from the prospective pool of participating groups.

Recruitment for online support group members differed slightly. A web search was conducted using keywords such as “peer support group,” “online,” “cyber support community,” “women with disabilities,” “disabled women,” and “young women with disabilities”. Social media sites were also heavily utilized. Once groups were identified, a single recruitment notice, Online Member Recruitment Document (Appendix L) was posted to online support groups for people/women with disabilities. Recruitment postings were made on asynchronous discussion boards or forums, on stand-alone websites, and on social media networks such as Facebook. Recruitment posts were submitted on publicly

accessible forums, or with the permission of the page master/administrator on private forums when applicable. I did not make initial contact with individual members of online groups. Instead, as stated in the online recruitment notice, members who wanted to take part in the research were responsible for initiating contact with me either via phone or email to convey interest in participating. Approximately 15 online group members contacted me via email to express interest in participating. Of the individuals who made initial contact, 11 were eligible for participation and were ultimately enrolled in the study. Two of the 11 participants recruited online had experience with both in-person and online group support.

In the case of in-person groups, the group facilitator was asked to distribute the Recruitment Document for Participation in Individual Interviews to all members between the ages 18-45. The women who receive this document and were interested in participating were asked to contact the primary investigator, or to sign the permission slip at the bottom of the recruitment document. The permission slip gives the group coordinator permission to pass along contact information to me. This recruitment effort resulted in only one in-person group member expressing interest in participating and signing the permission slip for me to contact her. I offered to answer any questions a prospective participant had and confirmed her desire to participate before screening for eligibility, completing the informed consent process and scheduling the individual interview.

The group members provided consent, either verbally or through email, to answer the screening questions (Appendix E and F). Members from online support groups were asked screening questions through whatever means of communication they used to contact me. The screening questions ascertained whether or not they were between 18 and 45 years of age, what their age of onset of disability was, whether or not they act as their own legal

guardian, and whether or not they had been participating in the group at least twice a month for a minimum of two months.

During data collection, the age limit for participation was raised to 46 via an Institutional Review Board approved amendment to the research protocol. This change was instituted to accommodate one participant who indicated she was between the ages of 18 and 45, within the age limit of the study, while answering the screening questions. At the end of the interview, which was conducted two weeks after screening into the study, she said that she was 46 and had miscalculated her age. She met all the other eligibility criteria and her answers to the consent comprehension questions prior to the start of the interview indicated that she had a firm understanding of her rights as a research participant. Literature on this topic indicates that young people with disabilities may have a prolonged development of identity or self-concept (Pinquart, 2014; White, 1997). The 45-year age limit was chosen based on this literature and prior research, but it was not a hard line.

#### D. **Participants**

As noted above, recruitment efforts yielded a total of 12 group members who participated in individual interviews. Due to illness, one participant completed only half of the interview. She did her interview via email and notified me after completing two sections that she was ill and could not complete the rest of the interview. She gave me permission to use the data she had already provided.

Participants reported being involved in support groups for an average of 5.55 years at the time of the interview with a range of one to 22 years of involvement. Ten of these participants identified as having a physical disability. One of these ten participants also identified as having a psychiatric disability and two also identified as having a chronic

illness along with a physical disability. Two of the twelve group members identified as having a sensory disability, with one of these two individuals also identifying as having a physical disability. The average age of the participating group members was 33.75 years with a range of 19 to 46 years old. The average age of onset of disability among participants was 6.42 years with a range of zero to 19 years old. With regard to race, eight group members identified as White. Three identified as Hispanic, with one of these three also identifying as Caucasian. Two participants identified as Asian. A total of 10 of the 12 participants live in the United States, one lives in Australia, and one lives in Eastern Europe.

A total of 11 group coordinators of in-person groups exclusively for women with disabilities participated in conversational interviews. The demographic data in this paragraph were collected a few months after their interviews took place because when I started analyzing the coordinators' interview responses, I realized that it would be helpful to have more background information about them as individuals. A total of seven of the group coordinators responded to my follow-up request for this background data. The average age of the seven group coordinators who responded was 46 with a range of 35-65 years old. Five of the seven reported having a physical disability, one reported having a physical disability and psychiatric disability, one reported having a sensory disability, and one reported being non-disabled but having close family members who were disabled. In regard to race/ethnicity, three identified as White, two identified as Hispanic, and two identified as Black. Group coordinators reported various reasons for becoming involved in facilitating a disabled women's group. These included recognizing the need to empower an underserved population, motivation from their own involvement and interest in civil rights issues and/or



their own experience with disability oppression, and recognition of the value of a support group space.

The full sample of 11 group coordinators represented a total of nine different face-to-face support groups. Six were sole facilitators and five were co-group coordinators. Two pairs of co-group coordinators took part in separate interviews for this research. Seven were currently facilitating a disabled women's support group while four coordinators had worked with a group in the past but were no longer doing so at the time of the interview. On average, the groups represented in this research were first founded 8.39 years ago, with a range of six months to 17 years prior to the interview. The coordinators facilitated the group for an average of 4.53 years with a range of six months to 11 years prior to the interview date. All of the in-person groups represented in this research were still active at the time of the interview, except for two, which were discontinued due to lack of participation. Most groups had a membership with a big age span of between 18 to 70 years of age with the majority of attendees being older than 45. There were a few exceptions to this though. One group had a membership with an age range of 16 to 26 and another group had a core membership of 18 to 45. Attendance also varied widely between groups, with attendance ranging from zero to 20 participants regularly attending meetings.

#### E. **Compensation for Participation**

All of those who participated in the individual interviews, including the group coordinators, were compensated for their time with an Amazon gift card valued at \$20.00. The cards were distributed upon conclusion of the interview. The participant who chose to withdraw from the study after the interview had begun still received this compensation. The gift cards were sent via the U.S. Postal Service, or through email.

All participants will be given a completed copy of the research report upon its completion. It has previously been noted that promising participants a copy of the research report is valued by the participants (Meho, 2006).

F. **Research Ethics**

The protocol used for this research was reviewed and approved by members of the Institutional Review Board at the University of Illinois, Chicago (Appendix M). The informed consent process used is reviewed below. Next, a detailed discussion of the measures taken to protect the confidentiality of participants is presented.

1. **Informed consent**

Participants had a choice of signing a consent form through a secure web application called Hello Sign, or receiving a hard copy of the consent materials through the mail. When a participant wished to receive a consent form as a hard copy, the consent materials along with the consent comprehension questions (Appendix N-Q) were sent via U.S. Postal Service, and the participant signed and returned the materials prior to conducting the individual interview. Consent comprehension questions were emailed to the participant if they wished to sign a consent form electronically. All the participants demonstrated sufficient comprehension of the consent materials.

2. **Confidentiality**

Several measures were taken to ensure that the privacy and confidentiality of participants was not compromised. All folders containing research-related documents were stored as an encrypted disk image using 128 AES bit encryption. This disk encryption is available through the Disk Utilities feature provided by Mac OS X.

Names and contact information of research participants were stored in a password-protected Microsoft Word document to which only I have had access. Participants did not have access to knowledge of which other group members chose to participate. Each participant was given a pseudonym, and all her data were linked to that pseudonym. I randomly selected pseudonyms for each participant using a common name list. The master list with participant's real names, pseudonyms, and contact information was stored in a password-protected Microsoft Word document that only I have had access to. Hard copies of the transcripts and coding schema are stored in a locked file cabinet. These documents contain participants' code names only. A separate locked cabinet contains the documents with identifiers, including the master list with participants' real names, hard copies of participant contact information, and signed consent documents. Only I have access to these locked cabinets.

Voices of the participants were recorded during interviews on a digital tape recorder. As soon as possible after the interview took place, I downloaded the audio recording into a password-protected and encrypted file on my laptop and erased the digital recording from the tape recorder. The digital tape recorder containing the interviews was stored in a locked cabinet. The laptop computer containing copies of the audio tape recordings, transcribed interviews and drafts of the research report, as well as participant contact information, is kept in my office. The office is locked when I am not on the premises.

In some cases, email interviews were conducted. I sent and received interview documents through my university webmail account hosted by Gmail. All Gmail email is encrypted. The contents of the email interview were copied and pasted into a password-protected Microsoft Word document. The participant's real name and email address were

deleted and replaced with their pseudonym. The original emails containing the interview data were deleted from the mail server. All identifiable data including contact information, audiotape recordings, and transcriptions of audiotape recordings will be destroyed by permanently deleting these documents from my computer. The hard copies of research documents containing identifiable information will be shredded. The destruction of these data will occur within one year of soliciting the participants' feedback on the draft of the research report.

**G. Data Collection**

This research employed qualitative data collection strategies. Conversational interviews with past and present group coordinators of support groups for women with disabilities lasting approximately 20-30 minutes, and semi-structured individual interviews with group members lasting approximately 90 minutes were conducted. The semi-structured Interview Guide for Online Group Members (Appendix D) and the semi-structured interview guide for In-person Group Members (Appendix C) contained both key and probing questions geared towards the exploration of the main and secondary research questions. The group member guides are divided into several subtopics. These topics were derived from my research questions and in response to gaps in the literature. Topics include the following:

1. Self-concept and group process;
2. Relationships with other group members and the development of self;
3. Group process and womanhood;
4. Group process and transition to adulthood;
5. Mission/philosophy of the group and self-concept; and

6. The format of the group.

The conversational Interview Guide for in-person Group Coordinators and the Conversational Interview Guide for Past in-person Group Coordinators (Appendix G and H) contains questions geared towards the following:

1. The Group's mission;
2. How objectives are accomplished;
3. Group coordinators' observations regarding the self-concept development of group members; and
4. Challenges the group has faced and how they have been/could have been overcome.

All interviews were conducted either over the phone or through email. Telephone interviews were audio recorded using a digital voice recorder. Participants were given a codename prior to the beginning of the audio recording and only referred to by their code name throughout the recording. Audio recordings were transcribed verbatim by a professional transcription service familiar with working with research data and issues surrounding confidentiality. I cleansed transcripts of any remaining identifying information as soon as the transcription was received.

The following procedures were used for individual interviews with online and in-person support group members that took place via email:

- There are four separate sections of the interview guide. Participants were emailed one section of the Individual Interview Guide at a time, including all key questions and their associated probes.

- Participants were instructed to use the probing questions to expand on their answers to the key questions as they saw fit.
- Participants were reminded that they were free to skip any questions that they did not feel comfortable answering, and that they were free to withdraw from the study at any time without penalty.
- A recommended timeframe of seven days was given for each section. Participants were given the opportunity to propose an alternate timeframe.
- Email exchanges included requests for clarification or expansion of previous answers.
- Participants received a response, including the next set of questions and any clarification needed from me within 72 hours of receiving their responses and/or inquiries.
- In an effort to protect individual privacy, all responses were copy-and-pasted into a password-protected Microsoft word document. Interview responses were stripped of identifying information, and the participants' real names were replaced with their codenames. The original emails were deleted from my email server.
- Participants' received instructions and the procedures outlined above via email before the email interview exchange commenced.
- In the event that a participant did not respond in the agreed upon timeframe, a reminder email was sent with a request to reply within two days with their responses, or with a new timeframe for completion.

The following procedures were used for the conversational interviews with group coordinators that took place via email:

- Participants received one email, which consisted of the questions from the Conversational Interview Guide for Interview with Group Coordinator.
- Participants were reminded that they were free to skip any questions that they did not feel comfortable answering and that they were free to withdraw from the study at any time without penalty.
- A recommended timeframe of seven days was given for completion. Participants were given the opportunity to propose an alternate timeframe.
- Email exchanges included requests for clarification or expansion of previous answers.
- Participants received a response and any clarification needed from me within 72 hours of receiving participant responses and/or inquiries.
- In an effort to protect individual privacy, all email interview responses were copy-and-posted into a password-protected Microsoft word document. Interview responses were stripped of identifying information, and the participants' real names were replaced with their codenames. The original emails were deleted from my email server.
- Participants received instructions and the procedures outlined above via email before the email interview exchange commenced.
- In the event that a participant did not respond in the agreed upon timeframe, a reminder email was sent with a request to reply within two days with their responses, or with a new timeframe for completion. Up to three reminder emails were sent.

## H. **Data Analysis**

In some cases the transcriptionist had difficulty deciphering the accents and/or speech patterns of the participants. In these instances, I transcribed the audio recordings myself. Data were analyzed in a manner consistent with grounded theory. A thorough line-by-line reading of each transcript took place. Margin notes were made containing keywords or phrases, i.e. codes regarding what each piece of data indicated that might be relevant to the study's primary and secondary research questions. In addition, longer memos containing interpretive thoughts regarding the data were written. Using data analysis techniques identified by Patton (2002), all data were organized into major themes and major categories.

Themes represent findings at the broadest level while major categories represent findings which are narrower in scope and used to illustrate the larger theme. Thus, the determination of what type of category each datum fits into was based on its scope and centrality to the research questions. Broad and all-encompassing findings were classified as themes and narrow related findings were classified as a major or minor category underneath broader themes. The data were searched for patterns or relationships between themes and categories that seemed theoretically interesting. Similar themes, sub-themes, categories, and sub-categories were merged when appropriate. Once this process was complete, the original transcripts were re-examined to make sure that all relevant data were accounted for and categorized appropriately. The coding scheme was created using Microsoft Word. This application was chosen because it met my accessibility needs and I found it to be the most efficient way for me to code and organize the data.



## I. Steps Taken to Ensure Quality of the Research

Several steps were taken to help ensure the rigor and trustworthiness of the findings. Within qualitative research it is important the results have credibility, meaning that they accurately capture the subjective thoughts and feelings of the participants (Patton, 2002). Triangulation is one technique used to establish the credibility of qualitative inquiry. This refers to representing different perspectives within the research. These different perspectives should coincide with one another and fit within the same theoretical framework but will not necessarily yield the same results (Morrow, 2005). The present study triangulated data sources by including the perspectives of both group members and group coordinators as well as incorporating the views of both women who took part in online and face-to-face groups.

As an additional means of enhancing credibility, every effort was made to maintain empathic neutrality towards the participants' responses. Patton (2002) identifies this as a process of conveying care and interest about what the participants are saying, while refraining from casting any judgment. During each interview I thanked the participants for sharing their perspectives, but did not convey approval or disapproval regarding the contents of their responses. This helped to ensure my own biases and perspectives did not unintentionally influence the participants' answers. The interview questions were framed in an open ended manner and invited a wide range of replies.

Reflexivity is another technique that helps the researcher remain cognizant of their biases throughout the research process. This is an essential aspect of rigor and trustworthiness. Reflexivity is an ongoing process throughout the research, and entails critical reflection on one's biases, theoretical predispositions and preferences (Niesz, Koch,

& Rumrill, 2008). Within qualitative research the researcher is considered the primary research tool. Although their principal concern is bringing the participant's subjective experience to light, their own subjectivity is always intertwined to some extent within the research. With this in mind, I continuously reflected on my own biases and tried to separate those as much as possible from the participants' perspectives. To these ends my interpretation and perspective on what was being said is delineated from the participants' actual responses in my interview notes as well as throughout the reporting of the results.

Morrow (2005) identified bracketing as a potential strategy for promoting reflexivity. This involves the researcher placing in brackets their own implicit assumptions about participants' emotions and words that were implied but not actually spoken by the participant. Bracketing was used throughout the reporting of results for the present study. Given that some of the participants in this research had speech patterns that were difficult to understand the use of brackets was particularly important. I was always extremely cautious about inadvertently inserting my own points of view when reporting this data. As Ashby (2011) argues, researchers need to resist the temptation to create a "beautiful fit" or a clear story out of the participant's narrative. We as researchers need to remain vigilant about the value of disjunction and diversity of lived experience.

Member checking is another hallmark of the rigor and trustworthiness of a qualitative research approach (Patton, 2002). This involves giving each participant the opportunity to review the research results and provide feedback on them. The member checking process for this research entailed sending each participant a summary of research results along with a list of research themes and exemplary quotes to illustrate the themes. The women were asked to provide feedback on whether the results correctly conveyed their

experiences. Eight participants responded to my request for feedback. All of the women indicated that they thought their experiences were accurately captured in the research results, which speaks to the credibility of this research. One participant who was a member of both an online and in-person support group noted she has less time to participate in disability related activities, especially face-to-face support groups since becoming employed. Another participant suggested a direction for future research, which is addressed in the Discussion chapter. Finally, one participant mentioned that she saw the sharing of disability related resources within support groups as promoting “disability literacy.” Based on this feedback I created a subtheme to illustrate the promotion of “disability literacy.”

In addition to participant member checking, I had colleagues from the University as well as my academic advisor review the transcripts and a draft of the results. Feedback from colleagues was provided in either a written or oral format. Upon completion of each colleague’s review I engaged in a phone conversation, in-person conversation or email conversation to discuss their feedback with them. Their feedback was incorporated into the report where appropriate. For instance, one colleague noted that the participants seemed to experience a wide range of emotions and the group provided space to process these emotions. Based on this feedback, more emphasis was placed on this finding within the coding schema and the reporting of results. All of the steps outlined in this section worked together to help foster the rigor and trustworthiness of this research.

#### IV. RESULTS

Qualitative analysis of group member interview transcripts revealed seven major themes: 1) Becoming comfortable with who I am: personal goals that are important to women with disabilities; 2) Intersections of gender and disability: challenges disabled women face that may hinder self-concept; 3) Who am I? Knowledge and self-concept before the group; 4) Relational dynamics within group support; 5) The influence of an engaged sharing process on self-concept development; 6) The power of community membership: the influence of the group orientation and platform on self-development; 7) Transition to adulthood for women with disabilities; and 8) Format of the group. Similarly, data analysis of group coordinator interview transcripts revealed three major themes as follows: 1) Getting in-person support groups started for women with disabilities; 2) The logistics of running and maintaining an in-person support group; and 3) Self-concept development and transition to adulthood: observations and conjectures from group coordinators. Major themes and major categories for group member data will be presented first, followed by the analysis of the group coordinator data. Outlines of the themes and their constituent subthemes are presented in Tables I and II.

**TABLE I**  
**THEMES FROM GROUP MEMBER INTERVIEWS**

- 
1. **Becoming comfortable with who I am: Personal goals that are important to women with disabilities**
    - a. Being outspoken and confident about who I am and what I need
      - Achieving comfort with your body promotes confidence
      - Achieving confidence promotes comfort with yourself
      - Advocating for accommodations
    - b. Independence
      - Living independently
      - Being financially independent
      - Being responsible for yourself
    - c. The necessity of flexible goals in order to achieve meaningful occupations
      - Flexible career/education related goals
      - Adjusting goals to achieve life enjoyment
    - d. Recognition of personhood
      - The realization that discrimination is not due to intrinsic qualities
      - Being recognized as a human being by others
  
  2. **Intersections of gender and disability: Challenges disabled women face that may hinder self-concept development**
    - a. Discrimination
      - Inaccessibility
      - Employment
    - b. Societal pressure to meet normative gender expectations
      - Pressure normative standards of appearance
      - Pressure to meet normative responsibilities
    - c. Out of touch with reality: Society's inaccurate and harmful perceptions about women with disabilities
      - Perceptions of malingering
      - Refusal to validate the disability experience
      - Inadequate and inaccurate information about reproductive health
      - Disability is horrible and shameful
      - Infantilization
      - Medicalization of disability and chronic illness
      - The interplay of cultural context and disability stigma
    - d. A disconnection with others: Lack of understanding and support
      - Feelings of isolation and loneliness
      - Lack of awareness of peer support outlets
-

**TABLE I (continued)**  
**THEMES FROM GROUP MEMBER INTERVIEWS**

- 
3. **Who am I? Knowledge and self-concept before the group**
- a. This is who I am! Affirmative self-concept
    - Positive self-concept related disability
    - Favorable body self-concept
  - b. Not comfortable with who I am: Insecure self-concept and emotional turmoil
    - General insecurities
    - Insecurities related to disability
    - Insecurities about body image and sexuality
4. **Relational dynamics within group support: Setting the stage for self-concept development**
- a. The interplay of gender and group dynamics.
    - Relatability in women only groups
    - Open discussion about women's issues in women only groups
    - Women only groups create a safe space to be yourself and express your feelings
    - Articles and resources on women's issues not as helpful as discussion for some women
    - Value in groups that include both men and women
    - Some women perceived no benefit of gender restrictions within groups
    - Intangible difference when both genders are present
    - Lack of participation of men in groups open to both genders
  - b. "We support each other no matter what." A distinctive relationship with other group members
    - Mutual support and understanding
    - Unconditional support
    - An "odd" intimacy
    - Preference for lighthearted communication
  - c. Mentoring relationships
    - Informal mentoring
    - Collective mentoring
    - Mentoring relationships with group coordinators
  - d. Maintaining relationships with fellow group members
    - Phone calls
    - Private messaging/text messaging
    - Occasional face-to-face visit
-

**TABLE I (continued)**  
**THEMES FROM GROUP MEMBER INTERVIEWS**

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e. Control over friendship formation online	Choice of who you can communicate with and become friends with
	Ability to block communication from certain online users
	Conspicuously ignore communication
f. Online group dynamics sometimes invoke feelings in some that may suppress positive self- concept	Shyness and anxiety
	Feeling a sense of vulnerability and loss of control
	Aversion to the language that the group uses
<b>5. <u>The influence of an engaged sharing process on self-concept development</u></b>	
a. "I am not alone": Sharing with similar others	Realization that others have similar disability/medical issues
	Recognition of shared humanity
	Promotes comfort with oneself
	Reduces isolation
	Increases sense of belonging
b. Promotion of disability literacy	Assistive technology
	Medical research
	Accessible transportation
	Disability policy
	Creative problem solving strategies
c. Promotes revolutionary thinking about disability	De-stigmatization of disability
	Perception of disability as a sociological category and civil rights issue
	Disability is a positive part of one's identity
	Acceptance and comfort with bodily differences
	Reaffirmation of body positivity
	Realization that disabled people can have romantic relationships and be parents
d. Affirmative thinking about one's body and sexuality	Promotes comfort with one's body and bodily functions
	Realization of sexuality and recognition of possibilities within the romantic realm
	Promotes accurate understanding of women's health information

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**TABLE I (continued)**  
**THEMES FROM GROUP MEMBER INTERVIEWS**

- 
- e. A boost in confidence
    - Optimism about the future and their capabilities as disabled women
    - Validation and reassurance about the disability experience
  - 6. **The power of community membership and the message and platform associated with it**
    - a. Kindling the desire to be an advocate
      - Overall platform of empowerment
      - Posted articles and discussions spark awareness of social justice issues
      - Willingness to advocate for self and others
    - b. Opportunities to be a leader and perceive one's self as a leader
      - Writing and circulating articles on disability issues
      - Initiating change in group culture
      - Teaching others about topics of interest
    - c. The development of a collective consciousness
      - Ability to situate oneself as part of a larger disability/feminist community
      - Awareness that disability issues affect us all
      - Anger regarding the discrimination disabled people as a whole face
  - 7. **Transition to adulthood for women with disabilities**
    - a. Defining adulthood and important milestones of adulthood
      - Self-supporting
      - Being a self-advocate and making your own choices
      - Being a leader/ being respected
      - Having people skills
      - Age, maturity and life experiences
      - Self-exploration
      - Vagueness of adulthood: "How do these things relate to me"?
    - b. Barriers to transitioning to adulthood
      - Bodily limitations and loss of independence
      - Not being able to drive
      - Low expectations from parents
      - Stigmatizing perceptions of others
      - Society only recognizes traditional markers of achievement
      - A stigmatizing self- perception: "Disability and adulthood are incompatible"
-



**TABLE I (continued)**  
**THEMES FROM GROUP MEMBER INTERVIEWS**

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c.	<p>The group's influence in transitioning into adulthood</p> <ul style="list-style-type: none"> <li>Learning from others' experiences, getting advice and encouragement</li> <li>Provides space to process and discuss emotions that hinder transition</li> <li>Social networking helps meet educational goals</li> <li>Raised consciousness about important issues of adulthood</li> <li>Helps shift goals from society approved goals to individual goals</li> </ul>
8.	<p><b><u>Format of the group</u></b></p> <ul style="list-style-type: none"> <li>a. Benefits of in-person meetings <ul style="list-style-type: none"> <li>A personal connection: a physical space to engage with others</li> <li>Guest speakers</li> </ul> </li> <li>b. Barriers to participation in support groups for younger women <ul style="list-style-type: none"> <li>Limited availability globally (both in-person and online formats)</li> <li>Lack of desire to identify as disabled (both in-person and online formats)</li> <li>Lack of availability and awareness of their existence (in -person groups)</li> <li>Trouble getting to a physical location (in-person groups)</li> <li>Scheduling (in -person groups)</li> <li>Lack of resources: Financial and personal (in -person groups)</li> <li>Personality conflicts (in -person groups)</li> <li>Anxiety and discomfort (in -person groups)</li> <li>Too depressing (in -person groups)</li> <li>Fear of not being believed (in -person groups)</li> <li>Age "lock-in effect" (in -person groups)</li> <li>Limited opportunity for carefree socializing (in -person groups)</li> </ul> </li> <li>c. Benefits of online peer support <ul style="list-style-type: none"> <li>Digital support is appealing to the younger generation</li> <li>Allows for experimentation with disability identity</li> <li>Online support groups erase the learning curve associated with disability diversity and etiquette</li> <li>Online support groups encourage people to be vocal</li> <li>The online platform creates boundless connections, instant connections to "people like me"</li> </ul> </li> <li>d. Differences in online platforms and groups: The pros and cons <ul style="list-style-type: none"> <li>Facebook versus Tumbler</li> <li>Facebook versus email listservs</li> <li>Ages of participants in the different online groups</li> <li>Facebook versus standalone websites</li> <li>Accessibility of Facebook mobile app versus Facebook website</li> <li>Synchronous versus asynchronous communication through Facebook</li> </ul> </li> </ul>

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**TABLE I (continued)**  
**THEMES FROM GROUP MEMBER INTERVIEWS**

- 
- e. Disadvantages of online support
    - Geographical barriers
    - Loss of physical presence and material spaces
    - Creates an illusion of closeness
    - Difficult to search certain platforms
    - Difficult to decipher tone of communication
  - f. Suggestions for improvement of the online support experience
    - Accessibility of platforms
    - Daily communication
    - Keep the amount of communication manageable and searchable
    - Find topics of interest for younger women
    - Make sure positive role models are visible
-

A. **Themes from Group Member Interviews**

1. **Becoming comfortable with who I am: Personal goals that are important to women with disabilities**

Many women spoke poignantly about the goals that were important for them to achieve. A prominent theme was their desire to become comfortable with who they are. They expressed a variety of goals that connected to achieving their ultimate goal for becoming comfortable with who they are. They also spoke about being flexible with the goals they set in order to achieve and maintain personal well-being as their circumstances change.

a. **Being outspoken and confident about who I am and what I need**

When asked to describe the goals they set for themselves the overall goal of comfort with oneself was often associated with being confident to speak up for your wants and needs. For some women being comfortable with who you are preceded the ability to project yourself with confidence, while for others it seemed that being confident and outspoken led to an overall sense of comfort. For Charlotte, who has a physical disability and is a member of both in-person and online support communities, the former was true. When asked to describe goals that are significant to her as a disabled woman, Charlotte stated,

Learning how to be more comfortable in your body is really important if you want to project yourself with confidence. There is all this pressure on women as it is, but it is much harder if you cannot do those things.

On the other hand Mia, an online group member with a physical disability, felt being confident to assert her wants and needs would lead to a more secure sense of self:

I feel like -- I think I have a few goals for the next few years on being more vocal about my issues. . . . As a woman, it's going to help me feel better about myself and

about my family. You know? . . . I wish that I was more vocal and I knew how to express myself in a way where I can be more of an activist through the Internet or disability community and not feel scared of what people are going to say or not feel like people are going to feel sorry for me.

Bella, an online group member with a sensory disability, also set goals for herself related to becoming comfortable with who she is. She spoke at length about her desire to be more comfortable with the effects of her impairment:

Being comfortable in public situations when I am by myself and when my disability becomes very apparent or makes things very awkward can sometimes be difficult for me. . . . I remember one time fairly recently where [a nurse] called my name and I stood up and I thought that I just needed to go straight because it sounded like that's where their voice was coming from and I did not know that there was a wall in front of me and I had to actually make a turn. And I kind of just felt like I was sort of stumbling and bumbling around and everybody was staring at me and, of course, I have no idea if anybody was staring at me at all or not, but I felt like I was on display. And I think I had to kind of just become more comfortable with the fact that, okay, this is the way life is going to be for me sometimes and that's no one's fault and it doesn't make me incompetent or inadequate.

In conclusion, for some women being comfortable with who they are was often interconnected with self-confidence and advocating for what they need.

b. **Independence**

Being independent and making their own life choices was an important goal and another key to them becoming comfortable with who they are. One participant proclaimed:

As a woman with a disability, my goal is to be financially, physically independent as possible. Yeah. To be independent as possible. So my goal is to find a job where I can be self-sufficient. So that's very important to me. Not depending -- not depending on a man [is also important to me]. Finding a job, buying a home . . . I want to do that. [Natalie, online group member with a physical disability]

Joanna, an online group member with a physical disability, also had goals that reflected a desire to be independent. Describing goals that were important to her, she said,

“just being responsible for yourself, having your own house having your own car, and living on your own.”

Being financially independent and not relying on others was a significant goal for Elizabeth, a member of an in-person support group for women with disabilities. “As a now business woman, my goal is to make my business grow and be financially independent from any type of help. I want to be a woman that’s capable of fulfilling my needs by myself and feel accomplished.”

c. **The necessity of flexible goals in order to achieve meaningful occupations**

Many of the women spoke candidly about the necessity of making sure the educational and avocational goals they set for themselves are flexible to accommodate the fluctuation of impairment affects. Emma, a long time user of online support communities for women with disabilities, spoke at length about the need to consistently adapt her recreational goals and the frustration that comes along with that. Ultimately, the most important goal for this participant was to be able to continue to do things that were meaningful to her:

I think my current goal is about just surviving and adapting. My disability is getting quite a lot worse lately. Or my impairment is getting a lot worse. So the stuff that I can actually do is just shrinking down a lot. That's really hard. . . . I figure out different ways to, like, scratch that same itch. Like, before, I was doing crochet and embroidery and then my hands got worse. I switched to drawing because it was easier on my hands. . . . I like to do stuff that makes me happy . . . I'm afraid of losing all those things that make life feel more meaningful. That’s probably most of my goals in the moment.

Other participants expressed how their careers and education shifted in order to accommodate their changing needs. For instance, when speaking about her education goals, Victoria, a long-time online support community member from Eastern Europe, asserted,

At first I wanted a career but I got held back and couldn't find another job. I didn't want to stay home. And I wanted a career so I tried translating from English to my language. It was not perfect because I realized my fingers hurt. So I came back to the university but I was too damaged. At first my goal was to have a career. Now, my goal is different: it's to do something I will be able to do when I'm in bed. This is why I am going for my university degree. . . . Long-term goal is to get the degree and be able to do psychotherapy from my bed.

Similar to Victoria, Sophia spoke poignantly about coming up with fulfilling career opportunities that will suit the changing nature of her impairment:

My main goal is just to find a job that will accommodate my needs and not be too stressful for me. I have a probably unrealistic dream of becoming an author, because when I can no longer work a job that requires me to leave the house, I feel like that would give me something enjoyable to do that I could still make a bit of an income with. But, until the time comes when I can no longer work, I don't think I will have enough time to hone my creative writing skills since I sleep in all my free time.

As illustrated above the participants had a strong desire to engage in meaningful activities. However, given the progressive nature of many impairments, occupations that were meaningful to them sometimes became very difficult or impossible to engage in. The women employed flexibility and creativity in order to continue to pursue activities that were important to them.

d. **Recognition of personhood**

Some goals participants set for themselves were abstract, yet an integral part of them becoming comfortable with who they are. Victoria spoke about how she has recently come to the realization that it is important for her to recognize her own personhood and that the discrimination she faces is not due to her intrinsic qualities. She asserted:

I realize that part of my goals is to be a person. In the last few years I was losing mobility, people started to think that I'm not a whole person. One of my goals is to see that it's not part of me! It is part of their upbringing, part of their misinformation when they think disabled people are totally different than they are! This is one of

my goals. . . . [I want to] live as a person, to have accommodations, to not end up in a nursing home.

Mia, who is blind, expressed a similar desire for others to recognize her personhood and gain personal comfort with how she is perceived. When discussing her current goals she stated:

Another thing that comes to mind is being comfortable with the fact that everywhere I go I'm going to be viewed as the girl with the dog and that's the way the public sort of associates you. I know when I was at my college campus, that's how I was viewed. Oh, it's the girl with the golden retriever. And I love the people who get to know me for me, and the dog is less of that equation. I mean obviously she plays a huge role in my life and I wouldn't have it any other way, but I am a person beyond my guide dog.

Elizabeth noted recognition of personhood was a primary goal of her in-person support group for women with disabilities, saying, "[our goal is to] have the normal population see that we're also human beings who are on this Earth like everyone else. We also want to be known and recognized."

In summary, participants had both concrete and subjective goals. These range from completing degrees, finding employment, being a self-advocate and recognition of personhood. The women acknowledged the need to be flexible with the goals they set, in part to accommodate the often fluctuating nature of their impairments. Accomplishing the goals they set for themselves was extremely important to them being comfortable and confident with who they are.

## 2. **Intersections of gender and disability: Challenges disabled women face that may hinder self-concept development**

Throughout the interviews some women spoke of the complex ways in which their gender and disability intersect. These intersections often created barriers to becoming comfortable with who they are and achieving their goals. On the other hand, some

participants perceived disabled women as facing similar challenges to women in general.

When asked about the ways disability and gender oppression intersect, responses included:

We all have goals, but as a woman with a disability, it's harder to reach those goals. We face challenges. [Elizabeth]

There's a lot of articles about how women who are disabled still struggle to make a name for themselves . . . at getting accounts out there; things like that. Articles like that, when I read them, it's a constant reminder that, you know, whether disabled or not they're still facing a lot of like things that they shouldn't be facing. Like this whole world should be more equally taken care of, you know, like helping out. I don't know, it's just like women, they still struggle even if they are disabled or not. [Mia]

We are at great risk of sexual assault. This is not something I want to talk about much. [Victoria]

I think perspective is important. I think it's important to realize that, you know, as a woman that puts you in a category, and then as a disabled woman that kind of puts you into another category, and if you're not careful, the mental kind of marginalization can become frustrating. [Bella]

I think that's true of women in general [that women face challenges men do not face]. All women have needs that men don't, and issues that are really gender-specific. Sex and sexuality would be a great example. [Harper]

Specific barriers the women spoke about included discrimination, society's inaccurate and harmful perceptions about women with disabilities, and lack of understanding and support from others. These barriers are discussed in turn below:

a. **Discrimination**

The women spoke of multiple ways in which they faced discrimination both because of their gender and because of their disability. Basic needs like obtaining women's healthcare was difficult for some because of the inaccessibility of health care facilities. For instance, Mia lamented about her struggles during a recent doctor's appointment at a women's health center:



I feel like when I have perceptions of things that are kind of hard, especially when you're disabled, I don't see a man go through that. . . . I went to the Women's Health Center take a test and their bathroom wasn't even big enough to get my wheelchair in. I had to struggle to get in to take my test. It was really hard because after a while I wasn't able to put my pants up so I needed to ask for help. It's just a very difficult situation to be in, especially being in really big hospital where they should have handicapped accessible bathrooms, but they didn't have one. It wasn't cool.

Victoria also noted the difficulty women with disabilities face when trying to locate accessible healthcare, stating: "Another challenge we face as women with disabilities is finding an accessible women's health provider. You don't only need women's health but you need urinary tract health."

When asked about the challenges she faced as a woman with a disability, Elizabeth spoke of the general inaccessibility that still prevails in our society today. She asserted,

Even though we're in the 21st century, not every place is accessible, which is very frustrating. Some of us have someone with us who can help with transfers, but many of us don't, so places and things have to be accessible regardless . . . . Sometimes we're so secluded because not everything is accessible and people forget about our needs!

In addition to facing daily challenges with inaccessibility, some women spoke of discrimination within the employment realm. The women were very cognizant of the disadvantages they have compared to their male counterparts. For instance, Victoria who lives in Eastern Europe passionately spoke of the widespread barriers disabled women face with regard to employment:

Women are disadvantaged! For example, in my country we have women doctors and some lawyers but there is a pay gap. In some ways my country is better than the United States for example. We've had maternity leave for a long time. But, there is discrimination for both my country and the United States, there is discrimination against women and it intersects with disabilities. Women with disabilities make less money than healthy women without disabilities and healthy women without disabilities make less money than men in the same field of work, in the same career. . . . As I said, there is a pay gap between disabled people and non-disabled people. There's also pay gap between men and women. These two disparities give you a big problem, a bigger problem together!

Joanna who is of Asian descent saw gender in particular as being at the forefront of discrimination with regard to employment, saying, “I think we live in a society that favors men over women. . . . For example they [employers] would pick an uneducated Asian man with a disability over me just because of my gender.”

As illustrated above, discrimination was a prominent barrier in the lives of the participants. Several women spoke about inaccessibility particularly in healthcare settings. They also spoke passionately about the intersections of gender and disability within the employment domain.

b. **Societal pressure to meet normative gender expectations**

Some of the women noted the pressures they faced to meet normative expectations and the socially constructed responsibilities of women. For instance, Charlotte noted, “as a woman you are expected to look/dress a certain way, but that is not something easily done depending on your disability.” Similarly, when discussing the challenges she faced as a woman with a disability, Mia asserted, “As a woman, you know, society tells us that we should be looking one way and not [another way], appearance-wise.” Even though Emma does not see these gender normative pressures as applicable within her own life, she reflected on how they apply to friends and acquaintances of hers:

I think that women with disabilities do have challenges that men with disabilities don't face, but I think a lot of them are around things that aren't relevant to me. Like, I've definitely seen women with disabilities who are raising children, who the men in their lives still expect them to do like all their caring role, even though they're not physically able to do that. I think with men with disabilities it's much less -- men in general, with or without disability, like much less are just assumed to always be the caring one, but, . . . haven't been able to have a family, so that's not a situation I've faced.

c. **Out of touch with reality: Society's inaccurate and harmful perceptions about women with disabilities**

Many participants were affected by the harmful misconceptions about women with disabilities, which are prominent within society. Sophia encountered perceptions of malingering and has concluded that society is quicker to discredit women's claims regarding their health than they are for men:

I definitely have seen a few posts . . . about people who don't believe you and think you're just faking it, especially because we're women. People and doctors believe that the pain we're in is not as bad as we say, think we're lazy if we don't do some activity because we know that would be overdoing it, and criticize us for not being successful because of our laziness when, if we didn't have these constraints, we would have great jobs and full lives. That is definitely the general consensus about the outside perspective of women with disabilities as seen through the eyes of those of us who have them, but in the community it is just something that is and that we can't change, so we accept it.

She hoped pursuing a master's degree would lend credence and validation to her claims about her pain and health. When asked to elaborate more on the differences between the way men and women with disabilities are treated, she continued:

I think part of the reason that I would like a master's now is that if I have a higher level of education, people won't look at me like I'm really lazy and whiny like they seem to do to women with disabilities, or at least not to the same extent. I think it's in the same realm as doctors and other people thinking that women exaggerate their level of pain and that men have better pain tolerance when in reality there is no significant difference. While I think men with disabilities and chronic illnesses face ridicule for not being tough enough, I think it is worse on the women who are looked at as less capable to begin with, and having to ask for accommodations on top of that is really difficult.

Victoria reflected on similar instances in her life. She had repeatedly been told that her inability to accomplish her educational goals was the result of laziness and lack of initiative. Reflecting on this, she stated,

And when the diagnostic papers are wrong, everyone is telling you that you're lazy; you don't need any extra accommodations because you are just lazy. If you try a bit

harder everything will be okay! When you live with this feeling for 30 years it is a huge setback that makes you un-finish your stuff because of complex trauma.

Another participant expressed society's propensity to stigmatize and distort the meaning of the term disability in a way that characterizes disabled people as lacking motivation. Emma asserted, "The concept of disability is perceived quite often as giving up or meaning that you weren't trying to improve your physical situation and a lot of other things that are not actually what disability means at all."

In addition to dealing with lack of validation and perceptions of malingering from those around them, many of the women recounted receiving a dearth of reproductive healthcare information. Charlotte discussed how she was never given any sexual health information specifically pertaining to women with disabilities:

This may seem crazy, but the idea of birth control or sex for that matter was never discussed with me. I learned about regular safe sex in public school, but nothing that was specifically geared towards women with disabilities (like the pill could possibly cause blood clots because we are sitting all day). Just information about sex in general (positions, activity, etc.); this is not something that was ever discussed with me by anyone. . . . While I do not have any intentions of having children, it was something that I had thought about when I was in my 20s, but did not know that pregnancy and motherhood was something that women with disabilities could do. I had never encountered another woman with a disability who had wanted to or had done it.

Similarly, Bella also wished there was more information targeted towards the healthcare and hygiene needs of women with disabilities. She recognized that women with disabilities face personal care challenges that men with disabilities do not have to deal with:

There are things that women with disabilities have to deal with that men don't or don't have to deal with in the same way. Personal care kind of comes to mind, kind of that top kind of worry that. . . . That would obviously be like menstruation and handling that as a woman with a disability. You know things like shaving your legs, shaving your underarms, alternative techniques for doing that.

When they did receive information on the subject they often found it to be inaccurate. For instance, Victoria, who very much wanted children said, “I missed my opportunity to have children . . . when [I was growing up], my mother was telling me that I’m totally unfit to have children because I am disabled and disabled people should not have children.”

Along with having their sexuality questioned and/or not acknowledged, some of the participants spoke of contending with notions that disability itself is a horrible and shameful occurrence that nullified personhood. This was especially prominent for Victoria, who lived in Central Europe. When talking about the barriers she faced as a woman with a disability, she said,

The social model of Disability is not implemented in my country. Nobody knows about it. In my previous training disability was something horrible and something you should be ashamed of . . . people with disabilities in my country are too scared to do anything. . . . People with disabilities in my country oftentimes are not perceived as people with personalities; they’re just seen as an object. . . . When I was in the hospital setting, because of my disability, lots of times I was treated like not a person . . . some second-hand person.

Joanna reported negative stigma around disability within the Asian community as well. This included the beliefs that disability is a terrible thing that should not be talked about and people with disabilities need to be sheltered and protected. When discussing the barriers she and other women with disabilities face, she stated:

In my case, in the Asian community, people see disability as a terrible thing. They don’t want to talk about it; they don’t want to do anything about it. If they have a child with a disability all they want to do is protect their child and that’s pretty much it. Women want to go out with a disability but because of their culture they may not be able to do that.

The notion that disability is shameful existed even within some online support communities. In the chronic illness support groups Emma is a part of, many of the participants choose to avoid the word disability. Emma reflected on this occurrence:

One thing that I've discovered about a lot of online support groups that focus on different chronic illnesses is that although most people in those groups are objectively disabled, most of those people also do not identify as a person with a disability. Like they are people who are disabled, but disability is almost like a dirty word or a forbidden concept. It's very odd!

When disability was not being stigmatized as shameful it was sometimes still being medicalized in ways that some participants found non-productive and harmful. Victoria spoke poignantly about how the perceptions of her teachers changed when she revealed her need for accommodations:

They started to judge me differently. They started to ask me questions like what happened to you? How do you get to school? Is there some kind of a [sic] experimental cure? They started to medicalize me. They started to see me as a patient instead of a student.

Emma also reflected on society's desire to cure disabilities, especially those considered chronic illnesses, and the toll this desire can take:

Like, if you have it in your head that your life is over unless you get better, which is a really common thing with people with chronic illness because, I think, unlike a lot of other sort of disabilities, when you first become chronically ill, you're surrounded by all these medical people who are telling you that you have to get better or the world will end. Those are really poisonous. It's really poisonous!

In sum, various misconceptions and prejudicial attitudes about disability played a significant role in many of the participants' lives. These misconceptions and prejudices were held by society in general as well as by people who were significant to them. This made it difficult for the women to accomplish their goals, fulfill their desires, and be comfortable with who they are.

d. **A disconnection with others: Lack of understanding and support**

Several women reported that a lack of support and understanding from others was a barrier they were constantly contending with. When discussing the barriers she faces to accomplishing her goals, Mia stated: “I feel like my biggest challenge is -- I just need more attention. I don't know. I don't really know. . . . Yeah, I think it's more of the support.” Emma saw this lack of understanding as applying to society as a whole, saying, “mostly in society we are all like ‘Hey, has anybody else done this?’ And everyone who's around you is like, ‘Wow, you're weird!’”

For many women, though, those close to them failed to develop the mutual understanding that they desired. For instance, Charlotte noted, “While the people in my life are pretty supportive, there are just some things they cannot understand.” Many of the women also reported feelings of isolation and loneliness, especially prior to their participation in online support. For example, Natalie reported feeling a disconnection and isolation before her involvement on the forums:

[Before the group] it was more of a solitary experience because I guess my peers or the people in my real life, as opposed to my online group, they don't share the same experiences. . . . I felt a sort of disconnection with others.

Similarly, Emma, who lives in Australia, also spoke of her feelings of isolation prior to joining online support communities:

I was massively more isolated before I found any online support groups. I felt really alone and I was feeling very sorry for myself. . . . I'd been a member of the American mailing list for it [my impairments] but that was [in America]. So many things in America are different about how everything works. So I didn't feel a really lot less isolated to be in that group.

Joanna spoke at length about her isolation and lack of connection with similar others prior to joining the group. She reported feeling lost in the world around her and this sparked feelings of anger and resentment:

As a person with a disability, it is kind of lonely in the world that you live in. Most of the time, I am with people who are able-bodied, and so you don't get others' perspectives except their perspective and it doesn't really validate your own perspective. . . . also [I feel] lost because there are a lot of things that I would think about as it relates to my life and living with disability. I don't have anyone else to bounce those ideas or concerns or issues that I'm facing. So kind of lonely and lost and thinking it cannot be just me feeling this way, even though I do have a supportive family, but at the end of the day, they don't know how to support me either in a way that's meaningful to me. . . . I go out and I see a world that's not made of people like me and I just didn't know where those people are, like people like me are. . . . There must be other people like me who share the same as I do, but I couldn't find them, you know. The injustice that happens to me as a person with disability I cannot talk about this to anyone because most of the people around me don't have disabilities and that's where that anger and the resentment come from in many ways.

She further elaborated on the disconnection she felt with her non-disabled friends and her reluctance to talk about disability with them:

[Before I joined the group,] talking about it [disability] would be embarrassing, not so much for me, but it will make my friends and other people uncomfortable about the topic. It's similar to when you are talking about racism. White people are uncomfortable, and they don't want to talk about that. And so, you feel like you should not be talking about it either because you're making them uncomfortable. So that's the same thing with disability, just because I have a lot of people who are not disabled in my life.

Bella also expressed reluctance to discuss disability with her non-disabled family and friends. Thus, she went through the process of reconciling her feelings about her disability alone:

And, you know, back then there weren't social media groups that you could participate in to ask questions and so for me that process [coming to terms with my disability] was experienced very much kind of alone but in the beginning I didn't really talk to anyone about it. . . . It was kind of a very internal private process that I went through.



Some women reported that they did not have access to or knowledge about resources that would help them end their isolation. For instance, Elizabeth said,

Before joining the group I didn't know about certain resources and that women with other disabilities were facing the same issues that I was facing. I didn't know that this organization even existed or that there could be an organization like the one I'm a part of.

As another example, Emma also remembered having trouble accessing support communities when she was growing up, stating: "I mean, it was a really, really, really long time ago. So there wasn't wide knowledge that online support groups were even a thing that existed."

In conclusion, the women reported facing many challenges that affect self- concept development. Prior to group involvement the women had experienced a significant amount of isolation and loneliness, cut off from other women who reflected similar experiences. They also reported a lack of resources, which made it difficult for them to thrive and come to terms with their disability.

### 3. **Who am I? Knowledge and self-concept before the group**

The data analysis revealed participants perceived themselves in a variety of ways prior to group involvement. Some women had a very firm sense of self and a broad knowledge base from the start of group participation. A majority of women, however, were not comfortable with who they were.

#### a. **This is who I am! Affirmative self-concept**

Some women expressed a very positive self-concept overall or in particular areas prior to joining the group. In the cases where a positive self-concept was already established, group involvement had little to no effect on how they felt about

themselves. For example, when asked to describe the group's impact on how she felt about herself, Elizabeth, presently in her 30s and involved in a face-to-face group, stated,

[When] I was in my 20s I learned to grow a thick skin and helping others do the same. I don't think there are any specific aspects about myself that I don't feel good about. Sometimes negativity creeps in my mind, but I push it out of the way because things can always be worse. It's up to us to live our lives and not let our circumstances get us down. . . . I didn't think I feel any different about myself [since joining the group].

Similarly, Addison, an online group member with a physical disability, also expressed an affirmative sense of self prior to joining the group.

Joining this group has not had any effect on my understanding of myself. . . . When I say that joining an online group didn't have an effect on my understanding of myself, what I mean is that I have always had a sense of self that I knew and loved. . . . I have always understood my own language and self. This group does not change my understanding or self-knowledge.

Sophia expressed a similar level of confidence shortly after her diagnosis, although this confidence declined over time. When discussing her self-concept prior to group involvement, she stated,

On the vein that I thought I would be back to normal again, I was really excited about my [professional] prospects . . . and figuring out where I wanted to travel when I was better. I was confident in my mental capacity thinking that the dementia-like symptoms would go away (they did to some extent but I still get brain fog and have trouble concentrating). So pretty much I was very comfortable with myself for a while after getting sick.

Like the others quoted above Mia expressed a level of self-assurance in some areas before becoming involved in online support communities. When asked to describe aspects of herself she felt good about prior to joining the group, she said,

I feel like I'm a good mom! I think I'm a good friend and I think I'm a pretty nice person. I'm very easygoing and I'm very understanding and I think that's what people like about me. I think that's what I like about myself, too.

It is important to note that she also discussed aspects of herself that she did not feel good about, which are presented under subsequent headings. In addition to having an affirmative general self-concept, some participants specifically discuss being comfortable and secure with their disability and their body prior to group involvement. Responses indicative of this included:

My disability hasn't bothered me since it is part of who I am and what we do. . . . I don't feel any different about my disability. There's nothing I can do to change it except live as I have lived and educate the people around me about it and [help them] open their minds towards us. . . . My body doesn't bother me too much, but sometimes that self-esteem sneaks up and of course, like almost every woman, I critique how I look. I am who I am and there's not much I can do to change it because that would be changing the woman I've come to know and accept. We should all embrace our bodies and love ourselves. Of course, if health issues are involved, then that should be a reason to want to feel and look better. [Elizabeth]

I just joined this group after I'd gone through the angst of disability identity. Not before. . . . I would describe myself in both before joining and after joining as a wife, mother, woman who is trying to make sense of the world, her life, and grow into who she was meant to be. . . . I don't feel any different. . . . I would not say it has changed the way I feel about myself or my disabilities. [Harper]

How I feel about my body came about when I started dating. I realized that there's nothing really awful or ugly about how my body functions. [Joanna]

The data presented above demonstrates that some women were able to achieve a positive self-concept at least in a few areas before involvement in group support. Particularly, some women expressed body positivity independent of group support. A few women also expressed acceptance and comfort with their disability prior to group support. Some of the participants quoted in this subtheme said they had already gone through the angst of identity development before their involvement in group support. However, clear commonalities among participants who reported positive self-perceptions irrespective of group support could not be identified with regard to age, age of disability onset or otherwise.

b. **Not comfortable with who I am: Insecure self-concept and emotional turmoil**

Contrary to the data presented above, some participants did not feel comfortable with who they were and expressed disdain for certain aspects of themselves. This was associated with emotional angst for many. Although Mia described aspects of herself, which she felt proud of, she also expressed being uncomfortable with her trepidation about the future:

I'm very scared about -- well, I don't like that I'm very scared at all of the outcome of my future and that worries me a lot. It just makes me uncomfortable and I think it adds more stress to me and I think that, because I do that, I take it out on people, on my husband or on my son. So I don't like that. I'm very, like, I don't know -- my energy changes and you can tell from just the mood of the house that things are not okay. I don't like that about myself. I feel too much, basically.

When Sophia realized that the physical endurance she experienced prior to acquiring her disability was not going to return, her self-perception declined. Discussing her self-concept before joining support groups, she exclaimed:

When I realized that my endurance, the feature I was most proud of prior to getting sick, was never going to come back, I didn't have such a great view of myself and my prospects for successfully getting and keeping a job.

Several women reported they had a negative view of their disability prior to joining group support. For instance, Victoria internalized and harbored various negative stereotypes about her disability, resulting in emotional turmoil. When discussing her feelings about her disability preceding her involvement in online support groups, she said:

Before I was living with the idea that I needed to get rid of my disability and that I was lazy and didn't exercise enough. . . . 35 years I was living with the belief that I was lazy and if I exercised enough I could be cured. . . . Before I was hiding my disability and it was exhausting! . . . Before I was never able to say the name of the diagnosis. I could say it in English but not in [my native language]. It was a trigger point for me. . . . When people talked down to me before starting the online group I

would feel very humiliated! I would feel like the "other," that I was being stuffed in a category of the disabled.

She went on to discuss her former prejudicial views about an aspect of the disability experience that did not yet apply to her, but could in the future:

I didn't think a person who uses a machine for breathing was a person. I was ableist and I didn't realize this. I had categories for people. I am a woman with a disability, and [I thought] people who had breathing disabilities were very frail people who didn't have their own personality.

Emma also experienced emotional turmoil regarding her disability. Describing her feelings prior to joining online support communities she said,

At the start [onset of disability] I was really angry and I was really depressed. And I felt very justified in feeling like that. I felt like, you know, anybody who has had their future ripped away from them would feel like that. I felt like I was almost justified to feel that way. And that wasn't necessarily wrong, but it was terribly unhelpful! You go through life being really angry and bitter and it doesn't make people want to be around you. It doesn't make people want to like you or whatever.

For some participants, negative views about their disability manifested as self-hatred, shame and a desire to distance themselves from others with disabilities. For example, Mia, an online support group user, said,

I've never gone to MDA groups in my area because I've always felt out of place. I think it's more of, like, an inner hatred with my disability, and inner part of me that, damn, I wish I wasn't sick or I just wish I wasn't the way I am. That's always been conflicting for me.

Overall, Addison reported having a positive self-concept prior to her involvement in online support. However, she did discuss internalizing negative views about disability. She acknowledged reticence to identify as a person with a disability growing up:

I must admit, I grew up with a lot of internalized ableism and I used to stay away/shy away, embarrassed, to engage with other disabled people. Though I am a "little person," I never grew up with the word/concept. My mother euphemistically always said I was not a "dwarf" as if that were a bad, bad word, but that I was just "slow growing." . . . I was "ableist-ly" trained and socialized at a very young age to "otherize" disabled people and to build a self-concept (defensively, unfortunately) in

relation/opposition to “THOSE other little people”, THOSE dwarfs, THOSE people who I am NOT.

Joanna did not want to be identified as a disabled person. She was subconsciously ashamed of her mild physical impairment prior to becoming involved in online support groups. This prompted her decision not to disclose to friends why she was unable to take part in the physical activities they had planned:

Before the group I think that I was subconsciously ashamed of my disability. . . . Like for example, if my friends were doing an activity that I can’t participate in before [the online group], I would just say I’m not available that day [instead of saying it was because of my disability]. . . . I would just say I’m not going to participate and wouldn’t say why.

In addition to the women expressing insecurities about their disability, some women also expressed insecurities about their body and sexuality. For instance, when asked if there were aspects of herself she did not feel good about, Mia exclaimed, “I’m not happy with the way I look and it’s always like a struggle for me just to face these daily things.” Similarly, Sophia expressed being very unhappy with her body image shortly after acquiring her disability. She recounted:

So, pretty much I was very comfortable with myself for a while after getting sick, and the only thing that bothered me was that I gained 35 pounds from going from being very active to bedridden. . . . My normal weight before this was 115 pounds but because a virus triggered my condition I had lost weight from that, so I went from 107 pounds to 143 pounds in about 4 months and I was pretty unhappy about it, mostly because my clothes didn’t fit and I didn’t have the energy to buy more and am ethically opposed to buying cheap clothes. . . . I was not able to see myself in the mirror for over a year (just my head, and most of the time it was bent down to concentrate on walking), so I think had I seen myself in the mirror I would have been very unhappy with my body image.

A few women used strategies they felt would address their insecurities about the way their body looked. For example, Victoria mentioned going on shopping sprees and buying extravagant clothing in an effort to compensate for her insecurities regarding her

appearance. She stated, “[to make myself feel better] I was going out and buying extravagant clothing and listening to underground music and stuff like that. . . . It was also very exhausting.” In addition to insecurities regarding the way she looked, Victoria reported internalizing her mom’s negative perceptions of her sexuality saying:

This [what I was told when I was younger by my Mom] prepared me for a long life of questioning my value as a sexual being, as a romantic partner and as a woman. . . . I accepted I was disabled. I accepted that I didn’t deserve a romantic and sexual life. It was 10 years ago.

In summary the women’s self-perceptions varied widely prior to becoming involved in group support. Some women reported having a very favorable self-concept in all or some areas. Others reported having a variety of insecurities about themselves. These left open the possibility for group support to have a positive impact in this regard.

#### 4. **Relational dynamics within group support: Setting the stage for self-concept development**

Data analysis revealed that there were several aspects of the relational dynamics that helped create an environment conducive to the development of a positive self-concept. There were also certain group characteristics noted that hindered self-concept development. The features of group support that did and did not support self-concept development are presented below.

##### a. **The interplay of gender and group dynamics**

Several of the participants who were involved in women-only online and in-person support groups noted that there was a relatability factor in these groups that is not present in mixed-gender groups and difficult to find in the world at large. For example, Elizabeth, an in-person support group member, discussed how she felt “at home” in her disabled women’s support group and felt comfortable expressing her concerns and needs:

To be a part of a woman's organization is similar yet different because with the group we're all women that can relate to each other and how our lives have been with our disabilities and also encourage those that have recently become disabled. Joining the group has made me feel like at home. . . . Sometimes as a woman with a disability, you can't relate to a normal woman. With these women in the group, I can relate a lot. It's important [the group is made up only of women] because, as women, we can all relate in that aspect alongside with our disability. We need to feel comfortable expressing our needs and concerns that women have.

Layla echoed this sentiment regarding the importance of women-only groups,

saying:

I felt like [in a women's only group] I would always have people that could relate to my struggles, or if I was having a bad day they'd be there to talk and give me tips instead of my friends just leaving me out.

Similarly, Joanna expressed the importance of women-only groups and the

relatability and validation they bring about:

To me it is [important the group is made up only of women] because there's a lot of things that we feel as a woman that only other women can validate that. For example, if you want to talk about your period as a woman with a disability I feel like only other women can understand that, the pain you have to go through and the challenges with your disability too, I feel like only another woman could understand that and can relate to that and those types of situations. And then I have also found that women are more forgiving and more supportive in a way. Being with other women you have more familiarity, you have more in common.

Several women reported that being able to have open discussions about women's issues was another important benefit of women only groups. Responses indicative of this included the following:

I've seen posts asking about how and when to tell your future boyfriend about your medical issues and how to have sex so it doesn't exacerbate their conditions and comments about how sex actually relieves some of the fibromyalgia pain in some people... topics that if there were a much more noticeable presence of men in the group, I'm not sure they would really come up. So I guess that could be a disadvantage to male participation and an advantage of an exclusively female group. [Sophia]

[It's important the group is made up of only women] when discussing for example, sex toys and what would work with a woman with a physical mobility impairment.



That is specific to women - talking about the clitoris/vagina, etc. and women with disabilities in particular. . . . It's really important [the group is made up only of women with disabilities]. I think a lot of us would not feel as open about things, or discuss the things we do if there were men present. [Harper]

I think women-only groups are really important because discussing women's health may not necessarily come up (or discussing it in depth) in a mixed group. I cannot speak for others, but I personally would not feel comfortable discussing sexual positions or other sex related issues in front of men. . . . I think that there are some topics would be better addressed if the group is only for disabled women as it is likely that people will feel more comfortable, and therefore more honest. [Charlotte]

One in particular is a group for disabled women to kind of discuss any grooming routines, anything of a like sexual nature or sexuality and I've gotten some ideas mainly from that group, but I think that group is very kind of empowering because disabled women that come together and just share experiences and ask questions and it seems very open and that people are extremely open-minded, which I love. . . . I think [women only groups are] important just because, you know, you can talk with other women about kind of more intimate topics without feeling like you have to censor yourself. [Bella]

In some groups some women will come out and identify as transgender women so just the things that we talk about and share about it's important that it is all women. [Joanna]

In addition to engaging in open and honest discussions about women's issues most women who were members of online groups said that they found posted articles on women's issues to be helpful. However, a few women specifically stated that they did not find this information relevant to them for a variety of reasons. For instance, Emma asserted:

I didn't really pay a lot of attention to it [the information posted on women's issues]. Just all information that is even not relevant to me because a lot of that is localized so if the women are posting stuff they're going to paste American information, like, about planned parenthood or stuff like that, that's not relevant to me here. Stuff about dating and gender discrimination I mostly just don't read. LGBT stuff, I mostly have read it somewhere else so I didn't really relate to that very much. . . . Also, although I'm female, I don't feel very female. I present as female, but I guess I would say I'm a gender, if you had to ask me. I don't really -- I don't really care about being female. It's not a thing that matters to me.

Regardless of the topics being discussed, a majority of participants said women-only groups provided a safe space where they felt a strong sense of permission to be themselves

and express their feelings. Mia said that her online support group exclusively for women with disabilities afforded her a safe space and a sense of comfort:

The fact that there is a group or place where I can just be myself and, like, ask questions that I wouldn't normally ask other people outside of the group -- knowing that I have a safe place like that is really comforting for me. I feel like it's very important for me to be a part of that. . . . I just really appreciate having a space where I can just say anything and I wouldn't be judged, basically.

Layla also expressed similar sentiments about support groups exclusively for disabled women and their ability to help women be confident and express themselves:

These groups are all about being you, if you want to wear a dress, wear it! If you want to have a drink and skip your meds to do so one night, do it. It's all about being confident in yourself, the cards you were dealt, and your choices on how to deal with it. With no hate or backlash by saying so in these groups.

For Joanna it was essential the groups she belongs to were made up of women only. This desire stemmed in part from gender discrimination she perceived as present in the Asian community she is a part of. When discussing the importance of women only groups she asserted,

When the worst things are going on in your life it's important to be able to share that and have other women be there for you. For me personally I've just been involved in a lot of groups that have only been made up of women, so that's part of the reason why I feel more comfortable on forums that are made up of women. In some ways you could say that I'm biased towards men [Laughter]. I can be more myself. . . . I'm Asian, there is a lot of discrimination on gender within that community. That really reinforces the need to be part of a women's only group, because you can really share your story and not have men saying your point is not valid, for example.

Emma, like the other participants quoted above, perceived a difference in groups exclusively for women with disabilities as compared to mixed-gender groups, but she was unable to articulate this difference. Speaking about the intangible distinction between women-only groups and mixed-gender groups, she stated,

I do think it would probably be different if it was, like, a majority of not women. I think that having at least half women makes the forum different, but I can't articulate

why very well. I don't know. . . . But I think if there was one that was mostly men, I feel like, maybe, it would be different, but I'm not really sure. But generally, I'm definitely happy to have some men and other minorities of non-binary people of any configuration around.

She went on to report she did not perceive many benefits of women-only groups compared to mixed gender groups, saying:

I don't really think about it separate from, like, disability in general. I don't think there's anything particularly special for me, personally, about having a group that's specifically for women with disabilities. I don't particularly seek them out, I don't think I've found any situations where it's been a negative to have men with disabilities around. . . . So yeah, I didn't really care.

Sophia also did not perceive any noticeable benefits of groups specifically for women, noting that the participants on the online forum are made up of 99.5% women regardless of gender restrictions for a particular group. She explained,

Because of their lack of participation [of men], I don't think I really see any advantages or disadvantages to men participating in these groups or how it would be any different if it were only females. The women who post don't seem to be restricting their topics because of the presence of men either.

Sophia went on to discuss possible reasons why men are less likely to participate in support groups. She surmised that it was likely due to the gender norms society has created:

I never see them [men] post and hardly ever see them comment. The only male participation I remember seeing is when someone asked if men don't get this diagnosis since she only sees women in the group, and one man commented and said "no, it's equal, just most men don't seek help or community for this." I think it has to do with preconceptions of how each gender should act – it is ok for women to seek help because they are "weak," but men should be strong and therefore might feel super uncomfortable or be looked at as wimpy if they do participate in support groups. So in a way, gender roles make being disabled and chronically ill more difficult for both genders because the men don't have a place to complain safely or seek advice to help them cope, and therefore it is not just women whom gender roles and expectations of society negatively impact. I don't think it is that women need it more than men at all, just that they are the only group for which this behavior activity is accepted.

In summary, the majority of participants stated they felt most comfortable expressing their feelings and discussing women's issues in women-only groups. However, a few did note that they did not perceive any benefits of women-only groups. This is in part because in-person support groups and online forums are almost always exclusively made up of women regardless of gender restrictions.

b. **“We support each other no matter what”: A distinctive relationship with other group members**

Another key factor in setting the stage for self-concept development was the unconditional support and understanding that emerged within many of the groups. The women recounted ways in which their relationships with their fellow support group members, both online and in-person, differed from other friendships in their lives. Many of the women spoke poignantly about the reciprocal relationship of friendship, support, and understanding that emerged among them and their fellow group members. For example, when discussing her relationship with her online group members, Natalie stated,

I guess it's sort of a sisterhood. You feel comfortable in talking, but not always about disabilities. . . . The online groups have helped me. I can experience making those friendships and staying in touch with them and just having someone to talk to about your worries, your challenges, that you both can relate to and both may share. It may be difficult in real life [to do so].

For some women, their support groups were the only place where they felt a strong connection to other disabled people. When discussing helpful aspects of her online group Mia related,

I think the theme for my online group for women with disabilities is mostly that it just brings women close together. Like I said, outside of any community online in my real life, I don't have any type of, not to say that I don't know anybody who's disabled, but I don't have the connection I do outside from what I do on Facebook. And now there's a community for women more disabled to support each other and be positive with things.

Addison perceived disability-related support in online communities as relational:

“Disability is a kind of relational dynamic and it is nice to have spaces that really understand my language.”

This mutual understanding between group members appears to extend to the face-to-face realm as well. For example, Elizabeth, a member of an in-person support group for women with disabilities, also spoke of the strong, unique bond she has with her fellow members:

The bond we have is like no other. Some members don't interact at all or aren't involved. Those of us that are, we just understand each other and communicate without having to deal with drama or hurting anyone's feelings. Regardless of our disabilities, we are women after all, so women are emotional. . . . I just love this group and the group of women that I'm close with. They're my support system and I love hanging out with them. It's hard for me to trust and find female friends, but these women I can completely call my sisters . . . my wheel sisters! . . . The things that I find helpful within my women-only support group are that we support each other no matter what.

Friendship and unconditional support were also the driving force among Harper's experience with her women-only support group. When asked what immediately comes to mind when thinking about her participation in the group, she responded, “Friendship is what immediately comes to mind! The community is friendly, and very supportive. It seems like nothing is off-limits and people are open and honest -- and highly respectful -- with one another.”

For Emma, the relationships that evolved with fellow group members often seemed somewhat “odd” because of the intimate nature of many disability-related topics:

They [online relationships] are very sort of odd relationships because they're close in some parts, but completely distant in others. . . . Because in support groups, you don't often have a lot of that casual conversation. So usually in real life or not real life, but, you know, offline relationships, you start off with casual conversation and you talk about the weather and the football and the kittens and maybe some politics and then you're not going to talk to that person about really, sort of, intimate stuff

like your incontinence or the way that you have this wound that won't heal, until you know them really well.

The support provided on the forums was not always intimate and serious in nature.

A few participants indicated a distinct preference for light-hearted communication on the forums. Sophia spoke at length about the type of atmosphere she enjoys within an online support community and the types of activities that lifts her spirits:

I prefer getting on the general chronic illness/spoonie groups on a more regular basis than the group for my specific diagnosis because they are generally more lighthearted, made to make you feel better. For instance, spoonie groups regularly posts a question of the day, which varies from silly questions like “would you rather have a horse-sized duck or a duck-sized horse?” to questions that are pleasant to answer like posting pictures of eight different style houses and asking which you would prefer. . . . Spoonie groups are dedicated to positivity in our lives.

Layla expressed a similar preference for light-hearted communication within her support communities:

In a group that a friend and I created, we do a thing each week where we ask for everyone to share 1-3 achievements that they've made through the week, big or small, we celebrate them all. Because too often it's easy to focus on what is wrong or bad with the day/week so we try to get our members to focus on that.

In sum, a sisterhood emerged within the group space. The relationship among group members was characterized as intimate and lighthearted on occasion. The women were a constant source of support and understanding for each other no matter what the circumstances. For many of the women this unconditional support and understanding was scarce in their lives outside of the group.

c. **Mentoring relationships**

As part of the relationship structure that evolved within support groups, an informal collective mentoring process often emerged. Several women reported that formal mentor-mentee relationships were rare within the online support communities.

But, small subtle acts of mentoring and teamwork among the members of online support communities were key to the success of the forums. For instance, Victoria spoke of her surprise at how group members worked together to accomplish a common goal and support other members. Being exposed to others with disabilities who were successfully accomplishing their objectives broke down her own negative stereotypes about disability. Discussing her relationships on the forum, she said,

Honestly, I don't remember being involved in a mentor/mentee relationship. What I remember is the group going towards the same goal. When I was starting I was kind of baffled and surprised. I remember thinking: disabled people can do this? I was surprised of my own thinking and it was prejudice breaking.

Likewise, Natalie discussed her delight at her fellow forum members' willingness to pull together and help her collect survey data she needed to complete her doctoral research:

A lot of people are taking my research surveys. I have ideas from many people that I can collect and it's like a group effort to improve their opportunities for the whole community. So it takes teamwork. But I'm getting all the insight and feedback from the individuals in the group and everywhere!

Sofia noted that many of the older, more experienced members are more than willing to provide guidance and advice to the younger or less experienced members. Discussing her observations regarding the emergence of mentor-mentee relationships on her online forums, she said:

Have not been in a mentor/mentee relationship in these groups, but I can definitely say that for a lot of the responses it is the older, more experienced people usually on disability because they are on more often who answer, but that really depends on the type of question; some questions attract the 20-somethings for whom the question is probably more relevant. I think us younger people tend to ask the older ones questions like at what age did it become too much to work full time and at what age did you go on disability, or what kind of jobs work best for these symptoms.

Joanna saw great value in learning from the group collectively without having the pressure associated with being in a formal mentor relationship. Discussing the mentor-mentee relationships within the group, she stated:

I look at it [a resource] with an open-mind and also keep it as a resource in case somebody else might need it, so I have something to share with that person. I find those resources useful whether they apply to me or not. . . . I haven't had a mentee and I have not been a mentor. . . . Learning from other people's experiences and being able to share my own personal experience is helpful without having to be officially in a mentee-mentor type of relationship.

Emma (age 42) spoke about the benefits and self-satisfaction she received from informally mentoring others on her support group forums:

I think, mostly, I'm on the mentor side of things now. Just because I've been impaired for longer than most of the people in my specific groups. I am just older than Facebook's average now. Time does that. But I'm sure that I did have--oh, I remember vaguely being on the other side of things, like, years ago. I think it's really awesome when you can mentor someone and see them feeling more comfortable about themselves or being more accepting of themselves or taking some advice that you gave them and then coming back and saying "hey, that really helped me." It's really a nice feeling that you can do something to have a positive impact on someone's life. It's so, like, good for your self-esteem to be helpful. As well as the fact that it helps them, which is nice as well. I think a lot of it [changing the way people see themselves] is about like having role models.

Joanna also spoke of the value of mentoring others, and saw the process as having a positive impact on women's self-perceptions:

Meeting others I have to say, I think will help them a lot to find out who they are and what they want to be in life. Because it comes down to if you're comfortable, who you are in your own skin; you're not going to let your disability limit what you can do in life. When you see other women with disabilities doing things in life you become more empowered and believe that you can do it too!

As illustrated above, several women recounted instances of informal collective mentoring taking place on the forums. However, a few participants unequivocally stated that they have not participated in a mentor/mentee relationship of any kind. For instance, when asked about mentee-mentor relationships that took place in her online support group



for disabled women, Harper replied, “Mentor/Mentee relationships have not formed for me, nor have any relationships formed in the group between myself and other members changed the way that I feel about myself.”

Most of the relationships, mentor-mentee or otherwise, were formed between fellow group members. However, the single participant who was solely a member of an in-person group for women with disabilities reported having a strong friendship with her group coordinator, though she noted that this relationship did not specifically influence the way she felt about herself:

The relationship [with my group coordinator] hasn’t changed how I think about myself. We’re friends and we bring out the best in each other. We both have the mindset of living life without others telling us we can’t do this or that. She has so many connections so she is always meeting new people that can help our group and get us out there. She leads with ideas and gets us all to bring our own ideas and discuss them too. [Elizabeth]

In conclusion several instances of informal collective mentoring were reported. This entailed working towards common goals and the whole group coming together to give and receive information as they see fit. This helped create an environment in which self-discovery and exploration could take place. Helping others even in small ways gave the women a sense of satisfaction and increased their self-worth.

d. **Maintaining relationships with fellow group members**

Many of the women maintained their strong bond with group members through multiple methods of communication. Responses that indicated ways they kept in contact with each other included the following:

We even have a group text going just to keep in touch when we don’t see each other and to talk about ideas. We love to hang out outside of our group meetings because we’re just normal women who like to do normal things. . . . We go to bars, out to eat, we go to each other’s houses, and we do makeovers. [Elizabeth]

I message many people outside of the groups, and we talk about just about everything, from college, to pets, to meeting up! [Layla]

We become friends then later just talk -- like have contact, private phone calls -- just like any friend. . . . I actually have met several people that I've met online in person! [Natalie]

Most of the group members were pretty nice. There were one or two people that I kept in contact with and would meet up with from time to time or run into at disability related events. [Charlotte]

Although in-person visits happened on occasion, health issues and geography prevented many of the online group members from meeting up in person. Discussing her efforts to stay in touch with group members and build relationships, Joanna said:

That [my relationship with group members] has only been online. When I first joined the online forum for disabled women I had the hope that we could do face-to-face meetings. And meet up and do a lot of things off-line, and join up with my non-disabled friends. It was an education for me that not everyone can do that, meet up face-to-face because of physical limitations whether it be transportation or that the disability makes it difficult for them to be outside. So online seems to be the best place to build relationships and friendships. . . . I met with a group moderator along with a couple other women in the group; especially when I first join the group I wanted to meet up with the women who live here.

As noted above the majority of interactions between group members did not take place in person. However, the availability of multiple methods of communication such as phone calls, text messages and emails made it possible to maintain strong friendships. These alternative methods of communication were important, since meeting up in person was often difficult.

e. **Control over friendship formation online**

Regardless of the ways group members stayed in touch with one another, control over the relationships and friendships that formed on the forums were very important to several of the women. Layla, for instance, liked having the peace of mind and

convenience of knowing she could simply block somebody from contacting her if issues arose:

I prefer online, because if you have an issue with someone you can just block them, then you won't have to be bothered with them anymore, which rarely happens for me! It's been [going] pretty well, nothing bad. Everyone is really nice and helpful!

The women also took comfort in knowing that they could choose to communicate with those they felt most connected with. Mia explained:

I'm very shy when it comes to making friends -- also online. I don't really have close friends in the community. I just know that it's a place where I can just feel comfortable going and talking and asking questions, because I know that there's places that are like -- this isn't a safe space. It's not like I would be shunned or, you know, thank God, I'm able to be open with strangers and be okay. I don't know. I'm not really friends with anybody, but it's just knowing that I can be there and not have to be friends with anybody. It's pretty comfortable for me.

Natalie reported she was not friends with everybody on the forum, but enjoyed striking up relationships with those who she felt inclined to do so. She stated:

Even within the group you don't necessarily talk to everybody, but the few people that you may find some similarities and you are curious about them and they will be curious about me. So that could help you to form friendships -- to find friends.

Although most of Emma's social life stemmed from her involvement in online support groups, she reported that she only became close friends with a select group of women. Speaking of her relationship with her fellow group members she reported:

Most of my friends now have chronic illnesses or disabilities of some type. They're not all people that I've met from support groups, but a lot of them are either people I met from support groups or they're people that were friends of the people I met through support groups. So probably most of my social life comes from there, either directly or indirectly. . . . I like generally find that there'll be a couple of members in the group that I'll really click with and I'll get to know those people better; outside the group as well. That's good because it's a way to meet new people and being housebound I'm pretty low on ways to meet new people.

Bella echoed the sentiments of other group members regarding the varying levels of relationships that formed through online communication. She was inclined to be closer to

members who shared common interests and were respectful and supportive in their communication. When asked to describe her relationship with other group members on the forums, she said:

I definitely have friends that I have become closer to and that I communicate more with like on a more intimate level. There are those group members that I mean they're just group members. I don't really have a relationship with them. I know them through Facebook. I have friends that I'd like to meet in person and then there are friends that I'm okay if I don't ever meet them in person, but it's really cool sharing experiences with them via like social apps on your iPhone of calling or texting or email. So I think there are different levels of kind of how I would think about group members, the majority of this being social media acquaintances. Then there are those that I communicate with more closely and definitely share more with about what might be going on in my life or I don't feel as judged by or I know I can speak openly about whatever it is that we might be discussing.

When asked to elaborate on the factors that influence who she becomes close with on the forums, she replied:

I think it depends on how you are treated or how you are responded to when you share insights or when you post in a group. I think that can influence who you become close with versus who you think of as kind of just a social, you know, "hey, I know you through Facebook."

In sum, the women conversed with many different people on the forums; however, close friendships did not always evolve. The women relished the opportunity to control whom they communicated with and whom they chose to form close friendships with. The opportunity to block unwanted communication and conspicuously ignored messages gave the women the ability to maximize control over their friendships.

f. **Online group dynamics sometimes invoke feelings that may suppress positive self-concept**

As noted above, a large majority of participants found the online platform to be a supportive and friendly environment that made it possible for self-concept development to take place. However, some participants reported that the online

environment evoked emotions that may suppress positive self-concept development. While answering questions about how participation in online groups has influenced the way they feel about themselves, some participants indicated that they feel a bit shy and anxious communicating openly online. For instance, Bella talked at length about how people in some of the online communities she is a part of ridicule her for sharing her opinion. This hinders her from participating further:

I think sometimes it [the group process] has caused me not to contribute where I would have or where I think about contributing, but sometimes I don't because I don't want to be judged or have somebody jump down my throat because I use this method or I feed this food to my [Service] dog or I do this task this way. So I think it's kind of a double-edged sword, so to speak. . . . Again, there's kind of a broad spectrum and I think it depends on the tone of the group or the reaction that you get from things that you post or comments that you leave.

Addison also experienced anxiety and reticence about participating in online communication. In her case, the anxiety she experienced stemmed mostly from how the text of her post is composed and perceived. She explained, "I am an artist, but I find in group settings, I'm typically feeling a bit shy. Online groups especially [make me anxious] . . . I think it's social anxiety. I re-read and re-read my text/paragraphs before I post them." Later on in the interview, she elaborated on how group settings and online environments evoke a sense of vulnerability and loss of control. These feelings are contrary to the immense sense of control she experienced when engaging in performance art in front of a live audience. She explains:

I used to do performance art -- on a stage; dance, wear glitter, peeling of stick-on letters of the word "midget" from my body in a kind of critical political neo-burlesque. On/in those spaces, I am raw, powerful and vulnerable, pulling from my creative depths, pushing through very conscious fear but driven by a creative impulse to shake up a state of status-quo. In/on those spaces, it is me and the rest (it is me with just ONE Other, a collective Other, the audience). I think this kind of experience offers me a sense of "Privacy" that disabled women have historically lacked; a kind of ontological containment that allows me to exist, define my

boundaries and express. In "group settings" however or even in online spaces, this anxiety stems from the fact that I cannot grasp or control the context in which my expressions are being engaged with. . . . It is like putting out a photo to a group of professional photo shoppers. How is it read? How will it be morphed? What tools do they have? It is quite a vulnerable place, I believe.

In addition to the online communication process contributing to anxiety and shyness for a few participants, two women also noted their hesitance to take part in support forums that use disability terminology they do not identify with. Harper, who is deaf, realizes that many support forums she has come across tend to use words that have historically been used to denigrate disabled people in a reclaiming and empowering manner. For her, this is problematic because she does not identify with words such as "crip" or "gimp" which are frequently used on the support forums. She has a firm sense of who she is and joined the support forums despite this, but notes that others in the deaf community might steer clear of environments that use this language:

To be honest, I also probably would not have joined it [online support group for women with disabilities] had I not already gone through it all. Reason being, I'm deaf and don't identify as a gimp or crip AT ALL, not even in an ironic or reclaiming way. I have nothing in common with those words. I walk. For us in the deaf community, it's a stretch for us to even call ourselves "disabled" since within the deaf community, deafness is only seen as a communication difference, NOT a disability. . . . That's kind of a bummer for me with the disabled community often choosing words like "crip" or "gimp" - very few deaf people will ever join a group with that kind of title. . . . I accept the word "disability" and see myself in that term. Just using that as opposed to "crip" or "gimp" would be awesome.

Addison took similar issue with the disability terminology used on the forums. For her the tendency of online support communities to use people first language, which separates people from their disabled identity, bothered her immensely:

I do not engage in online groups for "people with disabilities." . . . To me, it's akin to positioning myself in a group like "people with homosexuality" as if it is a separate attribute tacked onto our being, instead of it being embedded in our whole bones and social being.

As illustrated above some aspects of group dynamics may be problematic for some participants. A few participants experienced shyness over how their communication would be perceived and took issue with the disability language used on the online forums. For the most part, though, the relational dynamics within support groups, both online and in-person, created a setting for self-concept development. The majority of participants noted they felt supported and validated within their group spaces.

5. **The influence of an engaged sharing process on self-concept development**

This theme highlights the sharing process that emerged within many of the groups. This process was often validating and armed the women with the tools needed to gain and maintain a positive self-concept. The engaged and attentive nature of this process was evident in Victoria's narrative. When talking about supportive aspects of her relationship with her online support group members, she exclaimed:

I learn from them and they learn from me. They are friends but they're very skilled friends. Sometimes you have friends who go to the same school and know the same things with you but this is different. . . . They say "they've been in similar situations." They say, "this situation does seem to be painful." They say "how do you feel about it?" "They say "what happened to them if they've processed similar situations. Not reflection but . . . they let me know it's okay to feel how I feel, it's okay to process it, it's okay to feel this way.

Similarly, Sophia spoke of the benefits of receiving supportive words from her fellow online group members:

Even when people can't offer advice, little notes like "sending positive energy your way" or "praying for you" do make me feel a little better. . . . I think that when I post too, it is nice to read the comments and see the likes and hearts and sad faces because I know that people are reading my posts and thinking about me, and their advice can be very helpful.

a. **“I am not alone”: Sharing with similar others**

Sharing with others in similar circumstances was a key part of self-exploration and self-concept development for many of the participants. Openly communicating with group members led to the important realization that they are not alone in their experiences as a disabled woman. Armed with this realization, many felt more secure and comfortable with who they are. For instance, Mia, whose ultimate goal was to become comfortable in her own skin, said:

I think when I joined the group, I felt more relaxed because I don't really have any other disabled friends. So having, like, a community where I can actually talk about my feelings about things is just really important for me. . . . It's really comforting to know that other people are feeling the same way as I am. . . . These [discussions] make me feel more comfortable knowing that I'm not the only one when it comes to, like, the medical issues or women's issues.

She went on to discuss how her involvement in discussions on a forum for disabled women helped her realize she should not be ashamed about who she is:

It felt like, at the point of my life right now, I feel I need to embrace it more and to interact with fellow disabled people that are going through the same struggles as I am. . . . I feel more of a sense of relief knowing that I'm not the only one going through these things. . . . Now that I'm older, I have a son and I want him to know that I'm not ashamed of who I am, you know? It's been a long battle for me to accept myself the way I am and, again, it's just really comforting knowing that there's other moms out there as well, other women who feel the same way.

Emma also recounted feeling a sense of comfort and acceptance through the discussions on the online forums that helped her realize that she was not odd and what she was going through was part of a natural human experience. This awareness was reinforced many times over the 22 years she has been involved in online group support and it was now internalized in the core of her being:

In online support groups, you turn up and go “hey, I have this weird experience; am I the only one?” And five other people all turn up and go “no, no, I've had that exact same experience. I thought I was the only one, too. I'm so glad you brought it up.”



So it's really nice to have the opposite [of what usually happens in our society], where everyone validates that they experience the same stuff and that you're actually not this completely odd freak of nature, you're just reacting in a normal human way to a really weird situation. And I think also, even for the group discussions where I'm not a part of it, you can see the same thing happens over and over and I think it helps you internalize that. . . . I've really realized now that for any given question, no matter what the question is, the answer to “hey, has anybody else experienced this” is always yes. You're never as alone as you felt.

The realization she was not alone in her experiences even held true with regard to the rarest aspects of her medical issues. She knew that within her vast network of online support communities she would be able to find a group that understood portions of every facet of her experience. She continued:

There's no group where I can go and find people mostly like me in the group. I think that's part of why I'm a member of several different groups. For each of the groups, there's a part of my disability that they understand. . . . From my [disability specific] support group everyone in it is female so the affect is very similar. I guess the message would be like something, like, you're okay. Whatever weird thing you've experience and you think you're the only one that has experienced it, you're not. You're okay. And that the other group members are here for you.

Joanna experienced similar benefits of the sharing process that took place in her online forum for disabled women. In her case the sharing process helped spark a sense of belongingness to the world around her as well as a greater recognition of the shared humanity of disabled people:

So, when I see other people sharing experiences or sharing stories, makes you feel like you're part of this planet and this world. When you are feeling isolated and lonely and stuff like that and you hear their stories and you realize oh, we're just like everybody else. We just happen to have a disability and I think it's just that consciousness that I think in my case I feel like I didn't have that until I got involved in the groups and had a chance to see and read and hear their stories.

Even the women who reported limited change in the way they felt about themselves due to group involvement said that communication with other group members helped them feel less alone and reduced isolation. Examples of this include:

I think the only change in feelings about myself and my disability from participation in these groups is that I am more comfortable riding around in my mobility scooter, or using the walker, cane, and wheelchair because there are other people my age like this too. It was really uncomfortable for me for a while, but knowing that others exist in the same situation is really comforting and I don't feel like I stick out like a sore thumb half as much. . . . I feel normal again in these groups because everyone has problems like mine, and I know that there are people my age out there using mobility equipment and going through the same social problems as me because of it. [Sophia]

Just in general having people that you share your feelings with has been helpful. The sharing of information with each and being able to ask others questions that others can relate to and give advice has made me feel less lonely and sometimes even less anxious. [Charlotte]

Before joining the group, I really thought I was the only one out-there that thought about disability in a critical way. Every now and then there's an event at a local university, where I'd find "disability culture" -- but it is a shame that this "disability culture" is only really cultivated in academia. The online group helps to remind me that critical disability-thought and political crip femmes exist beyond the walls of academic institutions -- that we're out there in the world. [Addison]

In sum, sharing with similar others helped the women realize that they were not alone in the experiences and feelings they had. As a result, the women felt less isolated and reported greater acceptance of them. Additionally, a heightened sense of belonging and shared humanity began to emerge for some women.

**b. Promotion of disability literacy**

For many, the communication process within their support group space was a means to circulate and discuss a myriad of different information related to disability. Women spoke of a variety of topics that came up on the forum which were helpful to them. Responses that reflect the variety of topics discussed include the following:

One thing I really got out of the group was how helpful medical marijuana is to many, and what living with chronic pain is like. I am grateful for those perspectives. . . . I enjoy the company of other women and the discussions we have there. . . . [We also discuss] access, dealing with discrimination. For example, there was one where we were talking about sex and sex toys, and what might work if someone had mobility impairments. [Harper]

[I learned about a new drug] it's called Spinraza. FDA just approved it for Spinal Muscular Atrophy recently on December 23<sup>rd</sup>, and I didn't know about it until -- I only found out about it through the Facebook support group. So it's like even treatments breakthrough medicine and they were learning about it. . . . In the group they also share organizing techniques or emergency preparedness. . . . Some people offer tips of how they schedule their caregivers. [Natalie]

[I share] all different types [of information]. Some like really practical things like how does the local state funding for wheelchairs work or how do I organize district nurses or, you know, how do I tell my counselor this thing I'm scared about? Also, just like, really much more abstract stuff, like how do I accept that I'm not going to get better at all? How do I deal with this family that's not being supportive? Some stuff you can be helpful with and some stuff you just have to say "I'm so sorry you're in that situation. It's fucked up, you're just having a really bad time and I wish I could hug you." Both of those have values. [Emma]

Due to the current political climate there is a great deal of discussion going on about how this party/these politicians will impact our lives. Information relating to disabilities is not something that is easily found by other means, so it is helpful to learn about resources that you may not otherwise find. . . . Someone posted a map of the accessible stations only for the subway and it has literally been a godsend for me; it has allowed me to travel more independently and for whatever reason, the MTA won't do. [Charlotte]

We usually discuss, you know, just the elections or just anything that has to do with disabilities. It might have to do with disability or Medicaid, or with the whole election thing . . . I think the recent resources on the forum would have to be more involving with, like, the whole presidential election and how we're kind of concerned if disability payments would get cut off, or just basically more of the electoral things. [Mia]

We can ask what works for each other . . . where to find the cheapest while still effective supplements. . . . A lot of the articles they [online support group members] post are results from pertinent studies which could help some people, but because there is such a wide range of symptoms and specific diseases even within the community for my specific diagnosis, no one article will help everyone. The articles posted on things like meditation and mental health related topics seem to come from every age category but I think mostly middle-aged people (30s-40s). [Sophia]

They help me learn about insurance laws in America. I didn't know about that, they are very different in my country. . . . I'm learning about insurance discrimination and laws so I am grateful that they've told me about it. And what I'm giving back is the perspective from my country, a post-communist country and it's very different! [Victoria]

Group time was often used to brainstorm and bounce ideas and solutions off each other. For instance, when talking about what occurs in her in-person support group for disabled women, Elizabeth recounted:

Each of us brings something different to the table such as ideas and experiences. When we get together it's to work, brainstorm, and make our organization known and aware by others. And of course we like to have fun as well . . . it can't always be just work and no play.

Sharing ideas, gaining new perspectives, and obtaining problem solving strategies were also a key part of Bella's experience. When asked what immediately comes to mind when she thinks about her participation in the online support groups, she replied:

The discussions I find to be relevant are maybe things that I have like dealt with before or things that I might know that I will be dealing with in the future such as employment, adaptation for or strategy for completing tasks non-visually, you know, things like doing laundry non-visually. . . . I think that, you know, learning from each other and gaining, you know, perspectives from different experiences or strategies that people have for doing things, that's always, you know, helpful. I'm sure I've implemented strategies that I've come across maybe even unconsciously just because somebody said it, I tried it and it worked. . . . And I've learned things that I know I can employ later and I know I have people that I can ask, "hey, this is my current situation, how would you handle this or do you have alternative techniques for doing A, B, or C?"

As another example of disability-related problem solving strategies shared on the forum, Sophia recounted using the support group space to discover helpful and creative ways to de-stigmatize mobility devices:

I have been involved in a few discussions here [in one of my online support groups], one memorable one about how to make walkers and canes fit us early-twenties people -- since the ones in the medical supply stores are all flowery, and both assistive devices really draw attention to you since people stare at you if you're young and need tools to help you walk. Among the suggestions were using "washi" tape and buying one with a natural wood color so it is neutral and not shiny or loud, pattern wise.

As illustrated above, within their support group spaces the women share and receive information on a variety of disability-related issues, such as disability policy, disability-

related research, and practical strategies for solving impairment-related problems. This type of information was not readily available to them in their lives outside of the group.

c. **Promotes revolutionary thinking about disability**

The sharing process also helped to promote a sense of comfort with their disability and disability pride. Many of the women recounted how the group helped them transform their thinking in productive and empowering ways. For some participants these new perspectives helped dispel the myth that disability is an individual problem that needs to be fixed. For instance, Victoria discussed her introduction to the idea of disability as a human rights issue and sociological category. She recalled:

Before I joined online forums, I didn't know about the social model of disability. That's a great invention for me. . . . [The Group is] based on the social model of disability . . . we see disability as a sociological category. Similar to race, or being born into a poor family or a wealthy family -- something that does not make a person inherently angelic or inherently deficient. Something that does not make a person asexual . . . disability is a human rights issue of course! There are medical issues with disability. But, disability is not something you should be ashamed of. . . . Lots of the materials I came across [in the group] change my point of view of fatigue as the real issue NOT laziness and I started to look at how to accommodate for fatigue.

She further elaborated on how the sharing process within the group helped her destigmatize her perceptions of disability:

It was the story of a woman and her husband, and the story of another member and how she started parenting, and hearing a story about how a member got a career in a high-powered field she had similar experiences like me. . . . I think hearing the personal experiences of the women involved was the most helpful! When I started seeing myself as disabled and competent at the same time I realized disability doesn't spoil my identity in any way!

Sharing stories and hearing others' stories within an online support community for women with disabilities enabled Joanna to realize that it was okay to discuss disability issues with her able-bodied friends. This is something she was never comfortable doing prior to her group involvement:

I feel better about my disability! I feel better to talk about it and share that with people in my life. I feel more comfortable sharing things on my own page related to disability. I'm more vocal because of the group! . . . And now being part of this Group and this online platform I realize that we're just like everyone else; we just happen to have a disability. I'm more forward when I talk about disability like not afraid of offending somebody by talking about it or putting them on the spot. I'm more vocal about disability, I have a wider perspective of disability because I've heard different women in the group share their stories.

Emma also reported that her involvement in online groups helped her discover that disability can be an important and positive part of her identity:

My disabled women's group is very like positive about disability as an identity. . . . I found that the whole concept of, like, identifying as a person with a disability was massively empowering and very positive for me as soon as I found it. So I tend to, like, try and stay away from groups of people who think that it's negative. I see disability as an empowering thing and see using things like assistive technology as an empowering thing, which is how I see it, not as a negative.

Emma went on to note that discussions and debates about disability theory were unique to this particular online forum for women with disabilities. In her experience most of the support forums tend to shy away from discussions on this topic. She proclaimed:

So I think in a lot of online support groups people are really good with the immediate sort of day-to-day stuff. . . . But not so great if you turn up and go "hey, I was thinking the social model really doesn't apply to me; how can we think about this?" It was interesting to have other people [in this particular group] who are willing to critique it because I think a lot of the chronic illness groups just don't want to think about it at all because it doesn't seem to make a lot of sense for people with chronic illness. A lot of the disability groups don't want to hear people who say this doesn't quite represent my experience. It's sort of sacred to them almost.

For many women support group involvement helped them gain a positive and productive outlook on their impairment and the disability experience. However, this was not always the case for all the participants. For example, Sophia discussed how her involvement in a support group geared towards her specific diagnosis helped her gain a realistic but unpleasant realization of what to expect in the future:

Most importantly, I realized from my diagnosis-specific forums that people don't ever really recover from this – most of them are on disability and have so many problems caused by the diagnosis. They understand what it's like not being able to afford anything because the medication is ridiculously expensive, not covered by insurance and they can't work to make money. This kind of jolted me into reality that I would never play my violin again or go hiking in some wild corner of the earth again, and I was lost because all my hobbies were so physical. The one criteria I had for happiness in a future job was to be active and not sit at a desk in an office, and that's the only kind of job I can have now.

Although her outlook on some aspects of her future were bleak, she did note that through her use of online forums she had become aware of a resource on living well with a chronic illness that may help her reimagine her future.

The support groups were a place where the women had access to others' stories of living with a disability as well as disability theory. For some women this helped bring about the realization that disability is not inherently negative. This notion helped to facilitate the emergence of disability pride, acceptance and comfort.

d. **Affirmative thinking about one's body and sexuality**

In addition to supporting disability pride and acceptance, the communication process within many of the groups helped promote comfort with their bodies and their bodily functions. Sometimes this communication was covert in nature. Charlotte talked at length about how her involvement in an in-person support group for women with disabilities at a local hospital fostered comfort with her body. The support group space offered a welcoming environment, which did not call attention to her bodily differences:

It has made me feel more comfortable in my own skin, feel not so awkward about my scars and my poor posture. . . . It was more what they didn't say. In this group there was no one making comments that my shirt was too low or putting their hands on me to "fix" my shirt. No one stared at me because of my surgery scars, my poor posture or that I almost always wear sneakers regardless of what I am wearing.

For Joanna it was the overt process of sharing stories that reaffirmed her previous notion that there was nothing wrong with her body:

Being in the group and listening and reading stories from other women with disabilities reaffirmed that [my comfort with my own body], because many of them are pretty comfortable in their own body as well and are vocal about it as well. So it gave me that reaffirmation that how I feel about my own body was right!

Similarly, Victoria reported that since her involvement in online groups she has also become comfortable with her body and no longer feels the overwhelming desire to compensate by wearing extravagant clothing. She noted, “Now I still dress nice but it’s not so much of a priority. It was also very exhausting. Now I know I don’t have to overcome the shame of a disability. It makes me feel better!”

For some women their involvement in online groups helped them become more comfortable with their weight. Emma benefitted from seeing images of women that looked like her on her Facebook feed and from communicating with other disabled women who felt positive about their bodies:

I think a big part of it is just seeing other people that look similar to me being really positive about themselves. Also, just the fact of, like, filling up your feed, Facebook feed or whatever, with people who have been positive about themselves when they're in a similar sort of situation. I find that really is helpful. Like, if my Facebook is full of slender able-bodied women, I start feeling much more negative about myself. If my Facebook is full of all these, you know, happy, achieving, disabled and fat women, then I feel better about myself.

Beyond promoting a positive body image, the group process gave rise to affirmative thinking about sexuality. Some of the women spoke at length about how they achieved new visions of their sexuality and gleaned the possibilities that were open to them as a disabled woman. For instance, Victoria discovered that women in the group had romantic relationships and were parents. This helped her realize that the information she was told previously was inaccurate:



And then I got in the group, lots of them were medically more disabled than I am, lots of them were married and had children and had experience with loving relationships. Some of them had experience with domestic abuse and with marital life. And I think it was good to talk about both possibilities of what can happen. Yes, some women with disabilities were experiencing abuse but it wasn't because they didn't deserve romantic life. . . . And now I realize [that disabled women can have children]; I know a woman who has the same diagnosis and she has three children. Now, I feel like something precious was stolen from me! It's not like I have to have kids but I got bad information.

Charlotte reported that her involvement in an in-person support group for women with disabilities gave her access to information regarding disability and sexuality:

I think the group really helped in terms of sexual related matters -- that it is something we can do and it is okay to talk about. Feeling okay with myself physically. . . . In the hospital support group, there was one member that was older than most of us and she was really helpful about giving advice. She was also honest about sex and relationship advice. I had never had anyone acknowledge that women with disabilities have sex, let alone encourage us to be comfortable in our bodies. . . . It was so eye opening for me that I wrote my thesis -- I co-majored in Women's Studies -- on the lack of support women with disabilities have when it came to pregnancy/motherhood.

Unlike the outside world, the group space was a haven in which they could give and receive accurate information about their bodies and their sexuality. For some women this was the first time they had heard this information. For other women the sharing process within the group helped them realize that the disability and sexuality information they had received previously was inaccurate. What they learned in their support groups provided them with the tools they needed to be comfortable with their own bodies and sexuality.

e. **A boost in confidence**

Communicating with other women in their support communities also led to a big boost in general confidence about themselves. For instance, Mia spoke about how having access to other disabled women who were confident and successful gave her a sense of reassurance and optimism about her future. She stated:

I feel like there's a lot of women in this group that have a lot of self-confidence. I feel like being around a community like that is really helpful towards me, because I know if they can do things, I can do them too. . . . I just feel very comfortable being there. . . . Just knowing that there's also women living with disability who are writers and who are really involved in the disability communities. It's a confidence booster, because they have all these challenges too, but they're still making a need for themselves and they're still being out there performing and being involved and just being good people. As for me that isn't really what I'm doing as much, it just makes me feel proud that we have a safe disability movement going on.

Reassurance and validation from group members did wonders for the self-confidence of many of the participants:

It feels good for people to encourage and praise you for something that is difficult for you yet seems perfectly normal for anyone else. That recognition really helps in a lot of situations because the people I am with every day have no idea that this thing they don't even think twice about is so tough for me. [Sophia]

I think in a way it has helped me to gain confidence and knowing that I'm not the only blind person in the world who's had this experience. . . . I think I gained confidence from reading posts and commenting on posts. [Bella]

They [the other group members] tell me that I don't need to apologize for who I am, disability and all. That's what I was doing before; I was trying to make other people feel comfortable when I didn't need to do that. I realized that by doing that I was putting myself down, the way that I look, the way that I feel. So being part of the group and realizing that the other women don't apologize for being who they are gave me a lot more confidence in my life, in my interaction with friends, and the people I work with. [Joanna]

In conclusion, the sharing and communication process with fellow support group members was key to cultivating the realization that they were not alone in the experiences they had as a disabled woman. This realization brought about a sense of comfort with who they are, security, and belonging. The communication process was also essential in fostering disability acceptance, disability pride, and comfort with one's body and sexuality. Hearing about others' experiences expanded their perceptions of their roles and capabilities as disabled women.

6. **The power of community membership: The influence of the group orientation and platform on self-development**

Numerous women reported that simply being a part of a community filled with other disabled women brought about changes in their self-perceptions and their perceptions of others. For some participants simply being a part of a community spurred a feeling of comfort and security that they did not have prior to group involvement. For example, Mia, whose goal it was to become more comfortable with herself, spoke passionately about the value of being part of a disability community:

So I have, like, a platform [of] women who are disabled and it just gives you a sense of comfort. . . . I'm part of different communities. I'm part of disabled communities. I'm also part of body positive movement communities and I feel if I have those things with me, they help me feel more comfortable with myself. Just having a backup just makes me feel more secure with myself.

Emma also saw great value in simply being a part of a community of disabled women. She noted this promotes reassurance that life with the disability can be fulfilling, saying, “To exist in a support group space and be there is valuable to people, I think. It shows them that, you know, whether or not your physical ability improves, your life can improve and that's the part that actually matters.”

Many of the support groups the women were a part of had a strong social justice orientation. Thus, the women were exposed to social justice issues relevant to their lives; this sparked a desire to be an advocate for themselves and other disabled people. Relatedly, being part of a support group community gave rise to many opportunities to be a leader and perceive oneself as a leader. For some women the group process supported the development of a collective consciousness and sense of belonging to the disability community as a whole. These aspects of the group process are described below.

a. **Kindling the desire to be an advocate**

The women reported that discussions and posted articles sparked their interest in being advocates for themselves and others with disabilities. For instance, Mia spoke of how articles about women's issues that were posted on her online support group for disabled women motivated her to start sharing this information on her own page:

It gives me that kind of push to share these articles on my own dashboard. It starts conversations with friends. . . . It makes me feel I want to write to say I'm not the only one dealing with things like that. It just gives me that push that hey, I should put this on my own dash. If people want to ask questions or want to read it or want to share it, they can, you know. So I don't know. It just gives me that little -- it helps me be more vocal!

Joanna also had a similar experience within her online support group for disabled women. For her it didn't matter whether social justice issues applied directly to her, she saw it as important information to the community as a whole:

The group has increased my awareness of advocacy issues. . . . Just hearing other people talk about their challenge . . . or having to deal with the discriminatory policy in regards to getting a wheelchair and all the regulations that they have to face . . . or technology that will help their life get better. . . . It's not useful to me. I don't use it, but it's useful for me to know because then I can see that, okay, that's an issue there in our community.

Elizabeth, also reported that disability social justice issues are an important theme in her in-person disabled women's group, saying:

The issues we address are transportation, healthcare, and employment. We all struggle with these things and as an organization want to resolve them. . . . We also address healthcare issues such as doctors' offices not being accessible and how we can come up with a solution or who to contact.

For many of the women, the social justice orientation was a standout feature within the groups. This led to a sense of empowerment:

The group has a strong sense of power, overall, I think. It's not a whiny group; the members look for solutions and help, but it's not a board in which people sit around

with 'woe is me' or anything. I like that very much about the group and the members. [Harper]

I think 'empowerment' might be a big theme here. I think these politically-minded femmes have a working concept of sexism, and come from a fun place of critique that has both depth and levity. [Addison]

I think that's part of their statement where they just, you know, they want to support each other and they want to include everybody. . . . It strengthens each other up. It helps us to have a type of community for women, especially disabled women. . . . It makes me feel more empowered. [Mia]

The groups teach women to be empowered and to be vocal! And they provide support for people on their journey; that journey may be different than other people but just to be there for people when they need it. [Joanna]

The women were motivated to use this sense of empowerment and begin using their voice to advocate for what they want and need. For instance, Elizabeth spoke passionately about the social justice issues the group addresses and how this has motivated her to push harder to help solve the problems that she and other disabled women face:

The group's message just makes me feel stronger and deeply about wanting to help solve the struggles that we face. It makes me just push harder for us to be known, valued and respected. I've always known that things in life weren't going to be easy, but I didn't know that the world would be so judgmental and close-minded towards people with disabilities.

Online group involvement also cultivated a wonderful sense of empowerment and outspokenness for Joanna. She took great pride in using the knowledge she had gained to assist others in times of need. Discussing how the group has influenced the way she feels about herself, she exclaimed:

I feel empowered, empowered in many ways. . . . I am empowered to know that I can be a resource as well for others, others with disabilities. And then like again I'm also thankful and grateful that I can read or share personal experiences online and be able to help do something about it. . . . It got me to a point where I'm more hopeful and more empowered to do more things in my own personal life with my friends or colleagues or other people who are able bodied. I'm more vocal about being who I am as a woman with a disability where before I was not as vocal about that!

Joanna further elaborated that she has become empowered to use her voice when her friends make plans that are not physically accessible to her:

Now [after being involved in the group] I will let them know that I cannot participate because of my disability! I don't want to make them feel guilty but I want them to be aware that the activities they choose to do will limit my participation. So they can either choose a different activity or they can continue to do what they were going to do. It's important for them to know that I'm fine with that too. For example, if they're doing a hiking trip I can say "I'm not able to do that but I can meet you for coffee before." Before [the group], I wouldn't even make that suggestion. . . . I think when you see other women who have a lot of confidence in their self and don't apologize for who they are, I think it's empowering to see that, I can be that, I can be vocal!

Victoria also reported that her group involvement empowered her to become a better self-advocate. She has now channeled her anger towards advocating rather than toward herself. When discussing the transformation in herself since joining the group, she stated:

I feel very, very, differently, [since joining the group]! . . . Now I'm physically exhausted but I'm not hiding anymore so I have more capacity for doing stuff. Now, I don't think about how will I hide if I need assistance going downstairs. Yes, there are some people that don't like me needing assistance. There are people that need time to process it. [When DJing and ] I meet a party organizer who was talking baby talk on me, now I know it's not because I'm some kind of deficient. Now I'm angry; I allowed myself to be angry because to be honest it's better to be angry than to be self-destructive.

In sum, a strong sense of empowerment prevailed throughout the group spaces. The support group platform was used to share articles about women's issues and social justice matters. This inspired the women and sparked a desire to share the information with others. The women used their newfound empowerment to speak up and make changes in their own lives and the lives of others.

b. **Opportunities to be a leader and perceive one's self as a leader**

One of the biggest benefits of community membership was the opportunity to be a leader and authority figure to others in similar situations. This certainly

was the case for Emma. She acknowledged the change in her self-perception was hard to isolate. That said, she made it abundantly clear that the online forums gave her unique opportunities to be a leader and utilize her leadership skills. These opportunities were not available to her prior to her involvement in online support groups. When asked to describe how her involvement in online support groups influenced the way she felt about herself, she stated:

But things that I could think of that I think were probably related to the groups -- probably that I'm really good at leading and answering people's questions. . . . It was nice to be treated as someone who knew stuff because it's one of the, sort of, few areas in my life where I am the one that's treated as the one who knows stuff. Like, I don't have a profession. I don't have my own family. I don't have anything really where I'm the authority in it. But for this, I do. . . . I've got one of these brains that remember stuff. So when things come up on a group, like "Hey, I think somebody mentioned something about a homemade electrolyte drink six months ago, but I can't find it in the archives," someone will tag me and I will probably remember who talked about it and be able to find it. . . . It's like even in this weird situation where I'm sicker than almost everyone else, there's a thing I can do that pretty much no one else can do. So, that's sort of cool that we're being treated as an authority. That changed the way I see myself the most.

Emma took full advantage of her newfound leadership abilities. In one example, she discussed how the social media platform of her online support group for disabled women gave her the opportunity to use her leadership skills through co-authoring and circulating an article on the social model of disability:

I wrote an article a while back with a couple of the other people from my disabled women's online support group about how the social model of disability does and doesn't apply to people in my sort of situation. It ended up being published on Yahoo as well as on the group forum. It was on the Yahoo accessibility blog. So it got quite a bit of people reading it. . . . So, it's nice to have people commenting on the articles that I've written and also passing things around that I had written. Occasionally I find in a support group people passing something around that I wrote without knowing I wrote it, which is like massively awesome!

In a second example of her leadership within her online communities, Emma shared how she was able to encourage others to be more open and honest about their bodily

functions and the effects of their impairments. Her actions initiated a change in group culture:

I made this epic long post that was basically all of the most embarrassing things that I could think of. I wrote, I have shot myself like this and I've had these bladder problems and it was just really explicit. It was a list of, like, 15 completely, horrible embarrassing things that I'd been through. I just posted it on the groups and at the bottom I put I've been feeling like everyone's too embarrassed to post about this stuff even though we all experience it and I think that that's not really very productive. So I'm going to post stuff that's way more embarrassing than anybody else can think of. Then, at the bottom, I said now, you all have to make really supportive comments so that everyone knows it's safe to talk about this stuff and everybody did and it worked. Two years later, people are still making much more free posts on the same Facebook group and I fixed it!

A great sense of power and pride emerged from engaging in this leadership and letting herself be open and honest about her impairment. When discussing how making the post described above influenced the way she felt about herself, she exclaimed:

It just made me feel powerful. It made me feel like I can say all of these things which are, like, literally the hardest things about my impairment to discuss and I can say all of them, all at the same time together, in public and everyone is nice. So it was really super powerful for me as well, not just helpful for the other group members. It was pretty epic. I'm so proud of it!

Some participants engaged in leadership on the forums through sharing their interests and encouraging others to become involved. For instance, Natalie is very interested in assistive technology and is a frequent user of a mobile telepresence device called the Beam, which can be used to communicate with other advocates from around the world. Sharing the story of the Beam with her fellow online support group members and seeing them benefit from the technology gave her great happiness:

I also have connected with other people through Technology; it's a robot called the Beam and I've shared the story of the Beam, me using it, on video on many of the forums and because of that, that has helped other people get a Beam themselves or may at least use it because of knowing about it through me. . . . I mean, if other people can learn from me or take something from me to improve their life... The



more people are using the Beam to meet now, I am happy! I contributed in some small way to make that happen.

Like Natalie, Sophia also took great pride in being a leader on the web and being able to help others by sharing important information with them. She perceived opportunities to be useful and help as scarce in her daily life. The support communities she was a part of gave her a platform where she could give advice that was valued and made a difference in people's lives. In turn, this increased her self-worth:

I feel useful in these groups as well since I can answer some of the questions people ask and help them along in their journeys. . . . I really like responding to people's posts with helpful information or experiences that they could learn from. This has always been something I am drawn to: helping people in general and so being given the opportunity when I am not even around people and can no longer be helpful in the same ways I was or as frequently has helped me feel useful again, given me some sense of self-worth, and it kind of inflated me a little each time I respond in this way. . . . My interactions with others have made me value myself more again because even when I'm not around people or when I'm around them but not able to physically help them, I can still give advice and feel useful, feel like I've made some difference in someone's day, or even in their quality of life.

Group involvement prompted Victoria to begin using her leadership skills in the community at large. She discussed her involvement in activism since joining the forums:

A lot of the members are also involved in social justice work. . . . I think I'm a professional activist. . . . I started my own non-governmental organization and am giving speeches about women with disabilities; it's effortless for me. I can't imagine doing that in 2008 [before joining the group] so, yes, it is a big shift. . . . They have cultivated my leadership abilities. . . . Before that I was able to speak about other things but not about disability. It was troubling for me.

In summary, several women used the support group platform as a means to utilize their leadership abilities. They relished the opportunity to help others and be perceived as an authority. This was especially beneficial given that these types of opportunities were relatively limited in their daily lives outside of the support group community.

c. **The development of a collective consciousness**

Lastly, the social justice orientation within the groups appeared to support the development of a collective consciousness and sense of belonging to the disability community for some participants. For example, Joanna discussed how she now has a firm realization of the daily discrimination her fellow disabled group members face. This has further fueled her pre-existing anger:

I'm still a little bit angry after I joined the group. Not so much that I'm angry in a sense at the people in the group, but more that the experience that they have to take in their daily life. Such as discrimination, stuff like that.

For her, it did not matter whether social justice issues applied directly to her or others; she saw it as important information to the community as a whole:

The group has increased my awareness of advocacy issues. . . . Just hearing other people talk about their challenges . . . or having to deal with the discriminatory policy in regards to getting a wheelchair and all the regulations that they have to face . . . or technology that will help their life get better. . . . It's not useful to me; I don't use it, but it's useful for me to know because then I can see that, okay, that's an issue there in our community.

Furthermore, Addison said one of the only changes to her self-concept due to the group was that she had a greater sense of being part of a larger community and having a collective identity, saying: "[Group discussions have influenced the way I feel about myself] only to the extent that I can situate myself in relation to a larger community, a member of a kind of, a part of the world in a way."

For at least one woman, support group involvement has led to a more complete understanding of others with disabilities. Addison was clear that she has always had a positive self-perception regardless of group involvement. But, she noted that being part of the online group for women with disabilities has helped her grasp the complexity of the disability community and place it within a sociopolitical and ecological framework:

Joining online groups later on, helped me to differently understand others, helped me to find and appreciate the subjectivities of disabled folks and helped me to know that the world is larger and much more complex than meets the eye. As an artist and avid journaler, I have always appreciated my OWN complexity and fracturedness, but online community has allowed me to RE-Soc/Pol/Eco grasp the bigger "frames" of the whole of the world. It's always a process. ;) [Emoji inserted by participant during email interview].

In conclusion, group involvement helped women situate themselves as part of a larger disability community. The women realized that disability related problems were not individual problems, but rather applied to the group as a whole. In some cases this facilitated a desire to help solve disability related issues, even if the issues did not directly apply to their own lives.

#### 7. **Transition to adulthood for women with disabilities**

As discussed in the literature review, transition to adulthood is an important time for self-concept development. The next portion of this chapter presents data pertaining to how participants define adulthood and what influence the group had in helping them reach milestones of adulthood. Three major categories emerged related to these ends. They are: 1) defining adulthood and important milestones of adulthood as indicated by the participants; 2) barriers to transitioning to adulthood; and 3) the group's influence in transitioning into adulthood.

##### a. **Defining adulthood and important milestones of adulthood**

Participants' responses regarding what defined adulthood for them were varied. Some defining features mentioned were traditional in nature, while others did not necessarily fall within the traditional notions of adulthood. The ways in which participants defined adulthood often mirrored the personal goals they set for themselves discussed earlier in this chapter. Similar to their personal goal of being independent several

participants mentioned that being self-supporting was an important element to being an adult and feeling like part of adulthood. Responses indicative of this were as follows:

What I feel makes someone an adult is when they are taking care of themselves, self-supporting that is, their parents are no longer paying the rent, etc. [Harper]

When they start having to pay bills and taking care of other people and I think that's what makes me feel like an adult. . . . When you have to make your doctor appointments and you have to go, you know, by yourself. It's just like finding your own things and making your own food. . . . I think that you have to be more -- as a person with disability, it's hard, you know. So knowing the fact that I can do these little things to make me feel like an adult and it gives me some sort of, a sense of empowerment because I don't have to rely on anybody else. [Mia]

I think living alone, paying your own bills, having relationships [is an important part of becoming an adult.] [Charlotte]

I very much felt like an adult for a few years before I got sick. I was completely independent living alone, cooking, and cleaning for myself. [Sophia]

Like the participants above, Victoria who was 42 at the time of the interview explained that early on in her transition to adulthood she believed that not relying on assistance was the defining feature of adulthood. However, this belief has since changed:

When I was transitioning to adulthood I was proud and [thought] I don't need any government support, I don't need any accommodations. It was about not being disabled, although other people saw me as disabled. It was a very messy transition! I had a different definition of adulthood than I have of adulthood now. Now, adulthood is for me to be able to pay bills, and it's okay to rely on government assistance if you don't make a mess of your financial stuff. That's now!

Being their own advocate was also a distinctive marker of adulthood for many participants. For example, when discussing her transition to adulthood, Elizabeth spoke of how she grew up quickly, since she had to advocate for her needs at a fairly young age:

I had to grow up fairly quickly because my parents had to work and I had to attend school like everyone else did. So as a kid, I never had a nurse or a personal care attendant with me. I had to learn how to take care of my own medical needs and have a voice when I needed help if there was something I couldn't do medically for myself. I even had to show others such as teacher's aides very simple things that didn't require a licensed or trained person/nurse.

Charlotte spoke of how advocating for her own medical needs and making her own choices in general were hallmarks of adulthood. She asserted:

[Adulthood means to me] being responsible for your own medical care, and perhaps most importantly, being able to choose what type of care you receive, or don't receive for that matter. Not being forced to wear braces, etc. For me [being an adult is] finally getting to decide my choice of care, my relationships, and living on my own even if I still get a lot of physical help from my family.

Similarly, Mia spoke of how realizing she had to be her own self-advocate was a “wake up call” of adulthood:

Like, if I need to call on my social worker, I have to do it because if I don't do it, nobody else will and I'm going to get my Medicaid taken away. So those little things were stressful as hell! They're really annoying and scary, but if I don't do it I'm going to lose what I have. So they are wake-up calls of like adulthood. So if we don't take care of our stuff, things are not going to work out.

Sometimes adulthood meant not only making your own decisions but also being wise enough to make the right decision:

See, I think being an adult means you have choices, right? And you have to make the right choices in life to become a successful adult. So as kids, you have to make hard choices, right? But as an adult, you are given many options, many choices. And you have to be wise enough to choose the right choice that can maximize a successful outcome for your life. [Natalie]

Joanna noted that adulthood is reflected in the maturity of the things you say and choose to share with others, commenting, “I think once you become an adult the things you say and the things you share with other people reflect maturity as well.” She further noted adulthood is associated with self-exploration and self-acceptance. She said, “Finding out about yourself [is a defining feature of adulthood]. . . . And again, not making any apology for being that person. Acknowledging who you are, acknowledging your strengths, and everything else.”

Adulthood was not always easy for the participants to define. Emma, who was 42 at the time of the interview, struggled to pinpoint her passage into adulthood. She explained the uncertainty of her transition and how she entered adulthood through default:

I guess at some point I just started feeling like I'm so old now I must be an adult [laughter]. . . . I still don't have any of the standard markers of adulthood and I'll probably never get almost any of them. . . . I think that a lot of times wider society perceives you as an adult by when you get those adult markers in. So then you're perceived as not an adult even though you are one if you're locked out of those marker things because of disability, but I think eventually society just sort of goes: well, you're old enough now, you must be an adult and gives up trying to work out where you add off on the markers. I definitely haven't received nearly as much grief about it in the last sort of 10 years than I did in my 20s. . . . Yeah, adulthood by society giving up on hassling you and also maybe by me giving up on caring about those things. I cared a lot about it so maybe the marker of being an adult is not caring about whether society sees you as an adult.

She further elaborated on the vagueness of adulthood for her and other disabled people who do not meet the socially constructed markers of adulthood:

I don't know what makes someone an adult. I don't think anyone knows. I think about it sometimes in relation to my parents, like, when my parents were my age they had kids, they owned a house, they had all these external markers of adulthood, none of which I have, so how does that relate to me? . . . It's a very fuzzy concept, isn't it?

She went on to mention that creating her own online support group for women with disabilities helped her envision herself as a leader and as an adult:

I made myself a group when I was transitioning into adulthood. I think being a leader of that group partly did help me, because it was a part where I was considered as a leader, as an adult.

Similar to leadership abilities as a marker of adulthood, Natalie mentioned that “people skills” were essential to becoming a successful adult:

It's more helpful and you're getting more information when you talk to humans and not just reading text. So I guess that's what's called people skills. . . . So you need people skills the most to become a successful adult. It should be important for every adult living. The chance to talk to others and learn from others.

As presented above, some markers of adulthood for participants were traditional in nature. These included age, being self-supporting, and making your own choices. On the other hand, markers on the less traditional end of the spectrum included having people skills and good leadership abilities. The ways in which the women defined adulthood were reflective of many of the personal goals they had.

b. **Barriers to transitioning to adulthood**

The women reported encountering many barriers to their successful transition into adulthood. For instance, Victoria reported facing a multitude of obstacles during this time and is still struggling at 42 years old. She recounted the barriers she faced and how the stigmatizing perceptions of others actually became a reality:

So my transition into adulthood was very messy! And I started to study in another university and I was thrown out. I started to study at language school and it was horrible! . . . And I'm still struggling with finishing business from my transition to adulthood. . . . I think people see me as less competent. And it's because I need personal assistance from them. The government support for personal assistance is not enough and never will be enough for a long time, so what I do is to ask random people to lift me up from chairs even in the club scene. So because of that people see me as a less competent DJ. Because of being seen as less competent I actually became less competent.

The external barriers she faced were internalized and led to a stigmatizing self-perception. Discussing her belief that disability and adulthood were incompatible, and her propensity to deny her disability during this point in her life, she disclosed,

I still think I fail at adulting. . . . I don't know if I'm an adult now and I am 42! [Laughter] When I was in these formative years [18- 35] you mentioned, I was busy denying my disability. Denying, denying, denying, because I thought you couldn't be an adult and have a disability. Disability for me and adulthood was totally incompatible!

Several women reported that negative perceptions and low expectations from others hindered their transition to adulthood in a variety of ways. Joanna noted that as a woman

with a disability, people automatically assumed that they do not need to teach her independent living skills or job skills. She reflected:

In my case, being a woman with a disability, people assume they don't need to teach you skills about being independent whether it be renting your own place someday or finding a job, for example, or what did a job interview looks like. I mean they don't teach you any of those things most of the time.

Elizabeth also reported that people's prejudicial attitude towards disability have hindered her from becoming employed. She lamented, "I haven't been able to get employed because once they physically see me, they never call me back. I know that they're judging me based on my disability because in their minds I'm not capable of fulfilling my job duties." A few participants reported that people automatically made denigrating assumptions regarding their intelligence because of their disability. For example, when discussing barriers she faced when transitioning to adulthood, Sophia noted:

People also seem to be much more distant, as if my mobility scooter is a physical barrier and as if I'm somehow no longer intelligent because I have a disability. I have come to accept that I can't change people's preconceptions and things aren't going to go back to the way they were before.

Similarly, Bella spoke of the infantilization she experienced during her transition saying, "I know from my previous experiences I've had people think of me as a child when, in fact, I'm not!" The majority of infantilization and overprotectiveness the women faced came from their parents. They also spoke of how parents' low expectations of them made their journey into adulthood difficult. Responses that reflect these parentally created barriers to adulthood included the following:

Parents can make it difficult for someone to become an adult. Parents want to shelter us from the world because they don't want us to be exposed to the cruel world. They want to keep us safe and in a bubble, but reality isn't set up that way. If someone with a disability is sheltered, they will never know and learn that they can still have a life. They will never learn about life and how to go through this cruel world. Their opinions and voices will never be heard if their parents keep them



as a child forever. Our parents forget that they, unfortunately, won't be around forever to take care of us or be there when we need them. We have to learn how to do things for ourselves and learn to take care of ourselves. [Elizabeth]

When I was 13 my mother was controlling every aspect of my life including clothing, including what I eat, including everything and I learned from this transition part of my life. [Victoria]

In my family for example nobody ever thought I would have my own life so I didn't need any of those things. They just always thought they would be cooking for me, taking care of me. Like I shared with you earlier, I don't have a severe disability so it's a cultural thing in my family. It doesn't matter whether you have a severe or mild disability; it's the same thing in their minds. So they just want to protect me and they just don't think I can do things on my own. So for that reason they just don't teach you how to transition from a teenager to an adult because that means that eventually you'll have to get married, have children and rent a place and buy a car. They just don't see that [as a possibility for me] so they just don't see the need to teach me all of that. [Joanna]

Assumptions that disabled people are asexual may have contributed directly to at least one participant having difficulty in the dating and romantic realm:

The other aspect of adulthood that I am missing is relationships. I never dated anyone before [I became disabled] but there were quite a few people interested; I just didn't feel the same way about them, so I am clueless in that arena. But now [after I became disabled] no one even looks at me and I'm not an over-the-top person who wears makeup and short dresses, so I just don't feel like that's ever really going to happen, or at least that my chances of finding someone are greatly reduced. [Sophia]

Clearly, the discrimination and negative perceptions the women faced hindered the achievement of adult identity for many. However, Bella noted that experiencing a profound amount of discrimination during her college experience was paradoxically helpful in her transition to adulthood. These incidents were an impetus to be her own self-advocate and enabled her to develop confidence and grow as a person:

I think experiencing discrimination based on my disability in college was a very big step for me and how I learned and have grown from that experience and how it changed my mindset and my attitude about my disability. It, you know, gave me the confidence to advocate for myself and that confidence has only grown through experience. I think everything has really just come through experience for me and

that process will never be finished because you're always experiencing life and you're always growing from experiences and learning through trial and error.

In addition to the barriers already discussed, the women reported that society's unwillingness to recognize untraditional markers of adulthood thwarted their transition. Emma spoke at length about her frustration regarding people's constant questioning of whether she has met traditional markers of adulthood yet:

Well, people don't perceive you as an adult a lot when you haven't got those, sort of, external markers. I remember when I was in my early twenties, mid-twenties and everyone was constantly asking me if I'd graduated university, if I'd got a job yet, if I had a partner yet, it used to make me crazy. I think I was also in the time when I was still pretty bitter and twisted and angry about being disabled so that probably didn't help.

In a similar vein, Joanna spoke of how society has a very rigid definition of independence, a traditional marker of adulthood, which is often not applicable to disabled people:

Independency doesn't necessarily mean being an adult because you can be an adult and not be independent. Independency in the disability community can be two totally different things. . . . Independence is often times considered part of being an adult but in the disability community that's not a valid marker either, because you can be older and not be fully independent but still be an adult.

In addition to struggling with external socially constructed barriers, some women also reported bodily limitations resulted in a loss of independence. This made it difficult for them to meet the milestones of adulthood that were important to them. For instance, Sophia sorrowfully recounted how she felt she lost her adulthood when she became disabled:

When I became disabled, I felt like I lost my adulthood in a way. I couldn't do anything for myself, needing someone to lift me from the couch to the wheelchair and even help me drink and feed me some days that I was too weak to do anything. It was demeaning. There was nothing I could do for myself, and for a few months my intellectual capacity was compromised as well. How can you feel like an adult when that's what your life is like? . . . Also in relation to being an adult now versus then, I always used to get things done no matter what the time I was given or how much other things I had to do. I was taking 23 credits, practiced my violin 4-8 hours

a day, had a 4.0 [grade point average], and did quite a few extra things on the side. Now, I am taking 12 credits, not doing anything else, and am overwhelmed.

As illustrated above, the barriers to transitioning to adulthood were vast for many of the women. Several were external in nature and a direct result of society's stigmatizing perceptions related to disability. Other obstacles were internal and pertained to bodily limitations.

c. **The group's influence on transitioning into adulthood**

Similar to its influence on self-concept development, the sharing process within the group was also vital in the women's transition to adulthood. For several of the women, having access to other people who have gone through or are going through similar situations was most beneficial. For instance, Natalie discussed how learning from others' experiences was critical to helping her make the right choices as an adult:

[In order to make your own choices as an adult] what's important is information and talking to others, because if you don't talk to others and if you don't have the ability to discuss what's on your mind with others, then you're not guaranteed information. And just reading the text in books and reading things online is not going to be helpful. . . . That's why I really feel forums are helpful because you're not doing a website that has text. You're hearing information from real people and understanding it from their real experiences. . . . Meeting others, learning from their experiences and sharing experiences helped me become a better adult!

Like Natalie, 28-year-old Bella found that having the opportunity to share and hear others' stories was extremely valuable during her transition to adulthood. When asked to describe what comes to mind when thinking about how her involvement in various online support groups has helped her transition, she responded,

I think that learning from others' experiences is a big part of it too. Seeing what other people do or what other problems people are having or how they handle situations that they're faced with gives me ideas for, okay, if this happens to me I can employ this strategy or I can implement this, you know, tactic or I could use this adaptive technique. . . . There definitely are resources that are shared that are

helpful. There are articles that are shared that spark discussion and sometimes can spark debate depending on each member's perspective.

Similar to the online forums, sharing experiences also seem to be an important element of in-person groups for disabled women. Elizabeth noted that although she had completed her transition to adulthood before joining her in-person group, the opportunity to hear others' experiences is very valuable to those members currently in transition. She explained:

For someone that's just getting into adulthood, this group is for them because we provide not only resources and information but we provide experiences about how we've lived our lives with a disability and what we need to know as an adult. We need to be aware of our own finances and medical issues because that's part of being an adult.

Exposure to others' success stories with regard to meeting traditional milestones of adulthood gave the women the hope and encouragement they needed to continue in their own transition. For example, Charlotte discussed how hearing about how other members were living independently and starting families empowered her on her own journey to adulthood. It also helped her combat the infantilization she experienced:

[The group helped me with] not being treated like a child or ignored. Also, a lot of the group members lived alone. I was in school and while not living at home, it is not living as an adult, so it was just helpful to see other people with disabilities who had their own places, had relationships, had children, etc. I think the group was helpful because aside from having people you can discuss issues with, it was just helpful to see other people who had "made it". They lived in their own places, had relationships, families, etc. It essentially was very empowering.

Joanna, who was 46 years of age at the time of the interview, discerned the benefits of knowing that members of her online support group for disabled women have experienced meaningful relationships and motherhood:

[Helpful factors of transitioning to adulthood include], Somebody sharing about how a relationship can happen at any age, or somebody sharing about having a family. It's making me more of an adult because I realized all the responsibilities that we

have. Women who have disabilities sharing stories about their life as a married woman or as a mother kind of brings the maturity level up a bit because you can see a lot more things.

The advice and encouragement the women received from other group members helped them take the initiative to solve problems they faced as they navigated through adulthood. Victoria spoke at length about how the encouragement and tough love she received from fellow group members helped her take the initiative to accomplish goals that were important to her completing her transition to adulthood:

So [the online forum for disabled women] has helped me finish the transition that I didn't finish. When I go onto the page and I talk about my financial problems they will not judge me! They will not tell me "how are you paying this? This is impossible!" And won't say "you will not pay it because you're too scared to open the fucking letter!" [Instead they will say], "you have to open this fucking letter and face your fears!" I faced my fears so many times. I have a lot of baggage from facing my fears and they kind of know it.

Sophia noted that her support group involvement had limited influence on her transition to adulthood. However, like the women quoted above she did perceive the support and encouragement from other members as beneficial and helping her meet goals related to a successful transition:

I guess in some respects the groups helped me to move back to school. It would have happened anyway, but I asked some questions about people's experiences with mobility scooters and how they get things done without depleting their energy, and I have also received a lot of encouragement from people in the groups who were very surprised and impressed that I was going back to finish school given my condition. . . . There [are also] articles posted about meditations and that sort of thing that I feel like if I read and found time to implement would help in adult business with stress management and more efficiency.

In addition to providing vital support and encouragement, group involvement also afforded an outlet to process emotions that may hinder their transition to adulthood.

Responses that illustrate this important feature of the group process include the following:

I can process this feeling of inadequacy and incompetence in some areas with the friends from the disabled women's forum. With discussion [in the group] I know when I face something I can go to them and tell them. In other groups I would always feel silenced. I would recount these horrible stories about what happened to me and I would be blamed. There's lots of victim blaming in other support groups. So, that's something special with the disabled women's forum. I can process my feelings and get the feedback that my feelings are right! And it's usually enough to get the situation under control. And I can talk about my transition to adulthood and these types of problems. [Victoria]

The main topic could be their challenges of finding apartments. . . . Trying to live independently and there is a challenge with marriage inequality especially for people who receive government benefits. Those are a hot topic, in the group . . . [They share] mostly their anger, frustrations; things like that. [Natalie]

I just see women who can be super emotional. When they are mad, they are mad, when they're grieving they are grieving, emotions for the different experiences and it makes you realize, "oh, why'd you do this, because you get so frustrated"! You can get angry at things that happen. . . . Or you can just be happy; it doesn't have to be related to disability for example. That just makes us normal as a person going through life. [Joanna]

For two of the participants, involvement in online support forums raised their consciousness about important issues pertaining to adulthood and issues that affect all disabled women. Mia spoke about how the group helped her become more aware of significant concerns and empowered her to do her own research:

I feel like when I hear these articles and it's just, kind of, a wake-up call for me. It's like, I guess, grow up and to see all these problems and things that are affecting us. I used to, like, live in a bubble where all these problems that people with disabilities face, like, if it wasn't concerning me, I wasn't interested. Now, I'm more open and all these feelings just wake me up and I'm like "hey, like, I'm a woman and I am going to make [my] dreams." . . . I feel more like an adult because of it. . . . Because I'm being more aware and I'm learning these things that are affecting everybody. It's also learning new words and just having conversations. Now for me, it's more important to be a part of things.

Group involvement also brought about a raised consciousness for Joanna. She spoke about how conversations in the group helped her realize that the definition of independence can be fluid and subjective:

It [involvement in the online forum for disabled women] just makes me more conscious of different lifestyles of being an adult and being independent. That it comes in different shapes and forms. . . . You can be an adult and be responsible for yourself but because of your disability you may have a care attendant but you're still an adult you're still making your own decisions. It's just kind of helped me understand different ways of being independent and being an adult and having different living situations. . . . When I talk about independence with regards to myself it's about being able to make my own decisions, deciding where I live, renting my own place, having my own car, having my own money, having a job, all of that is part of being independent. But, like I said that is just me. I cannot speak for other people with disabilities because they can still be independent and not have the same definition as I do.

One participant noted that, had she had the opportunity to be involved in online forums during her transition to adulthood, it would have helped her realize that her individual goals are what matters. She was confident that if she had had access to disabled role models during her transition she would have realized that large or society approved goals don't have to be accomplished to be considered successful. When discussing how her involvement in the online disabled women's group may have retrospectively helped her transition to adulthood she said,

I think the groups would have helped me to change my goals as I transitioned to adulthood because the goals that I actually had which was I wanted to get better, I wanted to go study for a PhD, they were completely unreasonable goals. I was making myself miserable by judging my whole life by whether I had achieved these completely unachievable goals. If I had more appropriate goals, maybe if I had role models around that were, like, "well, I haven't achieved any of those goals, but you look up to me so what does that say about your goals?" Maybe it would have been, like, not quite so hard. I am hoping maybe I can be that for the younger people that are in the group now, that I can be like "well, think about what your goals are and whether they are absolutely important. Whether they are absolutely important for the reason you think they're important. [Emma, age 42]

In sum, group involvement helped or retrospectively would have helped some of the women during the critical period of transitioning to adulthood. The groups afforded an abundance of support and advice, as well as offering the women a safe haven to process emotions that could hinder their journey into adult life. Some women were able to use their

group involvement as a catalyst to raise their consciousness about important issues of adulthood. The groups also helped redefine important features of adulthood in terms of what fit their own circumstances.

#### 8. **Format of the group**

The women reported that there were numerous pros and cons associated with both the online and in-person group formats. There were six major categories that emerged under the group format theme. They are: a) Benefits of in-person meetings; b) Barriers to participation in in-person support groups for younger women; c) Benefits of online peer support; d) Differences in online platforms and groups; e) Disadvantages of online support; and f) Suggestions for improvement of the online support experience. These major categories are presented below.

##### a. **Benefits of in-person meetings**

Although the majority of group members who participated in this research were involved in online support communities, several of them noted distinct benefits of having in-person meetings and events for group members. The personal connection that in-person meetings often foster was noted as a distinct advantage of this format. Addison communicated her delight at seeing bulletins about in-person events in the disability community. She exclaimed, “Seeing posted ‘in-person’ events is often exciting to me because it comforts me to know that things are happening, social stirrings, spaces to laugh and see each other, engage with other bodies and embodiments.” Even though in-person contact was not an essential aspect of the support group process for her personally, Sophia, a member of an in-person support group, as well as a user of online support forums, noted the importance of personal contact for some people:



I think an in-person group can be beneficial for people who want real contact with people and can give each other hugs and see the people when talking to them, and I can't say this doesn't matter to me, but I can definitely go without it and can't tolerate too much of it, whereas other people seem to really need this personal connection.

Elizabeth enjoyed the chance to connect with others in her in-person support group for disabled women. She saw it as a unique opportunity to enjoy a compatible social environment:

The benefits of meeting in-person is that you're not stuck in your house with just your family doing the same thing and not be able to relate to them in many ways or them not relating to you. In in-person meetings, you're around other women and are not just discussing different topics, but you're also having fun and it's a completely different atmosphere.

Even though she had limited opportunity to attend face-to-face meet-ups with others in the disability community, in-person contact was also vital to Joanna. She explained how meeting in person could convey a fuller perspective of people:

I prefer face-to-face because you can really gain the whole perspective whether it's meeting somebody with a physical disability who's in a wheelchair, you have a holistic perspective of that person in addition to their own personality and their character. You meet them directly about the challenges they face and stuff like that. So for me I gain a lot more motivation and inspiration when I meet people face-to-face. But I haven't had much opportunity for this.

Joanna also pointed out that face-to-face meetings provide a valuable opportunity for women with disabilities to demonstrate belongingness within the community at large and to assert their rights collectively. She explained:

The important thing about a face-to-face women's group is if we go to a restaurant and come in with a whole group of people with disabilities, using wheelchairs and crutches or other accommodations, I want the location whether it's a restaurant or mall to see that we are part of the community. And they need to make accommodations for us as their customers and if they do, we will come and eat at their restaurant. This lets them know that they need to have accessible restrooms; they need to have accessible doors for us! So face-to-face groups have that advantage. I don't think online groups will help us break that wall and be part of the

community. . . . And I think it's really empowering because it creates challenges in that moment when they don't have accessible restrooms or whatever.

Guest speakers within face-to-face groups were also a way to connect to the community. For at least one participant who was a member of both an online support community and an in-person support group, guest speakers were a distinct benefit of the latter:

The in-person support group for my diagnosis that was specific to my area also posts about guest speakers who come to the meetings . . . two of which I went to and found really interesting and informative. Most of us also share the same two doctors and are mostly on the same meds, so we can ask what works for each other, if it is worth it to do the muscle biopsy or genetic testing, and where to find the cheapest while still effective supplements. [Sophia]

As the data presented above illustrates, personal connections are an important benefit to the in-person support group format. This face-to-face contact was felt by some participants to be essential in gaining a holistic perspective of fellow group members. Having a physical space to meet and claim as their own was also important. Meeting in person also led to valuable opportunities to connect to the community at large and assert belongingness within that broader community.

b. **Barriers to participation in support groups for younger women**

Despite some very unique benefits of participating in in-person support groups, it was discovered during the recruitment process for this research that women ages 18 to 35 are no longer likely to regularly attend face-to-face support groups for women with disabilities. The participants were asked to reflect on why this might be, and a variety of reasons were offered to explain the dwindling number of younger women attending in-person groups. Travel issues and lack of transportation were frequently mentioned barriers to attending face-to-face meetings. Many women spoke at length about

how difficult it was for them and others with disabilities to get to a physical location for a meeting. Responses indicative of this included:

Well, for me, I'm completely excluded from real-life, physical support groups because I'm homebound and bedridden. I've been either homebound or bedridden for basically the whole of my adult life so I didn't really have any experience at all of offline support groups. . . . I couldn't sit up long enough, I couldn't drive, if I did get there somehow then I felt so terrible because I travelled, so I felt so awful that I couldn't enjoy anything about the support group because I was busy trying very hard not to pass out or something like that. [Emma]

Transportation [barriers] are one main issue that our group has. Many can't drive or have a way of getting around on the days we have our meetings or they live outside of the bus transportation limits. [Elizabeth]

I think transportation is a big one, and I think it also depends on where you live and if there is a larger disabled population. . . . If you've got a face-to-face meeting, what about people who can't drive or if you're trying to use Paratransit to get there, you know, versus Uber or Lyft or any of those types of services, you know, it just gets very complex if you are a person with a disability and you want to participate in a support group that meets, you know, face to face or in-person. [Bella]

Scheduling conflicts was another prominent barrier the women faced to attending in-person meetings. For instance, Elisabeth, a member of a face-to-face support group for disabled women, commented:

Another issue is scheduling conflict. Some women have family activities or even sports that they're involved with and they can't attend. . . . Some disadvantages [to in-person] can be location and time conflicts where no one's able to agree when and where to meet.

Elizabeth also went on to note that personality conflicts can be an additional difficulty to in-person support group meeting, saying, "Not everyone will get along with each other either so that can be a disadvantage."

For women who use personal assistants to complete activities of daily living, scheduling their assistants to best accommodate meeting schedules may be difficult:

Having caregivers is a big challenge! So when you have caregivers for a specified time, you want to handle things that maybe link to your physical or personal care instead of devoting that time to go to meetings that are in person. [Natalie]

Several women wondered if lack of resources might also be an issue. For instance, Charlotte saw a lack of human resources to help get younger women to in-person support groups, along with others' doubts about its necessity, as possible reasons for low attendance:

I think one of the major issues is that when you are younger, you are more likely to be living at home or need more support, and it is unlikely that you can rely on others for help to get to a support group. It may not seem necessary for others so they may not be willing to provide assistance.

Mia also saw a lack of human resources as a barrier to attending in-person support groups but for a slightly different reason than Charlotte. It was important to Mia that she attend in-person support groups with a friend but this was not always easy to accomplish.

She surmised other women found themselves in similar situations as well. She commented:

Maybe it's the fact that -- like myself, if I would end up choosing to go like that I would want somebody to go with me and not go by myself. Then I face well, I don't want the person that I go with to feel uncomfortable because they probably don't fit in or don't feel comfortable being there because it's not a group for them.

Bella speculated it was a lack of financial resources that kept younger women from attending in-person support groups:

I think finances could also play a role where if you're holding an in-person meeting at restaurants or whatever, you know, maybe that's something that some people who are on a fixed income can't afford to participate in. If you have to pay for, for example, an Uber or a Lyft to get there and get back home, depending on where the meeting place is. It also depends on how much it would cost you to get to and from the meeting, not to mention if you're going to a restaurant that's going to add more expense. So I think finances can play a role as well.

Another common barrier to attending in-person support groups were the unpleasant emotions that often arose during meetings. Some women experienced social anxiety and

were unable to summon up the courage to attend face-to-face meetings on a regular basis.

For instance, Bella disclosed her experience:

I am very, very shy and very anxious and just nervous. Sometimes I would go to these meetings -- or just like from other groups and I feel comfortable after a while, but then I just never do again. It's not that it's inconvenient for me, it's just that -- I don't know, I just get really nervous and I just can't. . . . So I have this problem where I feel like I don't belong in a lot of places. So I just feel, like, out of place. I think that's what keeps me from going to groups like that.

When Bella was asked to expand on the source of the anxiety and embarrassment that kept her from attending in-person meetings, she responded:

I think it has a lot to do with, kind of, self-sabotage and self-hatred towards each other -- towards myself. I think that's what keeps us from doing this. It's not that I'm -- I don't think that I'm embarrassed of being in a wheelchair, but I think very deep down inside, I might be. These are the type of demons that I still haven't dealt with and it just keeps me from doing things that I probably should be doing.

Similar to Bella, Sophia also reported feeling out of place at in-person meetings and experiencing anxiety when participating in this type of support:

[The] ranting [that occurs in in-person support groups] can help some people, and if you're the type of person that benefits from that then you can sit through and listen to others while waiting for your turn, but for someone like me who hates speaking in public, or even for someone who feels out of place as the only one or one of two or three in the group, it is just uncomfortable and you feel out of place.

Sophia also reported that she finds face-to-face meetings of her impairment-specific support group to be depressing:

The non-guest-speaker meetings are just people complaining for the most part, too depressing for me. . . . Honestly, from the one meeting I went to, I think it's just because the older women complain and complain and complain endlessly and say the same things over and over and it's just depressing. One person dominates the floor for so long without saying anything besides how sorry they are for themselves and how frustrated they are.

One participant reported she felt that the fear of not being believed was a barrier to attendance, saying, "A barrier to attending in-person support group meetings for some

women [is] having people look at them physically and not believe them because not all illnesses you can see” [Layla].

According to the participants the mood of in-person support groups tended to be somber, leaving little time for fun and socialization. For example, Addison commented, “There are few spaces of engagement for simple social time, coffee cafes, meet-ups-just-because.”

Finally, Emma expounded on a particularly intriguing reason why younger women hesitate to attend in-person support. She thought that there was a possible age “lock-in” effect. She explained:

There's also a sort of lock-in effect, I think, with support groups where if everyone in your support group is older and you turn up as a younger person and there's this bunch of older people there, you're less likely to come back because you feel like you don't fit in. Then a similar thing happens next time there's a young person and then it's sort of self-perpetuating.

In conclusion, the women reported many possible barriers to attending in-person support groups. These ranged from transportation, scheduling conflicts, and lack of resources to experiencing unpleasant emotions during meetings. The participants in this research thought that these barriers might be particularly prominent for younger women and hindered their ability and desire to participate in in-person support.

c. **Benefits of online peer support**

The women saw the Internet as a way to break through the physical, geographical, or other confines of in-person support. Responses that reflect the Internet’s capability to overcome the barriers commonly associated with meeting in-person included the following:

I think that "disability community" is often cultivated (?) /found on a kind of meta-map -- that it's not location specific, or tied to certain "regions" or "neighborhoods” .

. . . but we find each other online, or in spaces like gatherings of conceptual interests. For example, I live in \_\_\_\_, but when I think about the folks who I consider my "community", we are scattered throughout the world: Disability artists are in the UK, or Canada, or Chicago (!), the Bay Area in California, Portland, Oregon, and many theorists are in South Africa, Australia, etc. . . . [Addison, punctuation inserted by participant in her email response].

I think one of the really big advantages to online stuff is that even if the group of people who are like you is really, really tiny, you can collect them up. One of my favorite ever support groups was specifically for people who were bedridden with [my specific diagnosis] and there was literally 10 of us, the whole group was 10 of us, but the number of people who actually really ever typed was four. That was the closest thing I ever came to a group of, sort of, people like me. There was four of us and it was a massively validating, supportive thing to have at that time. You would never be able to have a group like that in an in-person support group because collecting up the two Australians, one American and one person from the Netherlands who were similar enough. You couldn't. They're not close enough. [Emma]

I think the online format is helpful because I do not have to worry/struggle to get anywhere transportation-wise or weather-wise, it does not conflict with my work schedule, and I can choose when and if I want to participate. [Charlotte]

It really does give you the flexibility of checking in - in the comfort of your own home without having to think about the things I would have to think about if I was to attend a face-to-face meeting. I would have to think about the weather outside, the traffic, how I should dress and stuff like that. When you do it online the benefit is that you can be in your pajamas and be participating, you could have a very bad day when you start it; you don't have to put on a smile, you don't have to share your story or participate online so I think those are the benefits of online. [Joanna]

In addition to helping them connect seamlessly with other disabled people from around the world, the women also enjoyed the non-time dependent connection that online support groups afforded. For example, Natalie noted, "it does not depend on time. You can log in any time of day, right? [You can login on] impulse!" Layla expanded on the benefits of the instant connection the Internet offers:

What immediately comes to my mind is that I have access to so many people that also have chronic illness and deal with a lot of the same things I do in the palm of my hand literally. . . . Support 24/7, if you don't feel well enough to go out you don't have to miss out.

Another advantage of online support groups was its reliance on technology. Several participants reported that the online format uniquely appeals to the younger generation and provides a fruitful outlet for young people to seek support for a variety of reasons.

Responses that reflect this finding included:

I think the big thing is just that they happen in a place, online, where younger women already are. If you want someone to feel welcome in any general situation, you set up that situation to happen in a place where those people already feel welcome. Places like Tumblr or Facebook or whatever that already have lots of younger women are much more likely to be encouraging for younger women to join support groups. [Emma]

We all have access to a computer, so cyber meetings would be of benefit. . . . The new generations all about technology; laptops and cellphones. Also, it would help younger women if their parents don't want them going out and if their parents aren't supportive of them meeting other women and socializing. [Elizabeth]

Well, they are ONLINE. That, for one, encourages participation from younger women, as younger women tend to be more tech-savvy and open to online groups than older women. [Harper]

Knowing that you have access to them [other online support members] in the palm of your hands [encourages the participation of younger women with disabilities]. [Layla]

I think that online formats are more common, especially for the more younger women. I think it may be more appealing since it does not require physical traveling/dressing, or most probably the assistance of others. [Charlotte]

Sophia articulated the differences she's observed in the communication styles and preferences of older versus younger women within her support forums. She surmised that an online platform is particularly suited for younger people, while an in-person format may be better suited for older women. She explained the differences between age categories:

Most older women and some of us younger women too feel like others don't need to know what's happening to us all the time, whereas many people in my age category live off this social media communication. In another respect, I think it is more unusual for someone my age to go through such tough times medically than for older women, so there are less resources available, and these online groups are therefore the one place they can turn to. It's somewhere to open up about your condition and



how scared or frustrated you are, and the fact that people in these groups know what it's like and don't get annoyed by these posts as they might if it's your personal Facebook page, I think it is just a safe haven that is more in need for the younger people in the group than the older women. . . . People generally feel more comfortable and can relate more to people of similar age which is the groups you find online in general as opposed to in-person groups. The age categories cope in different ways . . . with the older people needing more human contact and the younger ones living on their computers through social media and Netflix, so I think that contributes as well.

In addition to lending itself to the communication styles of a younger age group, online support groups also allow for experimentation with disability identity in a non-threatening and anonymous fashion. When speaking about the benefits of an online platform, Emma explained:

One thing about online is that you can be more subtle about it. If you're feeling very unsure about whether you want to be seen as a person with a disability or about your status as a person with a disability, you can join an online support group anonymously or you can make a new profile for the online support group so that your other friends don't know you're doing it. You can experiment with that identity without compromising the rest of your life and if that's a big deal for you then that could be important.

Likewise, Sophia also commented on the benefits of taking part in a closed online disabled women's support forum saying, "It [the online support group] is also not super obvious that we are doing this because it is online and hidden from other people's judgments, which is appealing."

For at least one participant the online environment also relieved the anxiety that is associated with physically interacting with people who have different disabilities. As Joanna explained, it can sometimes be intimidating being around others who have disabilities that are unfamiliar. She had anxiety that she would say or do the wrong thing when meeting in-person. However, the online environment tended to mitigate this learning curve and lessen anxiety, thus making the support more immediate:

It [in-person groups are] something visible that you can see, people may not feel comfortable with people with different disabilities in the same room at the same time. . . . So on online forums all those visual things kind of disappear. For instance, somebody who uses a personal care attendant we never see that online. They may mention that they have one but we never see that. When you do a face-to-face meeting and in my case for example when you grow up not seeing a lot of people with disabilities it might be shocking at first to be in the room with a lot of people with disabilities. Because I don't know [any better] I might make the mistake of talking to the personal care attendant instead of talking directly to the person with a disability. So, there's a lot of learning curve when you do a face-to-face meeting before you even get to the support system and supporting each other.

Lastly, circumventing cultural and family barriers to attending in-person support groups was mentioned as a possible benefit to online support. In addition to the benefits she noted above, Joanna commented:

So an online Facebook group may be more accessible for her [someone who faces cultural stigma], because she doesn't have to leave her home . . . so she doesn't have to deal with her parents, her parents may not be willing to let her go out and be with other people whether it be other people with disabilities or non-disabled people.

In sum, there are a multitude of benefits to online support groups, especially for younger women with disabilities. This format uses technology they are familiar with and allows them to instantly connect with other disabled people from around the world. The online platform eliminated many of the barriers commonly associated with attending in-person meetings, such as transportation issues, increased need for personal assistance, scheduling conflicts, and problems that arise from inclement weather.

d. **Differences in online platforms and groups: The pros and cons**

The participants reported using several different online platforms to obtain support. For instance, Emma, who was 42 years old at the time of the interview, spoke eloquently about the evolution of her use of online support:

I've been in tons of different online formats. The first groups that I started were e-mail mailing lists because that was the only possibility at that time; there wasn't Facebook, there wasn't online message boards or chat rooms didn't exist at that time,

because I'm super old. The mailing list was -- I ran the actual mailing list. It wasn't something like Yahoo where some other person ran the software. I ran the actual mailing list software on my actual computer to run the mailing list. This is like the dark ages of computers. That was pretty cool. At that time because e-mail was the primary way of communicating on line, like, everyone checked their e-mail every day, so it worked pretty well. Now if you send people, in a message group, messages they probably just won't even see most of them. It wasn't like that before.

All of the participants were frequent users of the Facebook platform and many of them saw this as the gold standard to which they compared other platforms. For instance, Mia spoke about how she started searching for support through Tumblr, a micro-blogging site, and found her way to Facebook:

I was doing that [searching for support] through Tumblr at first. I was trying to find a community. I think that's where I found out about the Facebook group, through Tumblr, which helped me even more, because I think that I go on Facebook way more than I do on Tumblr.

Mia also found Facebook to be much easier to navigate and use than traditional stand-alone websites. She said,

I find it easier to do it [interact with the group] like, through Facebook. I feel like this is so well typed that I'm usually on most of the time. Just clicking or typing the disabled women support community thing on Facebook and just going there I feel like that's easier for me than going to their website and checking it out and going to the forum. So, I feel like a group on Facebook, it really works for me because also it pops up on my dash. So, if I miss something I can see from there or I can go on the Facebook page and check everything out. It's just way easier for me. . . . People are more than free to post their articles or post about questions or anything.

Similarly, Bella saw advantages to the Facebook platform over more conventional online communication platforms, but stopped short of saying one method was better than the other:

If you're comparing like Facebook to email I think they are similar like Facebook is to an email. I think they're similar. There seem to be more people who participate on Facebook groups rather than email and I know there are people who find Facebook to be more convenient than email is. I think it just depends on the mission of the group and the purpose of the group and also which format they've chosen to

communicate with. But I think they both are relevant. I don't really know that I would say one is better than the other. They both have purposes that they serve.

Many women found it helpful they did not have to be online at a certain time to engage with the support communities. For instance, Joanna spoke about how the asynchronous nature of Facebook support is easier for her than the synchronous nature of some online chat platforms:

I like the platform as it is on Facebook because I'm also extremely busy as well so I can come back to it when I get a chance to read it or when I have a chance to respond back. I know that I'm not too late to respond to the posts on Facebook [laughter]. When you go to Second Life you have to make that time commitment to spend one or two hours on a Sunday afternoon, and if it doesn't match my schedule I just cannot be part of it and it's frustrating. So I tend to gravitate towards the Facebook type of format because I can come back to it, I can save it for later and make a note that I want to respond to it . . . I know that my disabled women's online support group for instance has a lot of their meetings in another platform. They usually meet on a Sunday and for some reason I could just never make it; I always have stuff to do on Sundays.

Despite her misgivings about taking part in synchronous chat she did note the possible benefits of this for some women:

Well, I guess there's a purpose for that as well; there's a purpose for going outside the Facebook group to a secondary platform is that you get to know some of the regular members who really want to be there, who are going to keep coming back in meeting up on a Sunday. So you're going to have a deeper relationship if the same group members meet up every Sunday. So there's also a benefit to doing it that way--the same benefits you would get from meeting people face-to-face in a smaller group outside Facebook. But, for me I'm just a practical person. I don't want to go to the trouble of creating a new login or having an avatar or something like that, that's not productive for me to do!

In addition to the communication and technical differences between platforms one participant also noted an age difference between different groups online. For her it was important to be able to interact with people her own age.

I feel like a lot of groups on Facebook also, like the groups for my specific impairment, really focus more on kids and I'm 32, you know? I just don't feel like I

fit in because I feel like these things are more catered to younger people. I feel like with the disabled women's group there's different ages there. [Mia]

As illustrated above, the women had experience with several different web platforms, but by and large preferred Facebook for their support needs. This platform offered simplicity and allowed them to interact with others on their own time. Facebook opened a world of valuable support that had not previously been available to them.

e. **Disadvantages of online support**

Despite the many advantages of online support, participants also spoke of a few disadvantages to this platform. Many participants reported online groups were often difficult to search and locate information in a timely fashion. Finding the information they needed became cumbersome and frustrating at times. Responses that reflect this included:

I like online format for the group but there is a very minor setback. It's very hard to search for something that was in the group earlier. I use another online forum [in addition to the group on Facebook] that's really easy to search. But in every other area [this particular] online forum sucks. . . . The community group is a great group. Yes, the format could be a bit better but if the price would be losing the community I am fine! [Victoria]

[A disadvantage of online support groups is] There are too many things and there are too many people posting comments. [Natalie]

The one thing that really annoys me about Facebook groups is that it's not very good at preserving knowledge. When you had, in the past, stuff that kept better track of old friends or old posts or what have you. Now they scroll down and they get lost and you end up with someone going, "hey, I think Emma posted some recipe for a drink three years ago, but I can't find it." There should be a better preserving of old stuff. Old knowledge can be so very useful. I think for a support group that is a disadvantage, but mostly it's just awesome! [Emma]

I don't think I'd change anything about the format, except maybe making it easier to search for past posts. I've gone scrolling through a few times looking for one particular post that I remember reading and want to reference and check what people said, but only once was I successful in finding what I was looking for and it took me

forever. There are ways to search by people's names and what posts they made, but this is not information I'd ever remember. [Sophia]

The geographical distance between participants and online groups made the online platform cumbersome and impersonal at times. It was difficult for some online support users who desired to meet up in person to do so. Also, a language barrier was reported as a possible downside to communicating with people from around the world on the web.

Victoria spoke of these frustrations, saying:

The admin team [in my online group], I feel like we are friends but we cannot meet in person because I'm in Eastern Europe and they are in America. . . . It's frustrating that I have somewhat of a language barrier that I have to process everything into my language.

A few participants saw the lack of physical presence and material spaces to be a drawback of cyber support. Addison mourned the loss of a physical space to converse and affiliate with fellow members of the disability community. She saw this as very important to building solidarity and cohesiveness as well as mobilizing politically. It was essential to her that disabled people have physical places, which they could claim as their own. When asked to describe disadvantages of online support she responded:

The disability community is a non-geographically placed community. Oops! I actually meant "non-geographically-BASED community", but perhaps that was a Freudian slip on my part! . . . I think that we're in a time of a kind of 'identity crisis' as a community as we grapple with the pressures of the individualizing tendencies of neoliberal capitalism/neoliberal "governmentality" that actually politically keeps crip community apart, isolated perhaps, "de-unionized" so to speak -- all in the interests/facade of "integration" with the community at large. Much like in the LGBT community; now we can marry, but something of a political history or cohesive identity politic is lost amongst the community. . . . We're losing spaces of solidarity-building on the TERRAIN of where we're living, the grounds, the buildings, the centers with walls and doors. The material spaces to engage with each other; bodies in rooms, feeling and breathing together. . . . Online groups can be deceiving though -- I think it can create the impression that a community is emotionally close-knit and cohesive when in actuality, it is not.

Lastly, one participant noted that the absence of tone and intonation within an online environment was a major drawback to this type of support. It made it difficult for her to decipher the intentions of comments directed towards her. When discussing the disadvantages of online support groups she remarked:

I think that one of the biggest disadvantages is that you cannot hear how people mean what they're saying. There's no tone. There's no voice inflection. So you can't tell sometimes if you're being judged or attacked or you can't tell the tone and people can come across in a different way than they intended to. . . . There is the absence of intonation. There is the absence of voice inflection. It's all written communication so sometimes responses can come off as crass or judgmental or defensive when if you pointed it out to someone they didn't mean it that way.

In sum, the participants reported that online platforms have greatly evolved over past decades and as a result have become user-friendlier. However, some disadvantages of using online support still persist. These include difficulty searching and finding posted information, a lack of material spaces to personally connect with other members, geographical barriers prohibiting face-to-face meet-ups with group members and the absence of tone and intonation within posted communication. Although the disadvantages were frustrating and cumbersome at times, they were not significant enough to cause any of the participants to abandon their use of online support.

f. **Suggestions for improvement of the online support experience**

The group members offered some pertinent suggestions to improve the online support experience. Some women were quick to point out a search function would be extremely helpful within their online support communities. For example, Joanna saw a user-friendly search function, along with organization of information, as essential to online support:

The one thing I would change would be to have a search [method]. In Facebook for example the most important change is that there's resources available in one place so

that let's say you're a newcomer in the group and you have questions about how to apply for disability for example. You can look on the group and see what other people said on the topic, learn from other people's mistakes or challenges they have faced. And be able to contact that person and say, "hey do you have any advice?" . . . I know Facebook has that search button but it's important that the moderator make sure that the information is organized within the group as well for people to find the information they need. There's a lot of wisdom, anything shared will be beneficial to everyone especially newcomers in the group that might have missed all the other stories that were shared before [they joined the group].

Although keeping communication manageable and searchable was important to many of the participants, having daily discussions with fellow online forum members was also important to at least one participant. When asked what elements she thought would improve the online support experience in general, Layla stated, "I would post daily like we do in the group that a friend and I created; that way everyone knows that there is always someone there to talk to."

A few of the participants also noted that it was imperative that online communication be accessible to people with sensory impairments. For instance, when asked what she would improve about the online support experience, Bella, who is visually impaired, remarked:

I don't really know if there's anything I would change. I know I and a lot of other blind people sometimes get upset when Facebook decides to break the accessibility of their app or break the accessibility of their website where something that worked previously for us is no longer working. That's frustrating if you're using a screen reader. I would encourage people to post picture descriptions if they post a picture. Include an image description so that those of us who are blind know what's going on in your picture. If you post a picture of text, like here's a quote, but it's in a picture, post what that text is so that we know because screen readers can't read text within an image. . . . And I would also encourage, you know, if you post a video that has audio and you know that there are people who are hearing impaired, you know, create some sort of a description for them or if it's not captioned already, you know, try to find a way to make that accessible as well.

Relatedly, Joanna noted that the online support group for disabled women that she is part of makes sure to be inclusive and encourages their members to keep in mind



accessibility when posting on the forum. Even though she did not have a sensory disability and did not need accessibility features to utilize the forum, she saw inclusivity as vital to a meaningful support experience for all. When describing things she likes about the online support group, she commented:

They're inclusive, there are a lot of different disabilities represented on the forum and they are conscious of this. This is important to me! Just because it's an online forum you just assume everyone can read it. You just assume everyone can visually see it but this is not the case so we need to be conscious of that. The moderators do a great job making sure everyone thinks about that. We don't only need to be inclusive within the able-bodied community, but we also need to be inclusive within the disability community as well.

Keeping topics relevant and of interest to younger women was another suggestion for maintaining the most productive and vibrant online support communities for this population. For example, when asked for suggestions on how to improve online support forums for disabled women Victoria asserted:

So, young women now have particular interests. So maybe find topics of interest to younger women. Or maybe, I don't know, find some common connection for people with disabilities. I constantly think about how to get younger people interested in my music. So, my advice is to find something that catches their interest.

Bella echoed the need to keep topics relevant to participants in order to prompt their continued participation. Describing what types of information she finds most helpful as well as what motivates her to participate in online support forums, she said:

I mean if you're participating like there are groups for people who use guide dogs and so obviously those discussions are going to be different from the practical side of living with a disability. So I think it really depends on kind of the groups, the purpose of the groups that you're in as to which discussions you find helpful. I mean, for example, in a guide dog group if somebody's talking about grooming a Lab and asking questions about grooming a Lab, I'm not going to find that relevant because my dog is [not a Lab] so I may not comment on that, but I may also comment at the same time if I feel that I have something that's relevant to contribute.

When asked specifically what types of strategies would help encourage the participation of younger women with disabilities in support groups, Natalie noted the importance of making sure there were lots of positive role models available within the support group platform, saying, “I guess, you know, just seeing people succeeding; like being happy. That could make a difference. So of course, videos and pictures would need to help with that.”

In closing, participants suggested online support platforms be searchable, manageable, and have the ability to be archived. The availability of image and video descriptions of posted content was noted as essential for an inclusive and welcoming support environment. In order to initiate and maintain the interest of young women in online support forums, it was suggested content be relevant to their lives and include stories and imagery of successful disabled role models.

#### **B. Themes From In-Person Group Coordinator Interviews**

Three major themes emerged from data analysis of the group coordinator interviews:

1) Getting In-Person Groups Started for Women with Disabilities; 2) The Logistics of Running and Maintaining an In-Person Support Group; and 3) Self-Concept Development and Transition to Adulthood: Observations and Conjectures from Group Coordinators.

These themes and their related sub themes are presented in Table II.

**TABLE II**  
**THEMES FROM GROUP COORDINATOR INTERVIEWS**

- 
1. **Getting In-Person Support Groups Started for Women with Disabilities**
    - a. Barriers to getting the group started and sustaining participation
      - Attendance problems are self-perpetuating
      - Productivity and apprehension among group members
      - Transportation barriers
      - Parents
      - Conflicts between group members
      - Weather
      - Health problems
      - Schedule conflicts
      - Lack of trust in the sanctity of the group
      - Lack of funding
      - Members' hesitation to spend the group's budget
      - Members ready to move on from the group/change in facilitator
    - b. Factors that influence the participation of younger women in in-person support groups
      - Not enough younger women in the group to relate to
      - Younger women might want to be more active in the community
      - Time of the meetings not conducive to younger women's schedules, or they are unaware that the group exists
      - Younger women may not perceive the group as relevant to their lives
      - Younger women do not perceive themselves as independent enough to join the group
      - Young women not taught to be proactive/low expectations
    - c. Recruitment strategies and retention strategies: Successes and failures
      - Recruited from the school systems (made personal contact)
      - Giving the women ownership over the group
      - Networking, outreach and referrals
      - Being flexible with times and dates
      - Narrowing the focus of the group
      - Raising the age limit of the group
      - Creating workshops to help others start a women's group in their area
-

**TABLE II (continued)**  
**THEMES FROM GROUP COORDINATOR INTERVIEWS**

- 
- 2. The Logistics of Running and Maintaining an In-Person Support Group**
- a. Strategies for overcoming challenges and maintaining a successful group
    - Set manageable goals
    - Allowing honorary members
    - Creating a strong bond between group members
    - Assist with transportation
    - Provide funding for activities through fundraisers
    - Reminder calls
    - Having your own space
    - Use of the Internet
    - Be consistent and organized
    - Provide support to new members
    - Implementing conflict resolution strategies
    - Provide structure
    - Have adequate staff to support members
  - b. Outlining a path for members' self-development
    - Empower members and help them lead self-directed lives
    - Social support and education
    - Teach about disability rights and sexuality
    - Create mentoring relationships
  - c. Avenues for accomplishing objectives: Moving beyond support!
    - Community engagement
    - Support each other through formal and informal mentoring relationships
    - Workshops, presentations and guest speakers
    - Utilizing teamwork to accomplish goals
    - Provides a safe haven to process and discuss emotional issues
    - Sex education and discovering sexuality
    - Let the group members guide the way
    - Provide life skills resources and bridge the knowledge gap
  - d. Facilitating the group: The journey to being an effective group coordinator
    - Finding common ground
    - Guiding the way when necessary
    - Group coordinating and the kaleidoscope of emotion
    - Sharing life experiences with group members
    - Providing material in accessible formats
    - Moderating conversation
    - Being confident to make changes
-

**TABLE II (continued)**  
**THEMES FROM GROUP COORDINATOR INTERVIEWS**

- 
3. **Self-Concept Development and Transition to Adulthood: Observations and Conjectures from Group Coordinators**
- a. The creation of an atmosphere conducive to self-concept development
    - Openness
    - Trust
  - b. Finding their place in the world together
    - Sense of camaraderie
    - Sisterhood
    - Sense of belonging
  - c. Gaining a new vision of themselves
    - Recognition of the sources of disability oppression
    - From shame to pride
    - Increased confidence and self-esteem
  - d. Broadening Horizons
    - Speaking up in group settings
    - Participating actively, engagement in the community
    - Living independently
    - Gaining employment
-

1. **Getting in-person groups started for women with disabilities**

Getting in-person groups started from scratch was a very arduous process fraught with barriers. There were many factors that influenced participation in in-person groups and their overall success. Different recruitment strategies were utilized to try to build and retain a core membership with varying levels of success. Three major categories emerged under this theme: 1) Barriers to getting the group started and sustaining participation; 2) Factors that influence the participation of younger women in in-person support groups; and 3) Recruitment strategies: Success and failures.

a. **Barriers to getting the group started and sustaining participants**

All of the group coordinators interviewed spoke of barriers they faced when starting the group, regardless of whether their group ultimately was successful or not. Difficulty building and sustaining a core membership was one of the major barriers faced by group coordinators. Olivia had been trying to start a disabled women's support group at the Independent Living Center she worked at for six months prior to the interview. Sustaining attendance was a constant challenge. She explained her struggle with this:

I think the thing that most surprised me was I was really thinking that I would get a lot more group attendance than what I had gotten. We started off slow. I think the first group that we had in January of 2015 was probably about four people. And I thought okay, it's four people, it's like January. This will grow. And I really struggled with group attendance. . . . I created the group and created it in a format to where the women would be the ones deciding what they wanted from it. Which it's been so surprising that after all that, I haven't had much if any at all attendance.

She went on to note that attendance issues also persisted in the organization's other support groups as well, saying, "And we've faced a few challenges with some of our other groups too, so it's in the same way as my women's group." Like Olivia, Anna also

experienced significant attendance problems in her newly formed group for disabled women, despite initially having good attendance:

There was initially a lot of interest in the group, and we have an email list of over 30 women who expressed interest. Attendance started at from 12 to 15 and gradually dropped off to 2 or 3 at each group meeting.

Anna's group was eventually discontinued due to lack of attendance. Many group coordinators had a particularly difficult time recruiting younger disabled women. Faye, who is a co-group coordinator with Ella, noted:

One of the challenges originally, to be honest with you, is that I intended on beginning a support group for women ages 18 to 25. And when I sent out the invitations for women to come out in that age bracket I did not get any response at all.

Once the target age range of the group was raised, a solid core membership has emerged with limited attrition. She remarked, "I lost about three in the process of a five year run with them. We just celebrated our fifth year anniversary on Saturday together."

Unfortunately, Nora was not so lucky with her group. The attendance problems within her group were self-perpetuating. She explained:

I can't seem to get people to continue participation. Often, a new member has eagerly tried the group only to find they are the only one in attendance. This does not provide encouragement for the person to come back. The challenge is getting women to participate for more than a few group sessions.

One of the main reasons for attendance problems was lack of transportation. Similar to the group members interviewed for this research, the group coordinators predominantly reported that transportation to and from meetings was a major barrier to attendance and maintaining a thriving support group. Responses indicative of this included the following:

I've been trying to figure that out because you know, as I mentioned, I get calls from women saying that they're interested and they're going to be there. But then when it comes time for the group they're not. I thought things like transportation, particularly in the wintertime. You know, we have a lot of consumers that maybe

unless they live close by they don't always have transportation to get there. There are transportation services in the area. But, sometimes it's not the most reliable or consumers may say that they don't have the money to travel by transportation. That's one issue. [Olivia]

There are no afterschool programs at any of the schools for girls with disabilities, nothing, because of the buses. They were held hostage by lack of transportation, so they had to go home right after school and get the only accessible bus. We didn't have public transportation then. . . . It was hard getting people to let the girls take public transit. [Grace, past co-group coordinator with Lucy]

Transportation was a barrier because sometimes girls couldn't make it there or couldn't make it there on time or had to leave early. Those are the barriers that come to mind. [Lucy, past co-group coordinator with Grace]

Transportation was not just an issue with getting to formal group meetings; it was also a problem with regard to the group members being able to socialize outside of the group. Grace was a group coordinator of a very successful support group for young disabled women for 11.5 years prior to her retirement. She noted many apartments were not accessible and the women required help from family members to get in and out of the house. This lack of physical access was compounded by a lack of transportation to anywhere other than school, making it almost impossible for them to invite fellow physically disabled friends over. She reminisced about the barriers the women faced, especially in the later 90s/early 2000s when the group was just getting started:

And it was hard for people to get together outside of the meeting, because a lot of girls lived in apartments that were either inaccessible, so once they went home on Friday afternoon after school, it's not like they left the apartment of their family until Monday morning when the bus came, the accessible school bus. So, it wasn't like people socialized outside a lot, until they started taking Para-Transit, and then they started to quite a bit. But, still a bunch of them had to get someone to take them down the stairs. You know how it is asking for help from a family member.

Despite a majority of group coordinators reporting lack of transportation as a barrier to starting and maintaining a successful group, one person noted that this was not the case



for the group she led. Her group membership was able to successfully use the city paratransit system and get to meetings on a regular basis. She commented:

Actually the women, you know, they, in terms of transportation, we don't provide any transportation for them to get to the group. However, a lot of the women use paratransit. . . . And they tend to use this transportation to get there on their own. If not, some of them are, you know, accustomed to taking public transit to be able to get to the group. So, I fortunately have not had an issue where someone could not get there because we don't provide transportation. [Faye, co-coordinator with Ella]

Even if the women could get rides to their various groups, weather could often be a barrier to traveling to the meeting location. Responses that indicated this included the following:

Weather I know can often be a factor here [in the Midwest]. [Olivia]

I mean winter months, you see lower interest in group members that you know stop coming for the winter months. And then spring/summertime there are more members. [Claire, co-coordinator with a woman who did not participate in the research]

Since the winter months seemed to be more difficult for people to get out, we had fewer meetings during those months, and tried offering the group again over the spring and summer, but family and other activities then prevented participants from attending. [Anna]

Sometimes parents and families constituted an additional barrier to building and sustaining a group membership. For example, when asked to describe possible reasons why some women choose to participate in the group while others choose not to continue their participation, Scarlet, who had been facilitating her disabled women's group for the past six years, stated:

From what I've seen with some who are very sheltered, who have family members who -- especially with the younger ones, I mean, we're not like wild or inappropriate in any way in our discussion, but like I said, we're all adults. . . . So it's like a lot of sheltered, a lot of family members who treat them like children and shelter them from the hard conversations when they need to be had.

Similarly, Grace reported the parents of the women in the group she co-facilitated were uncertain about their daughters' ability to navigate their community independently.

This hindered group attendance at first:

We had very protective parents, families, and stuff and they really were unsure as to whether their daughters with disabilities could handle themselves out in the world. It was hard getting people to let the girls take public transit.

Lucy, Grace's co-facilitator, reported some parents were also concerned about the appropriateness of the topics discussed in the group. When discussing the barriers to getting the group started, she commented:

Parents were concerned that we were talking with their daughters about something that was irrelevant and might be over their head, or might be raising false hopes, or might be inappropriate in talking with their daughters about sexuality.

Lucy noted, though, that this overprotectiveness did not apply to all the parents.

Some parents were very enthusiastic about the sexuality information shared in the group and wanted to make sure that their daughters had opportunities to experience and express their sexuality. She explained:

Not all the parents [were overprotective,] like this one girl. Her mother was so excited about what we were talking to her daughter about that when it got to the point when we had some sessions on masturbation -- we were communicating with the mother and the mother knew what we were talking about, she said, "you know, one of the accommodations that we're going to make for her is we're going to stop putting her to bed with her diaper on because how can she even reach her vagina to even try getting an idea of what masturbation is, you know, if she's got a diaper on every night."

Health problems were another factor that was largely reported to affect the women's ability to attend in-person meetings. For instance, Olivia, who had struggled with attendance issues since the group's inception six months prior to her interview, said:

Sometimes customers' health problems [will prohibit attendance]. . . . [They will say] I am not feeling well today or can't make it today because I'm not feeling well

but next time you have the group I'll be there. So I think just sometimes the overall health can play a factor.

Claire echoed this, saying, "Some people get setbacks for -- just because of their physical condition or you know they get --sick." Similarly, Ella noted that within her group some women might need to recover from surgery, saying, "There may be points where some had surgeries [which makes it difficult for them to attend the group]."

Scheduling conflicts interfered with attendance as well. Ella encountered a variety of scheduling issues within her group that prohibited the women from attending on a regular basis. She explained the various reasons why timing conflicts may arise:

The time that they would meet can be a problem [in regards to being able to attend]. . . . Some of the other aspects could be a family obligation, [where] the women were asked to kind of babysit or take care of a younger relative . . . and that person in their life is not necessarily considering that this was an important part of their life participating in the group. Some have also had a job change where it wasn't easy for them to be able to participate fully with the group.

Anna experienced scheduling conflicts as a barrier to attendance amongst her membership as well. She commented, "When meetings were announced, often as the facilitator I would get emails or calls expressing an interest in coming, but conflicts with school, doctor appointments, and other activities, family activities etc. [prevented them from coming]."

Even when all the barriers mentioned above were overcome and regular attendance was established, many group coordinators reported passivity among their membership. It appeared that many of their members were not at a point in their lives where they were willing and able to take charge and make their own choices about the group. This made it difficult for the group to be productive and group member directed. Savanna, who had

acted as group coordinator for a little over a year prior to her interview, expressed her frustration in this regard:

Just being new was the hardest thing for me and feeling okay with the fact that they really didn't care what I changed, so if that makes sense. Like I want to make sure I'm doing it right, you know, and so when you tell me, "oh whatever," then that really puts me into anxiety overdrive because "what? Tell me what to do!"

Scarlet experienced a similar lack of initiative among the women in her group. Her group focused on many disability rights issues and she tried very hard to get her participants to advocate for what they believed in. But, she was not always successful in doing so, especially when it came to younger participants. When asked to describe the challenges she faced recruiting and retaining women ages 18 to 35, she recounted her frustrations:

I think, not only are they not connected to the issues, which they are, they just don't know it. . . . Sometimes like when I say, "it's not my group, it's our group," you know, and asking them to actually put in some [feedback] -- they'll complain about certain stuff. But, as far as the advocacy. . . . If I say, "okay, let's all contact our legislatures, let's, you know, plan a trip, go to [our state capital] to talk to -- to meet with"-- they don't want to do that, they get scared. . . . We don't get involved in say politics as far as party affiliation, we fight for -- we want to get involved with our legislatures as far as providing better access to women's health and transportation and things like that, but they want the leader to do all the work. So a lot of times, when I delegate and they say, "okay", they raise their hand to do something and I put them to the task, then they kind of step back a little bit. So they want give me, give me, give me, but don't want to do.

Ella expressed a strong desire for members to take steps towards meeting their personal goals independently. However, many of the members were not at a point in their development where they felt able to do so and sought Ella's assistance. Illustrating the tension between her desire for members to take their own initiative and the members desire for her assistance, Ella commented:

A lot of them come to me and they go "Oh well I'm looking for a job." And it's like "Okay well, what skills do you have?" and they'll be like "Well I don't know what like what do you mean by skills. I can come every day. I could help you wherever you need help." . . . I go "Do you have a resume?" and it's like they're looking at

me like “Well no.” I’m like “Okay have you gone to these different programs where they can help you learn how to put together a resume?” They look at me like “Well you can do that.” It’s like “Well I don’t really have the time to dedicate for that. You need to really go to a job training.” Then they say, “Okay well can you take me to the job training?” I was like “I don’t have time to do that.” You know, just really kind of navigate individually. Finding women who were more at that point to be able to say “Okay, I want to be empowered to live my life” seems to be a challenge!

Although not frequently mentioned, sometimes conflicts between group members also got in the way of retaining participants and accomplishing goals. For instance, Savanna spoke at length about a few conflicts that arose in the group because of the topics of discussion. Explaining one such instance she said, “It [a group member’s presentation on medical marijuana] wasn’t for everyone! So, we had one of our ladies who has stopped coming since that and I got a voicemail about that.”

She expressed her frustration at the arguing among her group members and noted that the women struggled to maintain boundaries with one another. This perpetuated conflicts and deterred some women from continuing in the group:

The most frustrating is when they fight amongst themselves because a lot of times they have to learn boundaries because it is such a close-knit group, leaving group at group. [They should be able to think,] “I don’t know you. We just come to support group together. It probably won’t be a good idea for us to live together for you to come stay in the house because you really don’t know me like that”, and so they have to learn that and so learning that the hard way brings me in because, “Well, I’m not coming to group if she’s coming.” It’s like, oh my gosh, I really would like for everybody to stay active!

Ella did not experience conflicts as complex as Savanna did, but did note that personality conflicts within her group sometimes deterred attendance. When describing the challenges she faced to starting and maintaining the group, she stated, “There were points it was faster and tighter than others. So you know, just I think, just by personality, you know not everybody gets along all the time and that kind of thing.”

Although Scarlet did not report experiencing conflict amongst her group members, she did report that the personal nature of group topics and lack of initial trust in the group deterred some women from attending. She recounted her observations during the inception of the group:

At first it was kind of like pulling teeth to get people to come, to get the ladies to come because I think they were, you know, I can understand, you know, trust issues and not realizing that it's a safe environment to express how they feel or to ask, you know, because I tell them, I said, "it's open to ask and talk about anything because we're all adults. If you want to talk about sex, if you want to talk about relationships," and it's like I could tell a lot of them were like, "ooh, gosh, that's too personal. . . . I think that initial trust factor [hindered attendance] because some of the subjects are really hard to talk about, you know. So I would say getting people there initially was pretty difficult.

Since Scarlet's group had several members who were in their early 20s their involvement in the group may have marked the first time they had been exposed to and given permission to discuss topics such as relationships and sex. This may have contributed to the apprehension she observed.

Scarlet also experienced funding issues, which made it difficult to sustain a thriving group that captivated the women's interest. She explained,

I would say [a challenge to maintaining the group is]-- well, to try to keep it interesting and going to different places, a lot of times some of the ladies can't afford to do a lot of stuff, so just trying to secure funding and becoming a stand-alone non-profit so that we can help fund, you know, say somebody's coffee or lunch or movie ticket or something like that. It's really hard because we want them to, you know, get out of the house sometimes and so it's hard. . . .

Similarly, Lucy recognized the importance of community outings for group members, but lack of funding in the budget for field trips prohibited them from taking place regularly:

What I think would have been a really great thing would have been more resources for more field trips. You know we took a few, but not a lot. I think field trips were exciting and fun and really kind of putting into action what we were talking about,

about helping those girls not be so isolated within their families or their schools or their neighborhoods.

Lack of funding ultimately led to the demise of one group. When Sarah, a past group coordinator was asked what the reasons were for discontinuing her group, she responded, “My particular role/job changed. I believe that there was no specific funding for the group.” Another group coordinator noted that even when funds were available her group members were hesitant to spend the money:

The agency provides the group with a \$500 budget per fiscal -- well, sometimes it's \$300, but this particular year it's \$500. At that point, they're able to get, you know, speakers from the community. I won't just have a speaker speak. I wouldn't pay for anything without their approval. So their lack of like, “Hey, we're not going to spend that much money!” They're frugal. They'll eat the money. As far as paying a professional to come in to discuss or to converse or train, [they say] “No”! So that limits you as well, but it's not really a frustration because I have to step back and remember that it's not my group.

Finally, a few coordinators reported that a change in group leaders made it difficult to retain and maintain a group membership. For instance, Nora who had been acting as group coordinator for a year prior to the interview, described how many of the women were ready to move on from the group and the group membership dwindled down to almost nothing once the former facilitator left:

Women's Support group was a support group at my Organization that had been meeting for years when I came on and stepped into the role as facilitator. The group was in a transitional period and included women who were ready to move on from the group and using the group simply as a social outlet. When the former facilitator left, almost the entire group disbanded. One member stayed, but only for 2 or 3 more group sessions. The group has been in a forming stage since. 0-2 participants will attend at one time, with the largest attendance briefly at 3-4 just before the holidays. All of those women stopped coming after the stressor of the holidays were over. No core membership has emerged.

Claire, who acted as a co-facilitator with a woman who did not take part in this research, reported similar observations about how a change in leadership discourages attendance and participation:

I have noticed, two of us running the program, unfortunately for the last three years each year one of the coordinators changes or may just you know leave. And that transition messes the group up. I try to just to keep up with group every -- you know every week because I don't like any, you know, interruption. I see how you know it can have a negative effect on group, but I have noticed changes like that it does have an effect on the group, . . . like the consistency is very hard to keep it up.

In sum, the group coordinators experienced a variety of obstacles that made it difficult to sustain and maintain a thriving group. According to the group coordinators, the women in their groups faced a multitude of barriers getting to the group. These ranged from transportation difficulties to overprotective parents who thwarted the women's participation. When the women were able to get to the group, it was often difficult to motivate them to make their own decisions and take initiative within the group. Dissension among the group members also was a problem for some group coordinators. These challenges led to frustration and disappointment for many of the coordinators.

b. **Factors that influence the participation of younger women in in-person support groups**

Throughout their interviews the group coordinators highlighted some specific reasons why younger women ages 18-35 rarely attend in-person support group meetings. One reason may be that there are not enough people in attendance to maintain the interest of young women. Although she has not seen a difference in age with regard to who chooses to attend, Olivia noted this as a source of frustration among younger group members:



Some of the [younger] consumers that would come to the group just like coming to have a chance to get out of the house and just, you know, be a part of an activity. They would say that they enjoy coming but there wasn't enough people so they didn't see the need to continue coming back. Or they might come and be the only person so they didn't see the need to continue coming back. But, as far as age ranges and attendance, I don't really see that as being a factor.

On the other hand, Savanna cited a noticeable gap in the attendance of younger women within her group. She believed this was due to lack of relatability and differences in interest between the older and younger generations:

When we've had a younger [member] they don't come back. Like they'll come and see what it's about and then they won't come back. Right now, within the last month or so we've had a 24-year-old and she's come a couple of times, but we haven't seen her in the last week. . . . The relatability is there as far as the disability piece, but the relatability as far as being a young woman with a disability is not there because in my situation I am younger than them, but I'm older than a 24-year-old. I can relate to her because that's where I was when I was her age, but then I can't because I'm not her age now. . . . I mean I can see why that could be a hindrance, just the age factor. . . . Some of them [current group members] are just getting touch-screen phones and then, you know, and then you have the millennials who, you know, were born watching TV and born on the phone and live on computers and phones and gadgets. So the interest level is probably not the same.

Lucy also shared thoughts in line with the observations presented above. Unlike a majority of face-to-face groups represented in this research, she along with her co-group coordinator, Grace, were able to establish a thriving support group of younger women. However, when asked to describe possible reasons for the finding that women ages 18-35 do not regularly attend in-person support group meetings, she conjectured that the group coordinators in my research might not be presenting information relevant and exciting to a younger audience. She commented:

When you talk about support groups, what kinds of topics is it that the facilitators are inviting them to participate in? I mean because when I think of inviting young women to come to a support group to talk about sexuality, to me that's such an exciting topic for an adolescent girl. . . . For me, someone saying come to a support group about disabilities, maybe that's not quite so exciting. So I don't know what the groups that you've interviewed with are talking or what their subject matter is

about, but I know that sexuality for young women, relationships and sexuality and dating, that's exciting! So I think that's one thing.

Younger women may not only have different interests, but also be at a different point in their life than older women. Young women may still be figuring out what they want to do in life and are not ready to embrace the support and empowerment within the group. Fay explained her observations in this regard:

Well, first let me say that I find from the younger women that I attempted to reach out to, I find that their mindset is a little different. It's still in that 'I'm in high school' stage and I'm not sure of what I want to do with myself after high school. The older women seem to already kind of know what they want to do with their lives if they haven't gotten started and need a little bit of help in, you know, kind of doing whatever it is that they want to do. They seem to be just a little bit more focused. And I find that the older women, most of them in my experience already have experience in having families of their own. And I found a few are already married and they kind of know what they want out of life. And I think that makes the difference then as to why there may be an older population participating in these groups.

Faye went on to give an example of a young woman who chose to leave the group because she did not feel the group met her needs at the current stage of her life:

And I'll give you an example [of a woman who left the group]. One, I just really don't think she was ready for what this group had to offer. And it was like everyone around her began to accomplish and she kind of stayed in that same place. Not that she couldn't accomplish anything, it was just more like where was she wanting to be at that time. So she made the conscious decision, you know, to leave the group. However, she does maintain friendships with other members who are still a part of the group.

Ella, Fay's co-group coordinator had similar observations. She noted during the formation of the group that the original intention was to recruit women ages 18 to 25, but recruiting within this age range was riddled with barriers. This left them no choice but to eventually raise the age range of the group:

Actually, our initial goal was looking for women who were between 18 and 25, I believe. And we ran into a lot of bumps. A lot of the bumps we ran into were some of the women, they never, they never thought themselves independent enough to be

able to participate in a group on their own. So when the women were let out of their family members, so kind of cutting that string [was hard].

Ella wondered if this lack of independence and trepidation to make their own decisions regarding their involvement in the support group stems from the school system's failure to teach young disabled women to be proactive:

I don't know if it was the way that the school system here places women with disabilities to not necessarily be proactive in like -- The pro-activeness is just kind of, you know, speaking to some of the friends that I grew up with, just getting along, doing well enough to physically pass, . . . they are content just enough to get by and not necessarily enough to live a more holistic way. I can remember when I was in school they would challenge me. And I would rise to the higher standards. And some of those students were never really challenged or just kind of put into play where they [were told] "Okay, here's what I need you to do, this is enough for you to get your diploma, good luck afterwards!"

In a similar vein, Scarlet reported that a lot of her younger participants don't yet realize that topics discussed in the group apply to them. When discussing why some women choose to participate in the group while others choose not to, she stated:

We start talking about relationships and dating and sex and all that stuff, but some of it -- in health, you know, making sure we -- and also, we advocate for better access to women's health, imagine that. So when we start talking about those issues, some of the ladies, they are -- like for example, we had a conversation on getting -- making sure you go get your pap smear done, right? One of the young ladies, she [said] "Well, I don't think that pertains to me because I'm not sexually active." So there's a lot of confusion going on, they don't go get breast health -- breast screenings, you don't have to be having sex to get breast cancer. . . . Not only are they not connected to the issues, which they are, they just don't know it!

In addition to the topics of discussion deterring some younger women from participating in face-to-face support groups, they might also want to be more active within the community during group time than the older women. One group coordinator noted:

The younger group might want to get out more often, you know, because these ladies they go out three times a year. They go to a restaurant for Mother's Day. They have a picnic in July and then they go out again around Thanksgiving or Christmas and that's it. So if you do have a younger woman, she might want to be a little more

outgoing, you know, “let’s do something. Let’s not just sit here and talk because you can be on Facebook for that.” [Savannah]

A few group coordinators reported that scheduling conflicts might be a particular deterrent for younger women when it comes to taking part in face-to-face support. For example, Savanna suggested that the time the meeting was held played a role in whether younger women were able to attend:

And the time of day too, depending on the young person and what they have going on, 11 in the morning might be too early. . . . Tuesday at 11 -- from 11 to 12:30 [is when we meet] and lunch is not provided every time. So that’s probably another thing too.

In closing, the group coordinators expressed interest in recruiting women ages 18 to 25, but it was often a struggle to accomplish this. Group coordinators reported there were a variety of factors that could influence younger women’s desire to participate in face-to-face support. These included lack of appeal of discussion topics and activities within the group, overprotective parents who were worried about their daughters’ involvement in the group, the passivity of younger women, and scheduling conflicts.

c. **Recruitment strategies: Success and failures**

Group facilitators implemented a vast array of recruitment strategies in an attempt to overcome some of the attendance challenges they faced. Each strategy employed resulted in varying degrees of success. Networking was a common strategy used. Many group coordinators reached out to contacts both within and outside their organization in an attempt to amass a group membership. Some group coordinators had great success with this strategy. For instance, Ella, who co-coordinated a thriving support group with Faye, noted that internal networking and referrals produced a successful recruitment strategy:

We have great social workers in our organization who said, “Okay, I have a couple ladies and I want them to participate; I think they need something or I think they need an outlet, I think they need to be around women who are doing things with their life and not necessarily sitting at home.” . . . [It is helpful] having people who are supportive of the group from the outside and who feel that the group is a valuable [resource]. . . . Some of our social workers here really see the positive aspects to our organization and inspire others to participate or figure out what we’re trying to do; that’s what I’m looking for. Having somebody that recommends the group to younger women and can advocate for the group I think has been really helpful.

Ella also noted that she has had some success with direct referrals from other group members saying, “The woman that I told you about that’s now the mentor. She’s brought about five other women who have come periodically to the group just because they have disabilities and they like to share and grow together.”

Internal networking was also fruitful for Claire’s group. Many of her group members referred their friends. Like Ella’s experience, she also got many referrals from other staff that worked inside her organization. She said:

The biggest solution [to recruitment problems] has been the same group members invite other people to come and that has really worked. Also, using some of the programs we have within the same department -- our extended services has many programs like peer mentoring. So, we have that and a lot of referrals for -- from the peer mentoring. From our stroke mentor, she invites a lot of women and I think the majority of women are stroke survivors. So, I mean using other programs to spread the word about this program has really helped a lot.

Scarlet networked both within her organization and within the community at large in hopes of recruiting members. When asked how she recruited for the group initially, she reflected:

Oh gosh, Facebook, you know, going to different places and you know, passing out my card. And it’s good, like if there’s a disability organization or women’s organization that I can go to and pass out my cards and talk to about what we do, I do that. I do kind of like Lunch and Learns, you know, or just go to different places just to let them know where we are. And all the hospital staff knows who I am, knows who our members are. . . . That’s basically it, social media and just, you know, getting out there and getting in the community. . . . I would say on average we have about eight to ten that are able to come.

Even the groups where attendance was a constant struggle had some success with networking strategies, at least initially. For instance, Anna, whose group was ultimately discontinued due to lack of participation, used varying networking strategies to get the word out about the group. She recounted her initial recruitment efforts, saying, “The initial process was pretty simple. We advertised in our newsletter and with flyers in the office for people who might be interested and developed an email list. The first few meetings were well attended.”

Being flexible with times and dates the group is held was another common strategy used to increase participation. However, this strategy was not very successful. Olivia spoke at length about her efforts to schedule group meetings at times that would be conducive to maximum attendance, but these efforts did not yield the results she was hoping for:

We initially, when the group started we had it where it would be twice a month, the second and fourth Thursday of each month. Then in hopes that it would increase group attendance we decided that we would do it monthly the second Thursday of each month. And then as of January of this year decided that we would meet quarterly in the hopes to increase group attendance. In January I had people who are interested but no one showed up. I’m hoping that in April we will change some things around. . . . [In sum] we’ve tried changing the date, several times changing -- Well we’ve tried changing the times that the group is going to be held. That hasn’t done anything.

Like Olivia, Anna also tried switching up the meeting schedule to accommodate the schedules of group members: “[I have tried] Surveying members via as to the best times for meetings, and trying meeting at different times based on responses. Afternoons were difficult for many of the participants, so we switched to evenings.” Ultimately these strategies were not successful enough to overcome the attendance issues and the group was eventually discontinued.

One pair of co-group coordinators tried raising the age limit of their Group. When they raised the age limit to include women over the age of 25, group attendance increased noticeably. Ella exclaimed:

What I noticed is that when we open up the age group to include people over 25 and we extended it to 35, then to 40, we found more women were willing to join between 25 and 40. You know, some working mothers who had different life experiences or who are disabled or became disabled through either a tragic situation or a chronic condition themselves joined the group.

Faye, Ella's co-group coordinator, also shared her observations regarding raising the age limit of the group, saying:

[Younger women ages 18 to 25 were not attending] so we ended up having to come together, meaning my superior and I and talking about how can we do it again in terms of reaching out to people and seeing what the response would be. So I changed the age group from 30 to 45 years of age and I found that that age group they responded quickly and rapidly. And now because of the, you know, change I have eleven women who are strong.

Olivia expressed similar intentions of starting a support group for young, disabled women. She was extremely passionate about the group being consumer driven right from the start and created a survey to discover what would be beneficial to potential group members. She described her initial efforts of reaching out to possible consumers and soliciting their feedback:

I created a survey and I sent it to various community service agencies for my area and asked that women of no particular age range fill out the survey indicating things like days of the week that they wanted to have a group, the times that they wanted the group to be beneficial for a women's group. So I was really excited to do something like that and really wanted to see back from the community because I felt like this was their group. . . . Like I've said, I've wanted to do something that I want them to feel like they're a part of. It's their group and I want to make things happen, you know, give them things that they feel like they need from a group. Plus, you know, let them decide what topics they want, let them decide what they want it to be. I want it to be driven by our female consumers.

Despite her enthusiasm and efforts to keep the group consumer-focused Olivia constantly struggled with attendance issues. At the time of the interview she was seriously contemplating narrowing the focus and demographics of the group in hopes of attracting more participants. However, she feared doing so would exclude women who could benefit from the group. She explained her dilemma at length, saying:

Just to say it's a women's group is really broad. So I've been thinking about, for example, women dealing with depression or a women's group for single moms or a women's group for women with disability that have children, something like that. . . . But, when I think about that I'm always thinking: well I'm excluding women in the community and I don't want to do that. But at the same time just having a women's social support group of which we changed the title . . . it was officially a women with disabilities support group and I decided to change it to a women's social support group. And I thought: 'well maybe if I had it more topic based for women that might bring more ladies into the group.' But then I don't want to feel like I'm excluding anyone. That's what I'm kind of struggling with now. [Olivia]

Although many group coordinators struggled to see results with the majority of recruitment strategies they implemented, Grace and Lucy did experience success with recruiting from the public school system. During the creation of the group, Grace took the time to go to the public schools as a representative for her organization and tell the female students about the new disabled women's group she and her co-group coordinator were creating. She recounted:

I had to get entrance to the schools. You know, I had to recruit, and that was kind of scary and hard. And I went into a lot of public high schools where they had any number -- any disabled people at all and asked to meet with the girls alone, give them a little talk, and meanwhile, you know, be going around the room with a sign-up sheet and making sure I got their phone numbers and everything. . . . They came from all over the city. . . . It was a work in progress constantly. You know, I was often going to high schools and recruiting.

While recruiting she realized it was the young women with the most visible and or severe disabilities that showed the most interest in what the group had to offer. She expounded on this saying:



. . . and it was always the most disabled girls that were interested, because they were the most isolated and had the biggest need, and more, I think, willing to acknowledge their own disabilities. I mean, there was just no way they were going to be able to hide that there was something different about them, you know, no matter what their disability was, psychiatric, or physical, or intellectual, or whatever it was. Lots of times people have multiple sort of stuff altogether.

In conclusion, group coordinators tried a variety of strategies to overcome the attendance problems they faced within their groups. Networking both within the hosting organization and the surrounding community, including local schools, was reported as the most successful recruitment strategy. Raising the age limit of the group was also an effective strategy for one group. Other recruitment and retention methods such as changing the time and date of meetings and narrowing the focus of the group yielded mixed results at best.

## 2. **The logistics of running and maintaining an in-person support group**

Once a membership, large or small, was established, there were many logistics associated with running and maintaining the group on a regular basis. In this vein, four major categories emerged from the data analysis: 1) Strategies for overcoming challenges and maintaining a successful group; 2) Outlining a path for members' self-development: Group objectives; 3) Avenues for accomplishing objectives: Moving beyond support; and 4) Facilitating the group: The journey to being an effective group coordinator.

### a. **Maintaining a successful group: Strategies for overcoming challenges**

Regardless of its size, once a core membership was established there were a number of logistical issues that the coordinators had to address to maintain a productive group. Throughout their interviews they shared strategies they implemented to overcome the challenges they faced within their respective groups. Assisting with

transportation was one strategy used to help sustain participation. Group coordinators and their hosting organizations played a critical role in directly funding and providing transportation to and from the group, or helping the women organize their own transportation through publicly available means. Some of the data that reflect group coordinators' efforts to assist the women with accessible transportation included the following:

[I am] trying to reach out to some of our local places that sell vans, like, you know, like that sell accessible vans to see if they would be willing to provide accessible transportation. [Scarlet]

I think transportation [helps]. . . . I encourage everyone to just apply for it. A lot of people don't really like to have to wait for a ride, so just like, you know, encouraging people to have as many options for transportation as they can. That way, if your ride with a family member doesn't work, or how they usually get here doesn't work out, at least you know if they make a reservation the day before they have that for sure, so that's a secure ride. [Claire]

They were never signed up for paratransit, even when there was paratransit. We had to go through all sorts of workshops and everything to teach them to use it and how to, you know, schedule rides and everything. But before that, we would be able to pay exorbitant prices for this kind of glorified taxi service. There would be an accessible van that would pick a bunch of girls up who would otherwise not have had any way of getting to the meeting. And the Organization paid for everything. . . . It [adequate funding] was something that we always had from the very beginning of the organization, just to bring people in who otherwise wouldn't have been able to. [Grace]

Lucy, Grace's co-group coordinator, noted that when paratransit was established the women started using it as a means to get to and from the group. They were always careful to accommodate women who would arrive early or late due to the unpredictable nature of the city's paratransit system. Discussing the importance of these accommodations and their flexibility, she said:

It's just kind of a fact of life that the paratransit is often late or misses and we just have to understand. If somebody missed a session because of that, well whatever it was a matter of bringing them up to speed and letting them know what they had

missed. You know if somebody had to leave early because their ride got there early, then, you know, we'd hand them the materials as they were walking out the door. Kind of being flexible enough to know that that's a reality of working with that group of women, that have had to be accepting of it and who have had to make do with that.

Grace and Lucy's organization was instrumental in a successful advocacy movement to make the public buses and trains accessible. Thus, some of their members were able to use public transportation to get to and from the group meetings.

A reminder call was another strategy to help ensure reasonable participation was maintained. For example, attendance was not an issue for Grace and Lucy's group. Grace attributes this in part to her calling to remind the women when the meetings were being held and when the van would pick them up. She explained:

I would call and everything. I knew that if I didn't call some of them every week and tell them that the van would be there to pick them up at a certain time, they would not remember to come, or maybe they just wouldn't have it together. Well, at least I felt like that. But, people always came. A lot of people didn't stay in the group as long as others, but they had some time in the group, some real time. And I think for them that was good. That was enough.

Reminder calls helped demonstrate to each woman that their participation is valued and desired. Relatedly, phone calls a day or two prior to the meeting provided the extra motivation needed to rearrange their schedule and attend the meeting.

One group coordinator mentioned funding for activities was very important. Thus, Scarlet and her group raised funds for group activities and outings through planning a variety of creative fundraisers and obtaining a fiscal sponsor. She described this difficult but necessary component of running the group:

So when we do fundraisers, we do try, you know, we do try to cover those costs [of group activities], but you know, it's really, really, really hard with that sometimes. . . . We are kind of like starting from scratch and doing a big fundraiser this year. . . . So, just beefing up our fundraising and we actually partner with a fiscal sponsor, so

that's new. So, that is going to be a huge help to us as far as fundraising and being able to apply for grants.

Scarlet was also working hard to secure funding for a physical space for the group to meet and conduct business. At the time of the interview, the group was meeting at community establishments such as restaurants and cafés. She discussed her hopes of one day getting a physical location, which she saw as important to helping the group meet their goals:

Eventually I would like for us to grow to the point where we can have our own like office because like -- everybody -- we're all doing everything from home and it's good, but it would be better if, you know, one day we can, you know, have our own space to do the work and it be more of a structured organization because right now, we're very, very grassroots!

Although big picture goals like the one mentioned above were important to a lot of group coordinators, Ella, a co-coordinator, noted that keeping group goals manageable and within reach was also important:

I think one of the challenges, and I think my perception because I don't necessarily sit in all the meetings. One of the challenges I've noticed and kind of facilitate over the group is just kind of making realistic goals because sometimes some of the big ideas that come across with the group can be almost untouchable from an organizational standpoint in terms of having the body to kind of make sure things happen to have the financial means as well. And kind of trying to trim down some of the big picture stuff and set smaller, more realistic or more tangible goals.

She went on to give an example of how scaling back plans led to great success for one of their fundraisers:

[For example,] the fashion show that we were able to do here with them. And you know, it kind of went from being a fashion show in a big location, you know, with multiple sponsors and multiple, you know, outreaches to kind of trim it down to a more grass roots kind of thing where there was a lot of in-house support to kind of use the facility instead of going out into the community where we would have to incur more fees. . . . The fashion show was able to be pulled off and it was a success. We did have a lot of attendance as well as some . . . who weren't necessarily members of the group. They really were able to get a lot of women older than themselves to come and help serve and, you know, be their audience.

Ella went on to note that a strong bond among group members was essential to maintaining the group. She and her co-coordinator made a point to cultivate this bond among their membership as much as possible. She surmised that this strong bond was why a lot of women chose to continue their participation in the group, saying:

I think even why some of the women do choose to participate because they just like to be, I've noticed they like being around each other. They like really have a very high sisterhood bond, kind of. I don't really even know how to describe it fully. I know they just spend time not necessarily they don't only meet here in the office but they meet off site. They meet in, you know, they have like a barbecue in the summers and you know, they have holiday parties together and you know, they find different ways to celebrate one another as well. I think that's another big reason. So like when someone gets an apartment they celebrate. When someone gets a job they celebrate. When someone has a child they celebrate. You know, they find there are so many reasons to celebrate their accomplishments.

Ella's co-group coordinator, Faye, noted the importance of the strong bond among their group members in regard to keeping information confidential and respecting others' privacy:

And what they've gotten from this group is a great sense of sisterhood and understanding that, you know, whatever is said in group remains in the group. And I'm grateful for the fact that we haven't had any issues with, you know, our privacy being violated by any member of the group.

The solid bond among group members was also noted as a motivating factor for attendance in Grace and Lucy's group. When discussing what motivates members to attend the group on a regular basis Lucy explained:

Well, partly I think there was a group of women that they liked. There was a lot of support amongst the group members. They liked each other and they were friends. So I think that was a motivating factor. I think support of their family was another motivating factor. So somebody who might not have had such a good friend would not have as much of an incentive to come.

Allowing honorary group members was another successful strategy for maintaining participation. Ella described this as follows:

So some of the folks just kind of stepped down [left the group] and not necessarily because they didn't want to participate in what the group does. But, their life changed. Their life changed to a new job or new obligations that didn't allow them to be as regular in participating, so the group has kind of made some people honorary members so that they still feel that they're a part of the group but they aren't necessarily obligated to participate as frequently as the regulars are.

In addition to accommodating long time members, it was also noted that providing support to new members was essential. For example, Savanna noted that participation in her group has steadily increased. This in part may be attributed to the support and empathy that the group provides newcomers. When discussing the increase in participation of her group and her observations of the group's interaction with new members, she stated:

When I started there were between five and eight active participants and now there are anywhere between six and I'll say eight and ten who come every week. What I like most about what I do with the women's support group is the optimism or their ability to -- you know you have some when we have new women who come, a lot of times life has affected them or they are coping with a new diagnosed disability so there's a lot of crying involved and the ladies in the group are really good as far as encouraging the new participant, which is why the numbers have increased the way that they have, and we have some women who've come and they participate or they got what they needed for that moment in life. They were able to get things together, you know, improve physically, socially, emotionally just from coming.

Although for the most part Savanna reported that her group had a solid relationship with one another, there were times where conflict resolution strategies had to be implemented to sustain a productive group and keep the peace. She found that using a democratic system to determine when and where activities would take place was helpful. She described one example when she instituted a majority rules system in order to resolve a conflict:

It was a point where it [group members request for very specific foods] was basically causing trouble because they were really limited what restaurants we could go to and it wasn't fair. So we ended up . . . having to have like a meeting like, "okay, this is what we're willing to do because it's really not fair to others at that point if we base all our outings on your dietary needs. We're voting and so sometimes you're just going to be outvoted and you don't have to come."

Savannah also noted the importance of being stern and reminding the group of the need to stay on topic in order to accomplish the objectives. She shared an example of a time when a guest speaker was stern with the group and did not tolerate their lack of attention. Savannah hoped to be able to implement this type of facilitation style in the future, explaining:

We have an individual and she covered a group for me and she's really like, "I'm doing a presentation and A, B, C, bam, bam, bam", and so when they would go off into a tangent and so she started packing her stuff up and they're like, "well, what's going on?" And she was like, "well, you guys really don't want to learn about couponing!" So, they got the feel of the two different facilitations down. So she's like, "I don't think they're going to be inviting me back," because she's one of those "oh, we're not going to go all off into left field. This is the goal. We're going to talk about it," and if I was a group member I would like her facilitation style. . . . I could be a little more stern with them when conflicts come up as far as that goes. I do remind them often about boundaries and rules when it comes down to things like that and respect and tolerance when it comes down to arguments.

As illustrated above there are a number of logistical factors that come into play when running and maintaining a face-to-face support group. Strategies that were reported as helpful in maintaining group participation included assisting with transportation to and from group meetings, holding fundraisers to obtain additional resources, creating a strong bond among group members, and implementing conflict resolution strategies when necessary. Although these strategies did not help every group solve their problems, they at least assisted in paving the way for groups to be productive.

b. **Outlining a path for members' self-development: Group objectives**

The different groups represented in this research all had unique objectives as reported by their group coordinators. However, their goals all in some way related to the self-development of their members. Many of the groups shared a general

objective of creating a member directed, safe space where social support and education on a variety of issues could take place. Responses indicative of this aim included:

The main objective, and this is something that the group at first decided that they wanted, was just a chance to relieve stress and a chance to have that social support with other women. And that was the objective that the ladies decided that they wanted. And that's what I was really looking for in terms of creating this group. I wanted it to be something that the ladies themselves wanted. I wanted it to be a place where they could feel like they could socialize with other women and get that support. I wanted it to be a place where they might be educated on different topics of interest. I wanted it to be a place where maybe they could come and talk about, you know, goals or things that they wanted to accomplish for themselves, you know, amongst each other. And then when we had our first group, the big thing that they said that they wanted was that social support and a chance to de-stress. [Olivia]

I think that for most women with disabilities the struggle is to feel like they can have self-directed lives that include things beyond survival. . . . I think the main objective was to foster a sense of safety. [Sarah]

The Objective is to provide a safe place to share struggles and triumphs and to support women with disabilities. [Nora]

The group was intended as a social and support group for women to benefit from social and recreational opportunities, as well as mutual support, and possibly advocacy activities. [Anna]

Some coordinators specifically made teaching about disability and sexuality a priority in their group. They saw discussing these types of topics as crucial to the self-development of young disabled women. For instance, when asked about the initial goals of her group, Grace responded,

I wanted them to be exposed to new ideas about disability and disability rights, you know, let them know that there was such a thing and disability activism and let them see what that looked like and alternative futures, but also just as importantly sexuality, which many disabled people grow up and even, you know, beyond adulthood are not really in touch with, because we're so kind of non-sexualized in the world, just in the culture, in the medical model, in just about every place that you look. So, those were the two main goals.

Asked to expand a bit more on what she meant by "new ideas" about disability she continued:



It was all new. To see disabled people working at the organization, that was new. You know, to hear and see disabled people in relationships, sexual relationships, that was new; to be given the right and the tools to discuss with each other and with other people disability sexuality and just plain old, you know, reproductive rights and all of that, that was all new; talking about different kinds of, you know, people with different gender kinds of self-definitions like lesbian, all that was new; to be able to say those words out loud--lesbian, masturbation. I don't even know if they could still, some of them still probably can't say masturbation. You know, clitoris, brand new things; so yeah, I think these were ideas that -- there was very little that one could bring up that wasn't sort of on some level new territory.

Lucy, Grace's co-coordinator, echoed the belief that young women with disabilities need information to counter the negative stereotypes that are prevalent in society at large:

The objective was to make a space for girls with disabilities to be able to talk about sexuality, from early sexuality in terms of being young women with disabilities, self-esteem and communications, but nobody was talking to these young women with disabilities about that. And really quite the opposite, more of the message that they were getting was that they're not sexual beings, that no one would consider them as that, and we wanted to counter that.

Scarlet aimed to teach the young women in her group about a wide variety of women's health issues:

I mean, I just think it's a great group of women and we do different things. . . . You know, our mammograms and our pap smears and, you know, mentorship in women's health and taking care of ourselves and fitness and things like that.

It was important to several of the group coordinators that their group catered to the needs of women who are transitioning into adulthood. For instance, when asked to describe the objectives of the group Ella spoke about how her younger colleague Faye requested her assistance creating a group that specifically addressed the needs of younger disabled women:

We had to kind of come together, me and the other group coordinator have been running this from the start; we kind of had to figure it out. She came to me and said, "Okay, well I want to develop a group for young women such as myself, who are working and living on their own." . . . It was like she thought there was a need for a group for women like her in her age range. And she was around, I think at the time she was in her late 20's, late 20's or early 30's and trying to say "Okay I can see

women who are members of our organization, who would like to be around other women like myself who are kind of in the same situation. Also, maybe there are younger women who didn't have the, you know, who didn't have what I had growing up and we can inspire them to want to achieve these same kind of goals of having their own apartment, getting a job and being able to, you know, look at them and say yeah, I'm going to work!"

Similarly, Scarlet saw a need to support young disabled women transitioning from high school. Discussing the need to serve women in this demographic, she said,

Definitely think if we can get them early, before they transition from high school, I think that peer support is greatly needed, and I'd say in women's health and realizing that our bodies are important too . . . learning that it's okay to advocate for yourself, teaching coping skills and advocacy skills to develop so that they can get what they need out of life.

The group coordinators were very passionate about empowering the women to lead self-directed lives. However, the term empowerment was operationalized slightly differently for each coordinator. A few coordinators perceived empowerment as teaching the women to live self-directed lives by overcoming their disabilities. Others saw empowerment as fostering disability identity and pride through relationships with other disabled women. It was also noted that empowerment is far-reaching and includes being able to make self-directed choices beyond those pertaining to daily necessity. Responses that represent the goal of empowerment and its various connotations included:

So the objectives of the group are really to empower the women to live more independent. Live independently of parents, live independently of children if they have any who are old enough, to not necessarily have their disability be a crutch, sorry for the pun, for how they live their life. [Ella]

The main objective of the group is we say we provide a safe non-judgmental space for women to get together. So that's pretty much what it is to empower other women, to encourage women. . . . So basically the objective is helping with life, dealing with life and getting through life. . . . So, there are different forms of empowerment. So disability pride -- the diagnosis isn't a death sentence. [Savannah]

I think that for most women with disabilities the struggle is to feel like they can have self-directed lives that include things beyond survival. I want to be able to talk about love and sex and relationships and friendships and leisure time and artistic pursuits. All of that can be a privilege if you are struggling to get your needs met. [Sarah]

As illustrated above, the group coordinators had a variety of objectives geared towards empowering young women to live self-directed lives. Although group coordinators attached different meanings to the term empowerment many saw education, specifically regarding disability rights and sexuality, as a priority. In addition to the educational component, creating space to engage in social and recreational activities was reported to be central to group objectives.

c. **Avenues to accomplishing objectives: Moving beyond support**

The group coordinators described many ways in which they attempted to accomplish objectives. As noted in the last subsection, giving members ownership and control over the group activities was paramount to the group coordinators interviewed.

This led to important knowledge development on topics pertinent to the lives of group members. Responses indicative of the different strategies used to encourage member ownership over the group included the following:

I let the ladies talk about what they're doing, if they're starting a new business, a lot of time to share and network, you know, pass around business cards, whatever the case may be, and we also -- they have a topic or a speaker for the day in regards to technology or employment, you know, adaptive sports, makeup, beauty tips, getting dressed, adaptive clothing, where to buy the best clothes. I mean, it could be any topic. Sometimes we just, you know, free form it. [Scarlet]

We have a calendar; we make up our own calendar. So, members suggest a topic for the month. . . . Also, we do a potluck style pretty much. All members, like, contribute something and the ones that can't bring anything, that's okay, I mean we -- so, we provide that. Like -- you can say that -- for some members or for those that are able to cook, they like to say, "Oh, I make this, you know, this chicken or this tuna salad." I mean it's just a good way to, like, contribute. [Claire]

In terms of me being a facilitator, I find that my personal experience is that at this time the women are capable of probably facilitating themselves. As opposed to me being a facilitator. I try to remember that I am one of them when conducting meetings with one another. . . . I pretty much go with as things come up is how I interest them. And I think that our longevity with one another kind of speaks for itself where these women are at the stage where they don't need to be facilitated because they kind of already know what they want out of this. [Faye]

I give the women the opportunity to go around and introduce yourselves, talk about your disability if you choose to, and if you don't feel comfortable then you don't have to. . . . And every year the agency they do a survey with me not present about their satisfaction with the group and the facilitators. So they have the opportunity at that point to say, "Hey, I don't like that." And there are some ladies who have relationships with other individuals in the agency so they're able to [speak up] if there ever were an issue. [Savanna]

In addition to the strategies mentioned above, Savanna encouraged her group members to give presentations during group time on topics of interest to them:

We have a woman who, her interest was in the legalization of medicinal marijuana, which is legal in Michigan, but on the ballot this year it's going to be the [legalization of] recreational use and so she did a whole presentation. She put it together and I thought it was one of the best groups ever because they were all participating and laughing and it was nice!

Giving the women ownership over the group was key to them feeling secure within the group. For example, when asked what were some characteristics of her group that made the women feel comfortable enough to be open and honest with each other, Olivia replied,

I think honestly . . . and I just say this with other groups as well, I think it's the facilitator. And our philosophy is the whole person, it's a consumer driven organization. So we want to allow the consumers as much control over how they go about getting the assistance that they need to having control over their group and what they want. So I think it's the facilitators allowing that.

Several of them perceived their group's activities and discussions as moving beyond that offered in traditional support group curriculums. For example, Scarlet noted that her group tends to steer clear of using the term "support" as this term often has a somber connotation attached to it, saying, "We don't really call it a support group anymore, that

tends to kind of be like ‘eehhh,’ you know, with people or something that they think would be depressing. So we meet at a coffee shop and we call it Coffee and Conversations.”

Scarlet’s group along with many of the other groups were very engaged in the community and prided themselves in taking part in community service and activism. For Scarlet, being involved in the community was an important part of reducing the isolation some women experienced:

Like doing outings and community service, so it’s not just a support group. We do things within the community so that we’re visible in the community, because that’s a part of it is ending isolation and making sure that we’re visible in so-called mainstream activities in the community whether it be a walk-a-thon or going to movies, I mean, anything, just community participation.

Similarly, Ella noted that community activities and activism often intrigue her members. When asked about what occurs during a typical meeting, she said,

So a typical meeting that I’ve noticed is that they would normally start kind of greeting each other. There’s a kind of talk about things that are going on in the community whether in their personal community like where they live at and it’s something that anybody would be interested in participating in. . . . A few of them have disabilities where they do walks and things like that. So they’ll discuss the upcoming walk or march or celebratory aspect of that particular disease or chronic condition and see if anybody is interested in participating. Everybody comes to participate.

Her co-group coordinator, Faye, reported that in addition to taking part in community activism the group also gets together for recreational outings, saying, “We have gone together to places like the Botanical Garden. We have also gone to the park together. And more recently we decided to go to a club setting.” Field trips for Grace and Lucy’s group were centered on sexual education and awareness. Lucy spoke at length about the variety of activities they did with group members to help increase their knowledge about sex and their own sexuality. She remarked,

The first group of women we facilitated we took them to . . . a regular, run-of-the-mill sex store. There were several of us facilitating that day I believe or even if it was just the two of us and we went through all this. We talked about masturbation. We talked about lesbian sex. We talked about heterosexual sex and we talked about the sex toys and how they could be used and how they can be adapted. We did workshops on birth control, talking about hormonal birth control, about barrier birth control. We showed them how to put on condoms. We talked about all kinds of sexuality with them.

Some coordinators expressed a desire to bring in guest speakers from the community or from their agencies to speak to the women about pertinent topics:

Maybe we'll bring a special guest in for our next meeting. . . . They have had staff members come into their meetings and discuss a little bit further of the role within our organization and how they can navigate our system at our organization better. [Ella]

Providing guidance through the development of both formal and informal mentoring relationships was another important avenue to accomplishing group objectives. Scarlet's group was the only group represented in this research that purposely matched participants in mentor-mentee relationships. When asked to describe the mentoring component of her group, she elaborated on the types of characteristics she relies on to make productive and successful mentoring matches:

It's not necessarily age specific [when making mentoring matches]. It's more length of disability specific and what they've been able to overcome. . . . Let's say we have a young woman with a disability who may have been born with her disability, and that way, who may be pursuing higher education, you know, who may need help with that transition from high school to college, or, you know, from elementary to high school and vice versa. I would pair them with a young lady with a disability who has finished her freshman year in college, who has experienced living on campus. So it's going to be on a case-by-case basis and what they need as far as mentorship.

Each pair chooses what they would like to do together. The activities chosen are far reaching and have implications with regard to successfully transitioning to adulthood. Describing the types of activities the mentoring pairs have done together, Scarlet said,

I mean, I've had some, they'll go visit the other one's dorm room to see what it's like and, you know, go to lunch or meet, or go or do something with -- if they attend adaptive sports programs together. I mean, yeah, it's just open to whatever those two come up with to show them their day-to-day life. You know, that's going to depend.

Although purposely pairing group members together seemed to be successful for Scarlet's group, several other group coordinators chose to let informal mentoring relationships organically develop. For instance, Nora noted that many of the women in her group shared similar experiences with one another. This commonality often led to mentor-type relationships materializing. When asked about the development of these relationships in her group, she explained,

Many times women who have a chronic condition share like symptoms and happen to be at the same group at the same time. There is always one who is more experienced in coping and one who is struggling. It's great to see a woman share what has worked for her and a "light bulb" going off for another. While I don't encourage phone number exchanges in the group, I know that women who have felt particularly connected have shared personal phone numbers outside the group. This has led to social activities outside the group that appear to be very positive. The feedback that I have heard from the group, when there is more than one attendee, is fantastic! It always amazes me how the people who show up for the group are exactly who needs to be there. They experience the group as either [being] a positive example of a mentor for another woman, or a woman who really needed to hear someone was out there in the same boat.

Informal mentoring relationships also took place in Savannah's group. Her group members range in age from 24 to 70. According to her description, many of the older women act in maternal ways towards the younger women in the group. When asked if mentor/mentee relationships have formed in her group, she replied, "You get a lot of moms and you'll have individuals who kind of want to be mother hen!"

The positive relationships that formed within the groups helped lay the foundation for working well as a team with fellow group members and accomplishing goals

collectively. For Example, Ella proudly recounted how the members of her group work together to travel downtown and participate in a fundraising event:

Another thing that they've done as well at some of the meetings is prepare for an autism walk which was being held for the grandchild of one of the participants. And yet amazingly, one of the ladies is old enough to have grandchildren. But it was a great way for all of them to kind of come together and kind of look at it in a different aspect of it [and discuss] "Okay, let's see how we're going to do this logistically, how are we going to do this, how are we going to sign up to participate, you know, the registration process." And also, because of the logistics of where the location was where they had to go for this particular march, "Okay, how are we going to logistically get there as far as the different parts of the city to get to where we're going." . . . To be honest with you . . . I kind of didn't even involve myself in how they logistically figured it all out and made it a nice day for themselves.

Claire also briefly noted the support that emerges from group work among her membership saying, "There's a lot of support. I think that's based more on like the benefits of group work."

Group discussions on a variety of pertinent topics were another important avenue to accomplishing group objectives. When asked to describe anything noteworthy that comes to mind about the group, Ella, who is a co-group coordinator, said:

So, I would say that the groups that I serve that I've been a part of or I've been privileged enough to sit in on when they meet, it's always a varying degree of subjects that come across. . . . So one of the earlier, first meetings, one of the emotional aspects of it was that they discussed like the different disabilities that they had and what kind of led them to connecting with one another. It was really like, I think that was like the first point where they kind of were open enough to each other and when they were opening up to each other and just finding out more about one another and their disabilities.

Discussions about body image were a crucial component of the group Sarah once coordinated. When asked how she accomplished the central objectives of her group, she said, "In general, people feeling sad and insecure sometimes. Talking about barriers to exercise, talking about barriers to eating healthy. Talking about feeling judged by others and not as good as other women." Regardless of the topic, the coordinators strove to



provide their members a safe space where they could talk about highly emotional issues in their lives.

Many coordinators also made it a priority to connect the women to a variety of tangible resources, which were pertinent to their self-development and transition to adulthood. For instance, the women Fay worked with were able to connect to various employment and housing opportunities through different community agencies which partnered with their organization:

The organization I work for, we have a partnership with [this other organization] and they're one of our community partners. The women are able to go there on the weekly or monthly basis, whichever one prefers to see what's available to, you know, us as a community. So, in doing so some women have found that they are able to put themselves on waiting lists for housing or look into jobs that will provide some sort of income without getting their monthly financial monies-- whether they're on social security or SSI--taken away all at once. . . . I think it [supporting their need for self-development] depends on the women. But in general I think they would probably need to know that there are resources available to you; it's something that you would have to look for and it depends on what you want for yourself.

Savanna also explained how her organization partnered with other organizations to help give the women resources that were crucial to their self-development. She noted,

We have outside agencies come in, so there are resources being shared. There are skills that they can take from the group depending on the topic for that day, be it self-defense, knowing your rights, obtaining free legal counsel, providing healthy meals.

As illustrated above the group coordinators employed many strategies in the service of accomplishing their group objectives. Although group coordinators noted the benefit of discussions and social support, many sought to move beyond activities done in traditional support groups. Coordinators gave the women ownership over the group in different ways and group members had opportunities to become involved in their communities. Creative

activities were planned for them to learn about important topics related to self-development and multiple connections to key resources were made.

d. **Facilitating the group: The journey to being an effective group coordinator**

The group coordinators spoke openly about their journey to becoming an effective facilitator and what did and did not work for them. For many of the facilitators it was important that they were able to find common ground between them and their membership. Grace, who is a wheelchair user, spoke eloquently about the need to find common ground with her membership. Asked how she thought being a disabled woman impacted group members, she said,

Yeah, of course [it does]! And I think it impacted me, because it gave me a common ground with a lot of them. Most of the girls were people of color, and I'm white and came from a relatively, you know, a middle class background, so relatively privileged, and they didn't. And so, that was important that we were able to kind of match as females and as disabled women. And as much as that provided ways, you know, common ground for all of us, we all took advantage of it, you know. We all made the most of this.

Sharing her own experiences as disability rights advocate was key to her success as a group coordinator. When discussing important aspects of being a coordinator, she noted,

I had been in the women's movement myself, which is why I knew from my own experience how important it was to my own growth and how I knew that it was key, a key thing to share all this stuff that I knew with them.

Likewise, Scarlet, who is also a wheelchair user, saw value in sharing her own interests and experiences with the women in her group. She described one instance where she shared her experience with adaptive kayaking and accompanied one member on a kayaking excursion:

She had never done it before so she really wanted to experience what that was like and I'd been doing it for like four years so I was able to, you know, to mentor her in

that area and actually went on the kayaking trip, you know, she came out there to do that together.

Although the group coordinators were passionate about giving the group members ownership over the group, many of them acknowledged there was still a need for some leadership and guidance on their part. Olivia, who had an unwavering commitment to giving group members control over the group, noted,

I see us as just, you know, kind of the guides along the way facilitating service to guide the group and kind of help to keep that control within the group and steer the group in the direction that it needs to go.

Savanna also used a gentle leadership approach to steer the group in productive directions. She noted her propensity for this type of leadership:

You know, I feel we should be able to approach each other and I'm not an "I'm-in-charge-you-guys-do-as-I-say" facilitator. I am a more so this is your group, so more like empowerment. "This is your group. What do you guys want to do?" I will step in or do what I need to do if we're at a dead end and there's nothing to discuss or I, for the most part, will get a topic together and we'll discuss.

At the time of the interview Savanna was a relatively new coordinator and was attempting to build a rapport with group members. She reported it was difficult for her to take the initiative to make changes within the group:

Well, the first thing about me is the group had already been going for between six and eight years before I started here, and so the members were already core members. So the group itself was already established. The rapport that they had with each other was established, before me coming in and I'm different from the last facilitator and I struggled with feeling confident to change things because, like I said, the nonchalant personality that they had, they've always had.

Providing guidance when new concepts or tasks were introduced was an important aspect of the nonintrusive leadership style used by many of the coordinators. The guidance Lucy and Grace gave their members during the creation of their own films is a pertinent

example of this. When discussing her role and her co-facilitator's role in assisting the women with these projects, Lucy said,

Well, we didn't throw them into anything cold [in regard to creating their movies]; it was always with explanations and demonstrations and doing those things first. . . . At one point we had them facilitate different parts of it and it was something that we had done with them. . . . So, giving them training on how to facilitate and helping them set that up so they were doing that with the support that they needed.

Grace concurred with this style of leadership. She noted,

And it was a while until I learned this, but I also began to see I needed not to be a group leader as much as someone who gave them experiences of leadership themselves and how to do that. And it's really a skill. It's really hard to do.

Many of the coordinators saw moderating conversations as an important part of their job. However, several of them reported that it was challenging to keep conversations productive and civil at times. Responses that reflect the role of moderating conversations and the challenges that arise, included the following:

In general with every group, sometimes we do get the members that either do all the talking, so that's part of our job [as group coordinator] to, you know, to monitor the conversation and make sure that everyone has a chance to talk, to express themselves or, if a member just doesn't want to talk that's fine, we also like to respect that. So, when we have maybe like new people that come in and don't really know how group is going . . . I mean that's a challenge, I mean it's our challenge. We just make group rules and stuff like that, it works out. [Claire]

So sometimes we have a difference of opinion, you know, topics that are hot topics like religion, politics, abortion. Those are hot topics and so we try to stay clear of that, but a lot of times . . . you have individuals who want to dispute because they're strong with their opinions, and so sometimes those days can get frustrating or because there's such a 'go with the flow' group of ladies . . . they're not really forthcoming when it comes down to ideas. . . . [It is a challenge coming up with topics] that are interesting, you know, keeping in mind that it's not about me. That would be the kind of frustrating things [I deal with]. [Savanna]

Sometimes I would bring an article that we would read and discuss. . . . Besides attendance and retention, I struggled personally with knowing what material to bring. Most of the group members were older than me and I wanted to make sure that my ideas were relevant and productive. [Sarah]

Making sure materials were available in accessible formats was another important aspect of the group coordinator role. For example, Lucy spoke at length about how she and Grace worked tirelessly to make sure everyone had access to the group's curriculum and activities:

And then another thing was all our materials were always adapted to the various needs of the participants. So that wasn't an issue for them, and I think that's empowering. I think that should be for everybody, that everything is adapted. . . . One of the interns was deaf. It's a woman who is deaf and so we have an interpreter there for her. We have the same personal assistants who are there for all the meetings so it was always somebody they were comfortable with to help with whatever they needed whether it was restroom help or eating help. . . . I'm pretty sure that we got the copy of a book called "Deal With It" for everybody, which is all about female sexuality and it's presented in a really fun way and I'm pretty sure that we have that put on tape as well.

Lucy further elaborated on how they made the information presented in the group accessible to two members who had limited verbal communication:

There was one girl in our group who . . . didn't speak. She made utterances that we could tell when she was happy or unhappy. And so what we would do is we would meet periodically with her and either sometimes her personal assistant, sometimes with her mother and go through all the materials, kind of broke it down into much smaller pieces, much smaller chunks so that we could ask her yes or no question and there was actually another girl who used the communication board although it was really rudimentary. So with both of those girls we put everything into yes/no questions that they could answer without [a problem]. . . . So that was another way that we accommodated the disabilities of the participants.

Group coordinating brought about a range of human emotions for at least one group coordinator. Reflecting on the emotions she encountered during her tenure of over a decade of facilitating, Grace said,

There were times when I would just be so, I would feel fairly helpless. But I have to say it was mostly a tremendous uplift to be with them. I laughed a lot, you know. Also, the girls were, you know, they really appreciated everything that we did at [our center]. And they would come to me for various issues, and I have to say, I loved it. I can't deny it. Sometimes I would hear them counseling each other about something, and I would hear one of them say something I had told her to her

girlfriend, and it was just really gratifying to know that they had internalized what I said every now and then.

As reflected above the group coordinating experience was challenging, but offered great reward and fulfillment. Group coordinators generally chose a gentle, non-authoritative leadership style to guide the group in a productive and successful direction. Leadership was expressed through the sharing of personal experiences and moderating conversations on topics of interest to the group.

### 3. **Self-concept development and transition to adulthood: observations and conjectures from group coordinators**

The group coordinators shared a number of observations and made some conjectures about how their groups influenced members' self-concepts and the younger members' transitions to adulthood. This data was divided into four major categories: 1) the creation of an atmosphere conducive to self-concept development; 2) finding their place in the world together; 3) gaining a new vision of themselves; and 4) broadening horizons. These are presented below in turn.

#### a. **The creation of an atmosphere conducive to self-concept development**

When group coordinators discussed the development of their members' self-concept, responses often revolved around the characteristics of the atmosphere, which promoted the development of self. Openness, particularly receptivity to sharing experiences and emotions, was mentioned as an important part of fostering a positive self-concept among their membership. For instance, when asked to share her observations of how the self-concepts of the women in her group changed or developed, Olivia noted,

The sense that I have gotten, I guess the word that stands out is that they felt really open. . . . In terms of those that were there, they said they felt that it was a group that was open and, you know, that they could talk about what they wanted to talk about. They felt listened to and they felt supported.

Anna's group was a relatively new group and had only been active for one-and-a-half years. But, the openness within the group atmosphere was apparent from the very beginning. When asked to describe her observations of how group member's self-concepts have developed since being a part of the group, she said,

In our first few meetings, the participants seemed eager to share things with the other participants that they expressed they were unable to share with family members, who had a limited understanding of how their disabilities affected their daily lives.

Shared disability status helped give the women permission to open up and express their feelings. When discussing how members' self-concepts have developed since joining the group Claire stated,

We had had members that mentioned, "Oh, I've been coming to group because it just -- this is a time that I can come and talk. I can talk without judgment with people who are going through the same similar situations." Or, that have a disability "so, like you guys understand what I'm going through, other people don't." . . . I have a fair number of group members coming to group because they find groups to be a safe place to talk about issues they may be having, maybe with a personal assistant. Also, maybe with their partners or the family members. So, or people that you know don't have really a strong support system. The group is one aspect of a support system for them. So, they like that because even though [group meetings take place] in a hospital setting, it's not like going to the doctor, it's more kind of to express -- like to, you know, a release of [emotions] -- more like that.

Likewise, Savannah also reported the women in her group used group time as a means to express a wide variety of emotions associated with adjusting to life as a disabled woman:

We have women who initially started coming and would just literally cry the whole time because "the sky is falling, and because my world is falling apart. My world as I knew it no longer exists and I don't know how to cope with this change. And now this is how I feel and what do I do next?"

Faye also noted that her group members felt free to open up and express a wide variety of emotions during group meetings:

We generally tend to, one minute we tend to be laughing, the next minute we find ourselves crying, and the next minute we also find ourselves trying to counsel somebody because of something that may have taken place during the week that we don't meet.

Faye had been a member of support groups prior to becoming a facilitator and noted that one of the greatest benefits to being a group member was knowing that there were people she could openly share her experiences with. When asked what type of peer support disabled women need for their self-development, she said,

I know for myself, because I've also been a part of support groups, one of the things for me when I was a part of the support group instead of being the facilitator is I just wanted to know that there was someone I could share my experiences with.

Trust was also an important prerequisite to creating an atmosphere conducive to self-concept development. This trust was fostered despite the long-standing stereotype that women should be mistrustful of other women. When discussing the self-development of her group members, Grace fondly recounted,

They would support each other. Often, you know, we would start the meetings off in a circle, and everyone would go around, take turns just saying a few words about how they were feeling at that moment. And you know there's almost always somebody that was not in a great mood or had something bad happen that week or something. And it was always a lot of support for that person coming from the girls and that was good, that was unbelievable. . . . And that there was that level of peer support, too, surprised me, because you know people can be hesitant to trust and to appreciate other girls, you know. It's certainly not a culture of that kind of thing encouraged between girls. I mean, I think I know that when people make connections between each other and between ideas, it does make a difference in your life.

She went on to note that the atmosphere of openness and trust within the group was likely one reason women with the greatest need for these qualities in their life stay in the group:



I guess that could be any number of reasons [why some women chose to stay in the group while others didn't] but I do think there was some people that had a greater need, you know. They were -- or there was something about the atmosphere that suited them in particular.

Trust and openness were reported to be scarce in some of the women's lives outside of the group. However, within the atmosphere of the group, trust and openness were able to flourish. Group coordinators consistently mentioned these two characteristics in response to questions regarding how their groups influenced the self-concepts of the members.

b. **Finding their place in the world together**

The trust and openness discussed in the previous theme was used as a springboard for the group to develop a sense of camaraderie. Members worked to find their place in the world together. When asked about the group's role in self-concept development a strong sense of camaraderie, even "sisterhood," and shared experience among members emerged as important to self-development. Group coordinator responses that illustrate the role of camaraderie within the group included the following:

There was a really strong fierce sense of camaraderie that evolved among the members of the group. Some of them had gone to school together. Many of them had gone to school together. I think this was a way to interact in a different way than in a school setup. So they developed camaraderie! I'm still in touch with several of them on Facebook and I see some comments that they're connected together as well. [Lucy]

Well, the main thing was they really became friends and confidantes with each other. And they would use the word sisterhood a lot, I mean, in a natural integrated way. . . . There were young women who really, really didn't want to leave the group, because they found it to be right up their alley, you know, and their friends were there, and they liked our organization, and all sorts of reasons. And you know, it was time away from their families. . . . They got to talk about things and be themselves. . . . It was a really important thing in their lives, and many of them would stick around. [Grace]

And what they've gotten from this group is a great sense of sisterhood and understanding that, you know, whatever is said in the group remains in the group. [Faye]

In the brief participation I have seen, the women who participate are always grateful to have someone listen to their stories and to experience an understanding that only comes from a shared experience. [Nora]

So although all of our disabilities are different, just the relatability is still there and so that is what makes for interesting conversation no matter what the topic is that day. You know there's always someone who can relate to something in the group. [Savanna]

Faye experienced isolation from the larger women's community prior to group involvement. Her narrative further illustrates the sense of camaraderie that emerges from finally being able to connect with other women who share the experience of disability:

I think one of the greatest things that has changed for me is that prior to being a part of and facilitating the group I never had a great support system when it came to women. I was always on the fence about that because there was just like I wasn't accustomed to having too many friends at one time. And now it's like there's this sense of family. And that sense of family has given me the strength to you know, want to see these women in even better places than they were previously. And that includes myself.

She went on to describe a specific example of how the group gave her a sense of family and camaraderie:

This past year I gave birth to my first daughter. . . . And I remember when I made the announcement that I was pregnant and having a baby they were all very, very excited for me. And one of the things that arose was that they didn't want to meet, they wanted to discontinue meeting until I came back from my maternity leave. And I'm like, you girls can't do this. You girls have got to meet. You'll be fine without me. And so, because they didn't want to meet without me they ended up coming to my home. And we would have our monthly meeting about a month after I gave birth. . . . And so it just showed a lot of growth on their part. And it helps me in terms of with the postpartum depression and things of that nature like there was none of that. And I think that was a result of having them in my life.

A sense of belonging, a related feature of camaraderie, was reported to be an important component of self-concept development. When asked what the ideal group would look like to promote the self-concept of young women with disabilities, Anna responded with a poignant quote:

I will use a quote from Starhawk here: “We are all longing to go home to some place we have never been – a place half-remembered, and half-envisioned we can only catch glimpses of from time to time. Community. Somewhere, there are people to whom we can speak without having the words catch in our throats. Somewhere a circle of hands will open to receive us, eyes will light up as we enter, voices will celebrate with us whenever we come into our own power. Community means strength that joins our strength to do the work that needs to be done. Arms to hold us when we falter. A circle of healing. A circle of friends. Someplace where we can be free.” (Starhawk as quoted in Pitonyak, 2013, p. 3)

The very strong sense of camaraderie within groups was in welcomed opposition to the isolation and alienation that participants felt in the world outside the group. The shared disability experience was the foundation of a sisterhood filled with mutual support and understanding. This gave rise to a sense of belonging that was unique to the group space.

c. **Gaining a new vision of themselves**

Armed with a sense of belonging, many coordinators reported that their group members were able to develop an empowered consciousness and “new vision” of themselves. For instance, when asked to describe elements of the group experience that stood out to her, Grace responded,

There was no one in their lives prior to me and other people at our organization that provided a different vision to them, in terms of their futures and their identities. And I think growing up as a non-disabled person, which is what my experience was, I was 24 when I was injured, I felt already a sense of entitlement and a sense of what my future might hold and what my options were and who I was in that picture. And I mean, how could a young disabled woman know that at that age, when there was no adults around with a disability . . . where there was an established social construct that sort of defined disability as negatives and undesirable. That they were able to really just embrace these new ideas and redefine themselves in a fairly brief period [surprised me]!

Achieving an empowered consciousness among group members was not an easy task. Discussing some of the barriers the women faced in society, Grace remarked,

I mean, it’s a very insecure time in one’s life, those adolescent years. And there really isn’t accurate information out there on TV about what a girl’s life is like. Not that I’m -- actually, I don’t know. I’m sort of out of touch with that. But it’s all

either -- it just sucks. The imagery in the culture, the movies, the TV shows, the books, it's just for the most part nonsense in terms of what -- life history on women and for girls.

Further elaborating on what needs to be explained to disabled women in order for them to overcome socially constructed barriers, she said,

It's important to understand why you have certain experiences that may make you feel bad, but you don't have a framework to figure it out in, you know, until you have someone or some people to sort of explain how things work and that there's a system of oppression, and you know why that is and that it needs to be confronted, and how one can easily make the error of thinking that what's wrong with them is that they're, you know, they were born wrong, and now they need to be cured, that there's a medical solution, the way the rest of the world sees us. You know, the problem with disabled people is that they are disabled, right [sarcastic tone]. And you know, help people understand, too, that they're just part of human diversity.

Savanna also recounted her group members' transformation from disempowered to empowered. She observed women in her group who were once very shy and self-contained becoming more open, gaining pride in their disability experience, and expressing a willingness to help others in similar situations. She recounted this change, saying,

A lot of times when women that I've encountered in my circle, when they found out that they have a disability or for some reason they're not able to work, then they take on the mentality of "If I have a disability I'm not able to do anything" and so they come in and they're shattered or broken or they have this perception of what disability is and what it looks like. And just from coming and meeting other women, they get this attitude of empowerment, like, "Hey, I can work" . . . as we keep coming and we keep encouraging each other and talking about different things and sharing different resources, then we get people who come from "I don't want to talk about my disability or disclose any of my information" to now a mentor and "this is my disability and I'm not ashamed of it."

Anna noted similar benefits of the close relationships that formed among group members during the short time the group was in existence saying, "A few of the women developed lasting friendships with women they met in the group. Their self-esteem and self-confidence grew as a result of these relationships and the support they felt from one

another.” Expanding on the phenomenon, Sarah articulated how exposure to successful similar others promotes confidence and helps to illuminate new possibilities for disabled women:

I feel that the group helped people to gain confidence and also since the group was varied in age, people got a chance to hear different perspectives. People had been living with their disabilities for different amounts of times and in different capacities. I think it was helpful for older women to see active and younger women with disabilities, and I think that it was helpful for the younger women to have older mentor types. A lot of discussion about love and relationships, for example, having older women who were married, etc., helped me to feel confident [as a disabled woman] that it was possible. [Sarah]

Grace, who is also disabled, saw access to positive role models as not just valuable to her group members but also valuable in her own journey of self-discovery as a disabled activist:

I know that for myself, I went through a very long period where I loved and needed to be around other disabled people, just to be okay, just to be sane, just to talk freely about the micro aggressions that one suffers every day out in the streets as a person with a disability and to have a channel or a way to channel my anger and fight back. But I was always a social leader. I liked doing political work, and I always thought of my work as political, and I thought of disability oppression as very political.

From the group coordinator perspective group involvement gave their members the tools they needed to obtain a new vision of themselves along with an empowered consciousness. Members were given opportunities to think about disability in new and empowering ways. Perhaps the most important factor in initiating a new vision of themselves, though, was that the group gave them access to other disabled women who were succeeding in meeting their goals. Thus, women were able to reimagine their own futures and gain confidence and self-esteem.

d. **Broadening horizons**

As a new vision of themselves developed, coordinators observed group members “coming out of their shell” and broadening their horizons. For instance, Scarlet noted the women who participate in her group are much more active in their community and more willing to try new things than they were prior to group involvement:

From what I’ve seen, they, you know, are doing things in the community more, I’ll say that for sure. And that’s outside of the group, you know, they’re doing more stuff -- say with their church or just, you know, connecting with people more, and just doing things on their own more. . . . Not being afraid of those anymore and actually going out to pursue, you know, past plans and going to work and, being productive members of society. I definitely see some of them coming out of their shell and doing more, for sure, in all those areas.

Savanna made similar observations with regard to her group. She spoke at length about the transformations she’s observed in her group members. Her members have consistently gained awareness of their strengths and a willingness to speak up for themselves as a result of group involvement. She explained her observations, saying,

[The women benefit from learning] what their own strengths are because sometimes it’s just a matter of speaking with someone and them bringing that out of you. Like, “you know, that is a really nice outfit” or, “wow, you brought the brownies. Maybe you should bake.” “Oh, I can do that.” Or “I love reading”; that kind of thing. So you figure out what your strengths are and what your goals are.

She went on to give a specific example of a member whose self-development during her time in the group was particularly evident:

I have an individual when she first came [here] she had a criminal background. Well, she still does, but she had recently been released from prison and there was a lot of turmoil with her family out of state and so she came and she was really a shut-off personality where she would answer the question but there would be no elaborating. . . . Now she’s at a place where she can say, “My name is, and I have a disability. . . . When she started she was really quiet, shut-off and not participating, but coming because it was good for her and so now she’s working with an employment coach trying to get work. She’s recently got her own place. She is always offering to do presentations on whatever, so she’s empowered in that she

knows who she is now. She's also in other support groups in other agencies, a mentor. So now she's at a place where she has people under her.

Grace and Lucy's group gained pride, confidence, and broadened their horizons collectively through writing and directing their own movie projects. Lucy recounted this experience:

In one of the later years of my group we started working with a filmmaker who ran a media company, who made independent films, and they made, I think, two films talking about sexuality and disability that they wrote out. They blocked out what the movie was about and figured out what we wanted to show and portray . . . and they interviewed people on the street. It was really powerful. And so I think they felt a sense of pride in that work that we did together.

A few group coordinators reported that group members were able to meet important milestones of adulthood including becoming empowered to live independently. This is in part because of what they had gained from the group. For instance, Ella proudly discussed the strides her group had made toward adulthood:

For some of the women who have been in the group, they went from living with their family to finding their own apartment and finding how to navigate through our Medicaid and Medicare system and the assistance that they need in terms of home care support, whether it's through the consumer directed program or a regular home care agency. And finding out and just figuring out how to live individually.

Scarlet, too, noted that her group members had made great strides towards important life goals thanks to the resources they were connected to. When asked how group involvement had influenced its members' transition to adulthood she said,

Of course, it's up to the woman to follow through, but just being that resource to say, "Okay, here's the resources and we're here to be a support to help you with these life goals," . . . [they are] actually doing what they need to do to go to college or really starting to go back to work and not being afraid because we talk about the social security disability, you know, work . . . and all that stuff.

Finally, Faye observed her group members using the resources gained from fellow group members to make positive changes in their lives and meet hallmarks of adulthood.

She explained the group's utilization of resources and their successes:

I've found that women, the women that like to participate in this group have really taken some of the resources that the other women brought into the group as to be able to help themselves. I've had women now; I've had two women move into their own apartments for the first time. And both of these women are in their mid to late 40's. And I think that's fantastic when you can utilize resources within the group that you participate in to be able to accomplish your own personal stuff. Women are moving into their own places and women are also utilizing resources of their own from the group to find their own, you know, jobs and things. It's great!

In sum, coordinators observed group members branching out and trying new things as they became comfortable with who they are. Some coordinators reported that the women were able to meet transitional milestones of adulthood because of their group involvement. These included living independently and gaining employment.



## V. DISCUSSION

The results of this research provide new insight into the goals that are important to young women with disabilities transitioning to adulthood, as well as the barriers they face to achieving these goals and a positive sense of self. The results also extend the current body of literature on support groups for disabled women to illuminate specific mechanisms within the support group process that help young disabled women achieve their objectives and gain and maintain an affirmative sense of self.

### A. The Relationship Between the Goals Young Disabled Women Set for Themselves and Self-Concept Development

A majority of the goals that the women reported setting for themselves revolve around being comfortable with who they are. Many expressed the desire to be happy and comfortable in their own skin. Some participants specifically noted the importance of being comfortable with one's body and how this comfort often radiates through increased confidence. Comfort with one's self both externally and internally has been reported to be an important component of both positive body image and a positive overall self-perception. For instance, Wood-Barcalow, Tylka, and Augustus-Horvath (2010) interviewed 15 college women with a positive body image and found that being comfortable and secure with who they are was key to their feelings of both inward and outward beauty. Respondents also noted that once you become comfortable with who you are, you also become freer in your communication. As one of their participants noted, "You just know that they feel comfortable in who they are. They're free to hug. They're free to compliment and free to joke. They radiate I'm happy to be who I am in this particular container" (Wood-Barcalow, Tylka, and Augustus-Horvath, 2010, p. 110). Being comfortable with oneself has also been

recognized as part of living a happier life (Haworth, 2017). Comfort with one's self was something a majority of the women in the present research had been missing, but longed for.

There were several related goals to becoming comfortable with who they were. These included being autonomous and advocating for needed accommodations. Making their own decisions and speaking up for their wants and needs appeared to be essential in bringing about the sense of security and comfort they sought.

Another important component of becoming comfortable with who they were involved being flexible in the goals they set for themselves. Many participants spoke of how having flexible goals was a necessity because of the changing nature of their impairments. The women in this research appeared to adjust their goals in a manner that fit with their capabilities at any given time. Doing so helped them reach important career and educational goals as well as helped them maintain a sense of comfort and security with who they are.

The importance of flexibility in the goals the women set for themselves falls in line with reports from disabled people in previous research. For instance, Ven, Post, Witte, and Heuvel (2008) conducted semi-structured interviews with eight individuals who had been living with a spinal cord injury for an average of 14 years. The interviews focused on the adaptive strategies they used post-injury. Respondents reported accepting their disability and changing their goals accordingly. They did not hold on to activities they did prior to the injury; rather, they found new activities and set new goals within the range of their abilities. They looked for alternatives for activities that had become impossible.

Goal flexibility appears to have important implications for general well-being and acceptance and adjustment to life with a disability. Elliott, Uswatte, Lewis, and Palmatier

(2000) conducted a series of different studies to investigate whether having a flexible, but durable, goal orientation predicted adjustment and well-being following the onset of disability. They determined that goal instability (flexible but durable goals) predicted acceptance of disability among individuals with a recent onset of disability. Additionally, they found that goal instability predicted well-being one year later among community residents with a disability. Goal instability was also associated with life satisfaction. These findings lend support to the notion that the flexibility the women had in the goals they set for themselves improved their well-being and help them along in their journey to becoming secure and comfortable with who they are. Group involvement gives the women an opportunity to discuss goals that are important to them and the ways these goals can be adapted to accommodate changes in impairment effects. Several of the women reported they had limited contact with other disabled people outside of the group space. Thus, the group provides a unique opportunity to learn ways to adapt their goals from people who have first-hand experience with doing so. Hearing from disabled women who have been flexible with their goals and are still successful and happy lets others know that even if their original goals are not met, it is possible to succeed and find meaning in life.

In addition to outlining general goals that were important to them as women with disabilities, the participants also discussed how they defined adulthood and what markers of adulthood are significant to them. In this vein, the women conceptualized adulthood as comprising several different markers, which often fell outside the range of markers thought to be traditional hallmarks of adult life. Indicators of adulthood mentioned included making your own choices and decisions, being your own self-advocate, being a leader/being respected, having people skills, and self-exploration. Some of these markers are consistent

with responses of emerging adults in previous research. For instance, as noted in the literature review, Sharon (2015) found that emerging adults in the general population valued individualistic and non-traditional markers of adulthood such as making their own decisions and accepting responsibility for their actions. My findings extend Sharon's results and demonstrate that both non-disabled and disabled emerging adults appear to be moving towards defining adulthood in more personally meaningful and non-traditional ways. This may have positive implications for self-concept development of disabled women who have historically experienced barriers to traditional goals, such as employment, independent living, and creating families of their own. The women in this study appeared to begin to reject traditional markers and define adulthood on their own terms. This may make it less likely that they will experience negative emotions from not reaching traditional milestones. However, the precariousness of feeling like an adult when one is unable to reach conventional milestones still loomed for some participants. As one participant noted, she considered herself an adult by default (due to age) and had given up trying to reach societally approve markers.

The narratives presented in this research revealed a link between the goals the women set for themselves and their achievement of a secure and comfortable sense of self. The participants' personal goals often mirrored the ways in which they defined adulthood. Many of the women set personal goals of being independent, being their own advocates and making their own decisions. Several of the women also articulated the defining features of adulthood in these terms.

**B. The Experience of External and Internal Barriers to Developing a Positive Sense of Self**

The women in this study reported experiencing a variety of socially constructed barriers that made it difficult for them to accomplish the goals they set and to achieve an affirmative self-concept. They reported experiencing a variety of discrimination, particularly in the domains of employment and healthcare. This is consistent with research discussed in the literature review. Women with disabilities consistently face both gender and disability discrimination when attempting to gain employment (Achterberg et al., 2009; Erickson, Lee, & Von Schraeder, 2012). Additionally, when asked what barriers they faced to reaching their goals as women with disabilities, a few women recounted vivid narratives of being discriminated against in healthcare settings, which prohibited them from maintaining their health and wellness. Some women could not navigate around their doctor's office and complete necessary testing due to the inaccessibility of clinic equipment and restrooms. Their experiences in this regard are not unique and have been well documented in previous literature. In a recent survey examining the barriers wheelchair users encounter to accessing healthcare, Stillman, Bertocci, Smalley, Williams, and Frost (2017) found that 54.1% of 432 wheelchair users felt they received incomplete care from their physicians. Many of their respondents reported a lack of physical accessibility within their healthcare facility. One in four participants reported the examination rooms were not large enough for their wheelchairs and more than half of the participants encountered barriers using the examination table. Only two thirds of the women in the study received pap smears within the past three years. Those who did not cited the absence of a physician's recommendation or inaccessibility as the main reasons for not receiving this test.

Even though the outright discrimination that the women in the present study experienced was hurtful and burdensome, inaccurate and harmful perceptions about women with disabilities appeared to be the most problematic. The participants recounted ways in which important people in their lives and society at large harbored a variety of negative ideas about disability and the disability experience. A few women recounted how medical professionals refused to validate their experience with disability and did not believe the accounts of their symptoms. Some of the women felt that such problems in the medical setting were more prevalent for disabled women than disabled men.

In addition to a possible gender bias, it is likely that cultural incompetence on the physician's part also plays a role in creating these inaccurate perceptions of the disability experience. Like the inaccessibility of healthcare settings, the cultural incompetence of physicians in regard to disability has been documented through previous research (Agaronnik, Campbell, Ressalam, & Iezzoni, 2019; Stillman et al., 2017). Agaronnik et al. (2019) conducted qualitative interviews with 20 physicians from five different subspecialties in order to assess their attitudes towards patients with disabilities as well as their cultural competence in this regard. Most physicians defined disability strictly within medical confines rather than taking into account the social and cultural factors of the disability experience. A majority of them also used culturally unacceptable language during some parts of their interview, such as “wheelchair-bound,” “handicapped,” or “suffering.” Furthermore, 57% of wheelchair users surveyed by Stillman et al. (2017) believed their physician had no more than moderate knowledge about their disability. Given that medical professionals are in positions of power, their perceptions of disability weigh heavily on the minds and bodies of their disabled patients.

The women in the present study also faced a barrage of negative perceptions from their family members as well as society in general. Some women said that the pressure to meet normative expectations of appearance and responsibility were omnipresent and detrimental. Relatedly, the women were exposed to the idea that disability is harmful and shameful and that it needed to be fixed. In addition to looming within the medical profession and society, these ideas often came directly from their parents. Since parents are authority figures, this made it even more difficult for the women to question or challenge the validity of these views. The women reported that they were often subjected to infantilization and overprotectiveness. Some of their parents had low or non-existent expectations for them in the sexual or domestic arenas. For instance, one participant provided a detailed account of how she had believed her mother's faulty assertion that she could never have children. Another participant spoke at length about how her family never expected her to live on her own or cook for herself, thus she was never taught how to do these things. This is in line with previous literature demonstrating that parents of women and girls with disabilities consistently have low expectations for them when it comes to having and raising a family, despite this being a desire for many (Hogansen et al., 2008; Rousso, 1988).

Given the barriers they faced and the negative messages they received concerning their worth and capabilities as disabled women, it is not surprising that the women overwhelmingly reported feeling a sense of loneliness and disconnection from others. These are unfortunate common occurrences among disabled people, at least until they find a way to connect with similar others. For instance, the disabled self-advocacy leaders interviewed by Caldwell (2011) also reported periods of loneliness and a lack of opportunity

to form meaningful friendships prior to their involvement in the self-advocacy movement. This finding is very similar to the reports of the participants in the present study. These feelings of isolation and loneliness are likely the results of being alienated from society at large and consistently receiving messages in various forms that a disabled person is less than and distinctly different than a nondisabled person. Lorrie, Sippola, and Bukowski's (1999) conceptualization of loneliness supports this notion. They explained that loneliness can either result from physical separation from others, or from feelings of psychological separateness from others around us. As the women received more and more negative messages from those around them, it is probable the psychological separateness they experienced increased. This likely contributed to the feelings of loneliness and isolation they reported.

The external barriers the women encountered while navigating the world around them eventually turned into internal ones. As discussed in the literature review, the experience of internalized oppression is a common occurrence among historically marginalized groups (David, 2014). This destructive process of internalizing the negative perceptions and attitudes that linger within the external environment results in a grossly inaccurate perception of oneself and others. For most of the women in this study, the process of internalized oppression appeared to result in a myriad of general insecurities about themselves, as well as insecurity specifically related to their disability, their body, and their sexuality.

This finding regarding internalized oppression is consistent with the experiences of the young disabled women interviewed in a study reported by Mejias, Gill, and Shpigelman (2014). The women who participated in this research recounted ways in which exclusionary



messages from the world around them became part of their self-belief schema and affected their sense of belonging to the world around them. The present study extends these findings to a sample with representatives from multiple states across the country and from Europe and Australia. It is important to note that in addition to the internalization of negative stereotypes about themselves, some women also reported that their bodily limitations affected their self-perception and made it difficult for them to reach their goals.

In contrast to most of the women who reported not being comfortable with who they were prior to group involvement, a few women noted that they already had a very positive sense of self before becoming involved in support groups. Although this pattern was not clearly discernible from the narratives collected for this research, it is possible that the women who reported a positive self-concept prior to group involvement had substantial support from family and friends outside the group. As discussed in the Literature Review, a significant positive correlation has been found between the global self-worth of young people with disabilities and their perceived level of support from friends (Antle, 2004; Shany et al., 2013). Furthermore, perceptions of family support among young people with intellectual disabilities have been found to be a significant predictor of their self-worth (Jones, 2009). Thus, a vast network of social support would make it more likely that the women in the present study could achieve a positive sense of self without the benefits of group support. It is also possible personality differences were at work here. It could be that certain personality traits lend themselves to greater resilience in the face of adversity. However, research on this topic appears to yield mixed results. Davey, Eaker, and Walters (2003) surveyed 181 eleventh grade students to determine whether two correlates of resilience, self-worth and coping, are related to particular personality profiles. They found

that the combination of being extroverted, agreeable, and open to new experiences was associated with high self-worth. Surprisingly, though, positive coping was also associated with the personality profiles of those who were high on disagreeableness and emotional instability suggesting that there may be an undiscovered compensatory element at work. It is essential to further examine other compensatory elements that promote or inhibit resilience in the face of adversity. This will help ensure that disabled women who are at greater risk for developing a negative self-concept are identified and support groups are tailored to best meet their needs.

**C. A Place of Comfort: The Communication Process and the Discovery of Self**

Overall my findings coincide with the research discussed in the Literature Review related to how support groups facilitate the coping process of women with chronic illnesses. Helpful factors in this regard that are documented in this research as well as previous research include giving and receiving information, the opportunity to be recognized within the group space, having access to role models who are in similar situations and sharing stories and words of encouragement with one another (Mundell et al., 2012; Steihaug et al., 2002; Winters & Sullivan, 2013). My findings go beyond this previous research and demonstrate that these factors are not just beneficial in the coping process as it relates to life with a chronic illness, but also facilitate a change in the self-concepts of young women with lifelong disabilities. One important factor in this regard was the gender composition of the group. This appeared to shape the group's relationship and what they shared with one another. A majority of the women in this research said there was a distinct relatability in women-only groups that was not present in mixed gender groups. Most women felt safer to express their emotions and discuss women's issues in a female exclusive space. As one

participant noted, an “odd intimacy” often develops within online support groups in which people are quick to disclose intimate details about their lives to one another.

Previous research has indeed revealed that the Internet accelerates intimacy within different types of relationships including friendships (Birnie & Horvath, 2006; Guo, Bricout, & Huang, 2005; Lomanowska & Guitton, 2016). Prager (1995) defined online intimacy as the “dyadic exchange that involves sharing what is personal and private” (as cited in Lomanowska & Guitton, 2016, p. 139). There is evidence to suggest that young women seek more intimacy and self-disclosure in friendship relationships than young men do (Buhrmester & Furman, 1987). This may make the support group realm more appealing to women in general.

Interestingly, a few women reported that even in online groups that were open to both men and women, it was mostly women who participated. This observation has been reinforced through previous research. For instance, Holmes, Ford, Yuill, Drummond, and Lincoln (2011) compared the attendance rates at a psychological support group for men and women with Multiple Sclerosis and low mood. They found that women were significantly more likely to attend the group than were men. Sophia, one of my participants, surmised gender norms has something to do with this. Her conjecture appears to be supported by previous literature. George and Fleming (2004) found that men experience social, psychological, and structural challenges to help-seeking. These include threats to masculinity, embarrassment, fear and guilt. On the one hand, the plurality of women using support groups is beneficial for women. Surrounded by a large majority of other women they likely feel free to speak their mind regardless of the gender restrictions applied to the support group space. On the other hand, however, this is worrisome for men, since the

majority of them seem not to be obtaining the psychological and emotional support gleaned from support group involvement.

Several support group members and group coordinators reported that the communication that took place in both in-person groups and online groups for women with disabilities was fraught with emotion. They often found the process of this emotional communication to be cathartic and freeing. This finding supports the idea of a distinct gender difference in communication styles in support groups. Mo, Malik, and Coulson (2009) conducted a comprehensive literature review of 186 studies in order to examine the gender differences in communication in online health-related support groups. They found that women participating in groups related to women's health were more likely to express emotion, such as using emotional words and disclosing feelings related to their lifestyles, than men participating in men's-related health groups. The men tended to focus on task-related or information-related discussions. These findings are in line with my findings. Women in my research consistently reported that the communication that took place within the groups was extremely emotional at times and this was a beneficial and unique aspect of the support process. This finding also highlights the importance of women-only support groups, especially since Mo, Malik, and Coulson (2009) found that gender differences within communication were less evident in mixed-gender groups. This suggests that women are less likely to engage in emotional release with men present.

Although the majority of women felt most comfortable in groups exclusively for disabled women, a few participants noted that gender exclusivity was not an important feature of a support group for them. It is possible that gender and issues surrounding gender were not a central part of their identity or that their gender identity was not exclusively

female, making the need for a female exclusive space not as pertinent. This appeared to be the case for at least one of my participants who indicated that her gender was not that important to her and she was not interested in many gender-related issues.

The distinctive relationship that developed between group members was another feature of support group spaces that helped lay the foundation for self-concept development. In the present study the connection and bond the women felt with others led them to examine their own life circumstances in relationship to similar others and share in their feelings of pride as a disabled person, as well as acknowledge the shared oppression they face as a group. In the context of the present research findings disability pride may best be understood as not necessarily being proud of one's impairment per se, but proud of the human diversity and valuable experience that life with impairment brings about. Disability pride also encompasses resisting stigma associated with impairment, embracing one's impairment, asserting one's humanity, and realizing that one can lead a rich and full life as a disabled person--a life that is possibly even richer than might be true if the impairment did not exist. Being able to internally integrate our similarities and differences from others helps create psychological wholeness and is an important part of building a positive disability identity (Gill, 1997). This is in contrast to separating your impairment from who you are and viewing it in negative terms. The groups represented in this research appeared to provide a platform for this identity integration and the pride that stems from it, to begin to flourish. As members of disability empowerment groups the women were able to integrate with the disability community, or, as Gill (1997) calls it, they "came home" to their disabled sisters.

This is similar to the experience described by the self-advocacy leaders who took part in Caldwell's (2011) research. His interviewees said that joining the self-advocacy movement initiated an "ah-ha" moment. When they came out from underneath the loneliness and isolation, they realized they were not alone in the experiences they faced and they collectively had the power to change their own circumstances. In the present study what the participants learned from other group members led to personal reflection and transformation. They became confident to speak up for their wants and needs and expressed a newfound sense of comfort that they longed for. In a sense, Cooley's (1902) concept of the "looking glass self" was activated through group involvement. The women began to see themselves reflected back in the accomplishments and pride of other disabled women in the group. For many women this process enabled them to recognize their own humanity and value as disabled women.

In almost all cases it was not just one relationship within the group that stood out to group members as beneficial. Instead, an informal collective mentorship process often evolved within both online and in-person groups. Group members and group coordinators spoke at length about how a reciprocal helping process emerged in their groups. Each member contributed to the support group space in unique ways. This nontraditional form of mentoring is beginning to be explored within the online context. Campbell, Aragon, Davis, Evans, Evans, and Randall (2016) interviewed 28 young authors who were members of fan fiction communities; they also conducted a nine-month participant observation of these communities. The researchers discovered that a distinctive distributive mentoring process emerged. This process encompassed seven unique features: aggregation (authors receive feedback from several members); accretion (the accumulation of individual knowledge);

acceleration of the learning process; abundance of information; availability (interactions are available to the larger community); asynchronicity; and affect (encouragement from other members). All of these features could be found in some manner within the online forums discussed in the present study. The women interviewed had access to consistently available information from a variety of people who persistently encouraged them to reach their goals and engage in self- discovery. This confirms that a distributive mentoring process does and can evolve in an online support group context.

Within the online forums the women had a variety of information at their fingertips including resources on women's issues, accessibility, healthcare and conceptual models of disability. This information, especially regarding the social model of disability, gave the women the framework they needed to begin to change their self-perception. Notably, Emma, a participant in the present study, commented that in her experience, discussions of the social model seem to flourish in disability empowerment oriented groups, but within chronic illness support groups, people were less open to learning about the social model. It is possible people in chronic illness support groups are older and have a later onset of disability than those involved in disability empowerment focused groups.

It has been previously documented that those who are older have lower levels of disability pride than younger individuals (Darling & Heckert, 2010). Additionally, those with lower levels of disability pride also have a later onset of disability. Older individuals with a later onset of disability have likely grown up as non-disabled. They have had ample opportunity to internalize ableist norms and values. Therefore, when disability or illness onset occurs at an older age it is difficult for people to perceive it as anything other than a loss of function and an individual problem. On the other hand, people who have early-onset

disabilities may be more likely to incorporate disability as a part of who they are and be exposed to other disabled people at a young age. These dynamics make it more likely that younger people will experience greater levels of disability pride and be more open to social model thinking than older individuals with a later onset of disability. These factors may be playing a role in Emma's observation that those in chronic illness groups are less receptive to the social model of disability.

Several of the women in the present study reported a direct connection between the communication and sharing process in their support groups and a positive change in how they felt about themselves. As discussed earlier, many conveyed the desire to be comfortable with who they are. They reported that highly attentive communication and being surrounded by similar others helped them feel free to disclose private thoughts and feelings. Oftentimes they were not comfortable discussing these feelings outside of the support group space. Huang (2016) conceptualized self-disclosure as encompassing five components: amount, depth, honesty, intent, and valence. These characteristics rang true in many of the conversations that took place in the support groups that the women were part of. Previous studies have revealed that self-disclosure and receiving caring words and support from other parties has a positive effect on social wellbeing and perceived emotional support (Huang, 2016). My findings go beyond this, however, and show that the self-disclosure that took place in the support groups appeared to lead to changes in how the participants felt about themselves and understood themselves as part of a larger collective of disabled women.

The online environment has been identified as particularly ripe for promoting self-disclosure and the expression of who we truly are (Bargh, McKenna, & Fitzsimons, 2002;



Valkenburg & Peter, 2011). Through a series of experiments, Bargh, McKenna, and Fitzsimons found that people are more likely to express their true self-qualities in Internet communication than in face-to-face communication. Some possible reasons for this finding have been investigated. Valkenburg and Peter identified three characteristics of the Internet that promote self-disclosure and controllability of self-presentation (how we present ourselves to others) within an online environment. These characteristics include anonymity, asynchronicity and availability. These features make this platform particularly appealing to young people. Each of these characteristics appears to play a crucial role in the online support experiences of the participants in this study. Anonymity may lead some individuals to be less concerned with physical appearances, which results in greater self-disclosures and more control over self-presentation. This seemed to be the case for many of the participants in my study. They consistently recounted how they and their fellow group members were open with one another about their disability experiences and some made mention of how the anonymity of the online environment can be used to experiment with disability identity. On the flipside, anonymity may stimulate impulsive reactions, which can lead to hostile communication. In fact, one of the participants in the present study noted that hostile communication in one of her online groups deterred her from participating.

Asynchronicity and availability of the Internet, the second and third features identified as promoting self-disclosure and self-presentation, had important implications for my participants. Valkenburg and Peter (2011) noted that asynchronous or non-simultaneous Internet communication gives greater control over self-presentation and leads to greater self-disclosure. Asynchronous communication gives people time to craft what they want to say and how they want to be perceived. In addition, the asynchronicity of most Facebook

communication is likely an important accessibility characteristic for many users with physical disabilities. These users may have difficulty with fine motor function and keeping up with synchronous online communication. The Internet was available to many of the participants twenty-four hours a day. They relished being able to log on to the Internet on their own time and not being bound to a scheduled meeting time. The women discussed how the Internet provided them with boundless connections. They took joy in being able to connect to people from around the world. For many of the participants this brought to light new and empowering perspectives of disability they had not previously been exposed to. The availability and asynchronicity of the web platforms they used gave the women the tools they needed to break down the negative views harbored of themselves and their disability. This helped ignite the emergence of a new vision of who they are.

Consistent with Baumeister's (1999) notion of reflective consciousness, discussed in the literature review, it appears that the women sought self-knowledge through their interactions with fellow group members. The women shared ideas with each other about disability rights, the roots of disability oppression and disability theory. They also learned about the possibilities available to them in the vocational, avocational, and relationship realms. For many women this knowledge was used to engage in self-reflection. This process of reflection helped replace the distorted self-concept they had previously. The groups acted as a stimulus to stop and reverse the internalization of negative stereotypes about disability.

Although most of the time participants' self-concepts flourished through the open communication process created in their support group space, it is important to note that on occasion the women reported the online environment evoked feelings that may suppress

self-concept development. Some women reported that at times they were anxious during online interactions. However, previous research seems to suggest that, in general, online communication evokes lower levels of social anxiety than off-line interactions (Yen, Yen, Chen, Wang, Chang, & Ko, 2012). For the few individuals who reported anxiety during interactions in their online support communities, these anxieties in part stemmed from the fear of being attacked for sharing their opinions and the possibility that their written words may be interpreted the wrong way. This could be the result of a lack of emotional intonation within Internet-based communication.

The terminology used within group conversation was another aspect of the communication process within online support groups that posed a barrier for a few women. For instance, some women expressed reservations about taking part in a group that used language such as “people with disabilities” (which for some people contravenes a strong disability identity) or the terms “crip” or “gimp” even if they are used in a reclaiming and empowering manner. For these participants these words were just too far afield from how they identify themselves to warrant their participation.

Words are powerful tools that have a profound effect on the way people view themselves and the ways others view them (Clinton & Higbee, 2011). As such, words have the power to build bridges to relationships or create boundaries. Expanding on this Clinton and Higbee proclaimed, “Language is the invisible hand that possesses incredible power to hold people down or give them a boost. The scope of one’s grasp of language as a tool can shape or limit one’s perception of the world. It is imperative that words or phrases convey the meaning that the speaker or writer intends” (2011, p. 15). Thus, it is essential we choose words carefully within support group communities to ensure that the language we choose is

welcoming and inclusive. This way, the widest population that the community is intended for is inclined to participate.

As illustrated above self-concept development flourished for most in support group spaces surrounded by similar others. These spaces promoted free and open communication including self-disclosure about intimate aspects of themselves and their impairment, expressions of emotion, and exchange of pertinent information. Through this process the women began to gain a newfound sense of comfort and security with who they are.

**D. The Strength of Community Belonging and the Emergence of Collective Leaders**

Asked to describe aspects of the support group process that influenced the way they felt about themselves, several participants responded in part by saying that just belonging to a supportive community was influential in this regard. The simple act of belonging to a community, whether it be in-person or online, was reported to ignite a boost in self-concept. Being part of a community that provided them with great emotional support and friendships helped them become more confident and assertive about who they are. This notion is consistent with social identity theory, which posits that group membership is an important part of a person's self-concept (Tajfel & Turner, 1979).

Support group membership allowed the participants to situate themselves as part of the disability community collectively. This newfound collective consciousness gave many participants a scaffolding to become self-assured about who they are as disabled women even in life outside of the group. For instance, Sophia said she no longer felt she stood out like a "sore thumb" when she used her mobility device out in public. She attributed this change in feelings to her membership in a support group with other people who also used

mobility devices and faced the same social problems as she did. This finding is consistent with Marmarosh and Corazzini's (1997) research discussed in the literature review. They experimentally demonstrated that salient support group membership is a source of both individual and collective self-esteem and helps people cope with situations they face outside of the group.

All the women in my research participated in empowerment and social justice oriented groups. Many of the women took great pride both personally and collectively from being part of a group allowing them to explore and assert their rights as disabled women. Laura Hershey (2017), a disability rights activist and journalist, articulated the pride that stems from collectively asserting our rights as disabled people which seems to mirror the experience articulated by many of the participants. In her acclaimed poem, *You Get Proud By Practicing*, she writes:

You can add your voice  
 All night to the voices  
 Of a hundred and fifty others In a circle  
 Around a jailhouse  
 Where your brothers and sisters are being held  
 For blocking buses with no lifts,  
 Or you can be one of the ones  
 Inside the jailhouse,  
 Knowing of the circle outside.  
 You can speak your love  
 To a friend  
 Without fear.  
 You can find someone who will listen to you  
 Without judging you or doubting you or being  
 Afraid of you  
 And let you hear yourself perhaps  
 For the very first time.  
 These are all ways  
 Of getting proud.  
 None of them  
 Are easy, but all of them  
 Are possible. You can do all of these things,

Or just one of them again and again.  
 You get proud  
 By practicing. (para. 4)

This orientation gave the women a strong desire and platform to emerge as leaders both within the group and the world outside of the group. Those involved in online groups often took advantage of the access to a large community of similar others to express their ideas and get others involved in issues near and dear to them. For instance, one woman used her online group to let others know about a telepresence device she found very fascinating and helpful. She encouraged others in the online community to begin using it as well. Another woman spoke about how she emerged as a leader in her online groups through her blog posts about the social model of disability and the importance of not being embarrassed by impairment effects and bodily functions. Opportunities for leadership also emerged within face-to-face support groups. According to group coordinators these opportunities came to fruition through member presentations and giving women control over the structure and content of the meetings.

Other research has shown that being part of a community can spark the desire to be a leader and an activist. Mejias et al. (2014) found similar results within the narratives of nine disabled young women who participated in a face-to-face support group. The women in that study recounted how their participation in the group broadened their horizons and empowered them to assert their right to belong in the world around them. Likewise, leaders within the self-advocacy movement interviewed by Caldwell (2011) experienced a similar trajectory to the women interviewed in the present study.

My research demonstrates that both online and in-person support communities for disabled women are valuable resources as their members enter adulthood. Although the

support groups in my research were a very small subset of the disability community, being a member of them appeared to have similar implications to being a member of the larger disability advocacy community. The majority of participants reported that being a member of their support group helped initiate their desire to be an advocate for themselves and others. Additionally, through group involvement participants recognized that even if a disability rights issue does not pertain to their particular situation it is still of their concern. This recognition is further evidence of the development of a collective consciousness.

The leadership style that emerged within the support groups themselves was not the traditional hierarchical style of leadership, but rather collective in nature. This collective leadership is often observed and advocated for within the disability community at large. Foster-Fisherman, Jimenez, Valenti, and Kelley (2007) conducted qualitative interviews with 21 disability rights leaders at the grassroots and states level. The leaders interviewed expressed the need for a more inclusive approach to leadership. They saw a collective style of leadership as more effective than the traditional hierarchical and individual styles. In their view, leadership development needs to focus less on developing individual leadership skills and more on developing the skills within groups collectively. One participant in their study articulated the collective leadership style and its benefits, saying, “We have to think about leadership development not as developing individual leaders but as developing collective groups that are capable where everyone has some leadership skills” (Foster-Fisherman, Jimenez, Valenti, & Kelley, 2007, p. 347).

Similar to the finding regarding collective mentoring, the support group environment provides fertile ground for collective leadership to take place and was evident in the responses of participants in this study. None of the online groups had a single individual

leader. Likewise, the group coordinators of in-person groups indicated that a collective leadership style was present in their groups. The members themselves were responsible for making important decisions about the groups' activities and structure. In both the online and in-person formats it seemed group members took their own initiative to chime in when they saw fit and in so doing developed leadership capacities. The support group environment gave each member an avenue to practice leadership skills and be connected to others who demonstrate leadership skills. This hands-on practice is extremely important, especially given that traditional leadership training has not been found to be effective in producing successful leaders within the disability community (Foster-Fisherman et al., 2007).

E. **Comparing the Views of Group Members and Group Coordinators**

The group coordinator data and the group member data provided triangulation for the findings. Even though the group coordinators were speaking from different positionality than the group members, their views were remarkably similar. Both samples reported comparable barriers to in-person support group attendance for women with disabilities. From both perspectives these barriers included transportation, health problems, schedule conflicts, and lack of awareness that the support groups exist. Both groups also noted that younger women are hesitant to attend in-person support groups for various reasons. These consisted of meeting times not being conducive to school or work schedules, topics within support groups that do not cater to the interests of younger women, overprotective parents that are worried about their daughters' traveling to and from the group, and not enough younger core group members to maintain their interest. The fact that both group coordinators and group members noted that there were not enough younger women within



in-person support groups to maintain their interest substantiates Emma's assertion that women are hesitant to attend in-person meetings when the majority of the group's membership is significantly older than they are.

The finding that there are many barriers to the sustained participation of younger women in in-person support groups is not surprising. During the recruitment process it was exceedingly difficult to locate groups with a core membership between ages 18 and 35. A majority of the groups contacted had a core group membership of 45 years old and above. Many groups reported having only one or two members who were in their 20s or 30s. This lends credence to the notion that younger disabled women prefer to get their support online instead of face-to-face.

Previous research has documented similar barriers to attending face-to-face support groups, mostly within samples that included individuals with cancer and chronic illness (Delisle, et al., 2016; Ussher, Kirsten, Butow, & Sandoval, 2008). For example, Ussher et al. (2008) interviewed 113 individuals who either dropped out or never attended a face-to-face support group for cancer survivors. Forty-one percent of individuals reported practical reasons such as transportation difficulties, scheduling conflicts, feeling like it's time to move on from the group and health concerns as the reason for dropping out of their support group. Reasons cited for not attending a support group at all included a lack of knowledge about how support groups can help, a lack of awareness that they existed, resisting the role of a "cancer patient," the feeling that support groups are negative places, and difficulty finding a support group comprised of similar others. One of their participants specifically mentioned that being unable to find a support group comprised of individuals of similar age to her own hindered her desire to participate in a support group, saying, "I felt too old for

the younger woman's group. I like to be in a group with people who have the same problems as mine" (Ussher et al., 2008 p. 24). Although in my research it appeared younger disabled women were less likely to attend face-to-face support, the experience of this individual does complement the feelings expressed by my participants and supports the notion that the age composition of the group may affect the attendance rates of those who fall outside the group's age range.

While research on attendance rates within support groups specifically for women with disabilities appears to be sparse, Morrison, Colbourn, Budhathoki, Sen, Adhikari, Bamjan, and Manandhar (2015) explored the attendance rates at community support groups in Nepal for women with and without disabilities. They found that those with the most severe physical disabilities were less likely to attend community support meetings than non-disabled women or women with other types of disabilities, including sensory disabilities, behavioral disabilities, and intellectual disabilities. The reasons for not attending included family members having low expectations of them and being overprotective, and practical barriers such as transportation and distance. These are similar to the barriers reported in the present study, which supports the idea that these challenges to attendance, at least for physically disabled women, persist across geographical boundaries.

Despite challenges to attendance within in-person support groups, both formats appeared to yield similar results with regard to a positive change in self-concept. Group coordinators of in-person support groups and members of online support groups reported an omnipresent atmosphere of openness and trust. These components were important antecedents to self-concept development. The similarity in atmospheres between the two formats is evident in the quotes below from Olivia, a group coordinator of an in-person

disabled women's group, and Bella, a member of an online support group for disabled women:

They felt really open to discuss whatever issues that they needed to discuss and they liked, you know, felt like they got something from some of the topics of discussion that we brought in. . . . But in terms of those that were there they said they felt that it was a group that was open and, you know, that they could talk about what they wanted to talk about. They felt listened to and they felt supported. [Olivia]

I think that group is very kind of empowering because disabled women that come together and just share experiences and ask questions and it seems very open and that people are extremely open-minded, which I love. . . . I think it's [Women Only groups are] important just because, you know, you can talk with other women about kind of more intimate topics without feeling like you have to censor yourself. So I think it's important to have a place to have that sort of space to ask questions and come together and share experiences. [Bella]

It was within this safe atmosphere that the women gained confidence and reassurance to broaden their horizons and pursue goals that were important to them as they navigated in and through adulthood. Both group formats appeared to help transition into adult life. Interestingly, the in-person group format appeared to provide women with more tangible resources to help in their transition to adulthood, while the online format provided more subjective psychological support in this regard. The group coordinators of in-person groups reported connecting their group members directly with transition services, such as assistance with writing resumes, vocational rehab services, and outlets to find affordable, accessible housing. One group coordinator mentioned that some members of her group were now living independently, thanks in part to the resources they received from the group. While these resources appeared to be available within online support formats, many of the online group members spoke of how emotional support and the sharing of experiences regarding important issues of adulthood were most valuable in their transition. The online group members spoke passionately about how the group gave them a space to process and

discuss emotions related to transition issues. Through the discussions with online group members they were also able to redefine independence in a way that recognized and destigmatized the interdependent nature of all human beings. There was also evidence that communicating in the online groups helped the women shift their goals from society-approved goals to individual subjectively important goals. There are a few reasons why emotionally oriented transition support appeared to take precedence over tangible resources within an online support context. It might be that the women have less salient moderation in online groups to help them navigate tangible resources within a virtual environment. This in turn would make it less likely that they would seek out and be able to effectively utilize these resources. Online support users appeared to take full advantage of the Internet's unparalleled ability to seamlessly connect similar others from across the globe, thus allowing emotional support to flourish. On the other hand, the face-to-face support group users have the benefit of a group coordinator who is presumably well-versed in helping individuals find and utilize pertinent transition resources. This may help explain why tangible transition resources were discussed at length and noted as helpful by the group coordinators but were not prominent in the narratives of the online support group users.

The group coordinators and the group members seemed to relish having a physical space to convene and connect with one another. Group members cited the lack of physical space to connect as a drawback to the online format. They saw a material space for meetings as important to encouraging mobilization for collective action. For some of the participants meeting face-to-face in community spaces was essential to sending a message to the community at large that they had a right to belong in society. Group coordinators reported similar benefits to meeting in person. They said group members benefitted from

community outings and having guest speakers present pertinent information. These opportunities are hard to reproduce in a completely virtual meeting space.

In summary, despite some distinct advantages to the in-person support group format, there were some major barriers to establishing and maintaining face-to-face support for disabled women. These included attendance problems, lack of funding/resources and conflict among members. In a few cases these challenges were overcome, and successful and thriving in-person support groups were established. Comparatively, though, the majority of barriers that the in-person group coordinators reported were not reported in the online support environment. It appears the online platform circumvents many of the barriers to in-person support, while producing similar benefits to those of face-to-face groups.

#### F. **Limitations and Directions for Future Research**

Although valuable information was gained, there are several limitations of this study that should be noted. The disability diversity within my sample of group members was low. Ten of the 12 support group members interviewed identified as having physical disabilities with one of these 10 individuals also identifying as having a psychiatric disability. Only two group members identified as having a sensory disability. One of these individuals identified as deaf using a lowercase “d” in her email interview and the other individual with a sensory impairment identified as blind. This sample does give insight into the aspects of the support group process that are beneficial for people with physical disabilities. However, it only provides a glimpse into what is helpful for those with sensory disabilities and psychiatric disabilities. It does not provide any information about the beneficial aspects of the support group process for those with other types of impairments. Future research should focus in-depth on aspects of the support group process that are beneficial for those with

disabilities other than physical disabilities, such as intellectual disabilities, psychiatric disabilities, and sensory disabilities.

The sample of group members also lacked ethnic and racial diversity. A majority of group members identified as White (eight participants) with the remaining group members identifying as either Hispanic or Asian. The ethnic/racial makeup of my sample of group members gives a limited perspective of how support group involvement influences the self-concept of people from diverse cultural backgrounds. One participant, who is Asian, specifically mentioned how culture played a significant role in her family's behavior toward and expectations for her as she transitioned to adulthood. Further research is needed to determine exactly how, if at all, support group involvement can navigate such cultural barriers. Furthermore, since participants identified family members as barriers to pursuing their goals and achieving a positive sense of self, future research should examine disability perspectives among parents and family members of young women with disabilities. In so doing we can work to better alleviate these challenges.

Another limitation of this study was that it did not examine longitudinally the change in self-concept that occurred during group involvement, as originally intended. The newest member recruited had been involved in her support group for a year at the time of her interview, and the average length of involvement at the time of the group members' participation in the research was five and a half years. Unfortunately, recruitment efforts did not yield new members of support groups, which made it difficult to examine a change in self-concept over time. Although the data did include retrospective responses regarding participants' self-perceptions before and after support group involvement, this does not provide a focused, dynamic view of the path taken to achieving a positive sense of self.

Additional research is needed to examine the longitudinal trajectory of the change in self-concept due to support group involvement.

During the process of member checking, one group member noted that it would be interesting to examine whether people who are born disabled are less likely than those who acquire their disability later in life to utilize support groups. She believed individuals who were born with their disability might be less likely to seek out support since they have never had to “mourn” a loss of mobility. The sample in the present study included members who are all actively involved in support groups and acquired their disability at a young age. As such, my research is not able to provide insight into this question, but the possibility of this phenomenon would be interesting to explore in the future.

What this study can report about the in-person support group process as it relates to self-concept development was limited by sample composition. Recruitment efforts yielded only one user of exclusive in-person support and two other women who used both in-person and online support groups. Nine of the 12 group members had experience with online support only. This limits the study’s ability to explore the benefits and drawbacks of the face-to-face support group process for the population. Also, it is difficult to compare and contrast the online support format with the in-person support format. It will be advantageous for future research to directly compare the benefits and disadvantages of online versus in-person support for young women with disabilities.

If adequate sample size can be recruited, it might be helpful to conduct a quantitative investigation regarding the benefits of the support group process for young women with disabilities. For instance, drawing on these qualitative research findings, conducting pre- and post-measures of characteristics such as self-esteem, disability identity, and leadership

qualities may be helpful in further investigating the beneficial outcomes of the support group process for this population.

Future support group research could focus on populations other than young disabled women. It would be interesting to explore whether an all-male support group would have similar beneficial effects on disabled men's self-concept development and their ability to reach important milestones of adulthood. The group dynamics could also be investigated to explore whether support groups composed of all men produce a culture of shared leadership similar to the one found in the present study. It would also be informative to examine the women's observation that disabled men do not often participate in support groups. Additionally, it would be useful to examine the helpful aspects of support groups for women age 45 and older. This research could shed light on how older women view their disability and whether support groups are effective in helping these women gain empowering views of themselves.

The data from in-person group coordinators in the present study was enlightening, but this information also had limitations. The serious problem of recruitment and attendance of younger disabled women in in-person support groups became apparent during the recruitment process. Thus, the focus of this research began to shift away from recruiting in-person group members and more toward exploring the group coordinators' perspectives on the recruitment barriers they faced. That said, the group coordinators' perspectives ended up playing a larger role in this study than originally intended. Because of this late turn in research focus, some important demographic data for the group coordinators were not collected during their initial interview. Attempting to collect the demographic data several months after the initial interview proved difficult. Only seven of the eleven group



coordinators responded to my request for follow-up information. This makes it hard to examine the effects of age, ethnicity, and disability status. According to the data collected from the individuals who did respond, it appears the group coordinators came from fairly ethnically diverse backgrounds with all but one identifying as having a disability. They were on average 12 years older than the support group members that took part in this research. Exploring whether the similarities or differences between the group coordinators and the group members affect the outcome of group support presents an intriguing avenue for future research. Also, it would be interesting to explore the value a coordinator adds to the support group process and whether coordinator background and the coordinators' beliefs about disability and the origins of disability oppression influenced the group. Difference in outcomes between peer led groups and coordinator led groups should also be explored through future research.

G. **Implications of Findings and Recommendations for Disabled Women's Support Groups**

The discovery of the components of successful support groups for women with disabilities helps create a support group model that can be helpful in planning groups that assist women with disabilities in achieving and maintaining a positive self-concept. Also, this research helps us understand the critical components within the support group process that assist women in reaching subjectively important milestones of adulthood. Relatedly, these data can be used for funding applications that are targeted towards programs for women with disabilities. My findings inform the following recommendations for the creation of online and face-to-face support groups that help young disabled women gain and maintain a positive sense of self.

1. **Recommendations for online support groups for young women with disabilities**

Since participants in this research highly favored the Facebook platform as a means to achieve support, individuals looking to create a new support group are strongly encouraged to consider using such platforms. Users should be instructed to make the content they post as universally accessible as possible. The use of video and image descriptions and closed captioning for audio is strongly advised. Many of the participants in this research also noted the need for group content to be well organized and searchable. This can be challenging using the Facebook platform. Thus, the group administrators ought to take the time to organize the content into albums that are clearly labeled and easily navigated. Additionally, users need to be encouraged to communicate regularly, openly, and honestly with fellow group members. One way this could be accomplished would be for group administrators to start a conversation by posting an honest story about their own lives, which their fellow group members can relate to. This is similar to what Emma, a participant in this research, did to create a group culture of candor and honesty about bodily functions and the disability experience. Keeping in mind the intimate nature of the topics often discussed within the group, it is important to establish firm group rules. Communicating the expectation of confidentiality among group members is essential. Members must feel safe in order to self-disclose and discuss information and feelings with others.

It is important not to rely exclusively on the written word within the support platform. As participants in this research reported, it is vital that they see positive visual imagery of disabled women accomplishing their goals and being successful. This appears to

be critical for raising self-confidence and self-perception. In this vein, it may be helpful for group moderators to post weekly videos and photos of successful role models in the disability community.

According to the participants in this study, opportunities to be leaders within their support group community helped increase their confidence and advocacy skills. Thus, it might be valuable for online support groups to set up a “member of the month” recognition program. This would allow an opportunity for the featured group member to write a guest blog about a topic of interest to them and/or a life experience they would like to share with others. They could also be encouraged to share photos and videos as they see fit. This would naturally increase sustained participation as the women wait for their turn to lead the discussion as a featured member.

Finding topics of interest to the younger cohort is another technique that the participants reported as essential to maintaining a successful support group for young disabled women. It may be useful to conduct member surveys, which will help determine what content is desired and what should be featured on the group’s page. The results of this research indicate the Internet holds great promise as a platform for support groups, but it will take time and effort from all those involved to make sure the groups are and continue to be a success.

## 2. **Recommendations for in-person support groups for women with disabilities**

Although the data from this research suggest that establishing and maintaining an in-person support group is fraught with challenges, it is possible to have and maintain a successful face-to-face group. The 11 in-person group coordinators that took

part in this research shared some insightful information about what worked for them.

Networking was one of the most successful recruitment strategies. Coordinators used a variety of sources including internal contacts within the group's hosting organization, external contacts outside the group's hosting organization, and word-of-mouth to recruit individuals. Thus, when first recruiting for a new in-person group, it would be advisable to cast a wide net within the target community. Recruitment efforts should not be limited to one or two points of contact. Recruiters should strive to be creative with outreach approaches and encourage others to help spread the word. Making personal contact with potential recruits is also recommended. Grace, who ran a very successful support group for young women with disabilities for over 11 years, had considerable success reaching out to the local school district and going to talk directly with young disabled female students about the group and what it had to offer.

Reminder calls were also seen as essential to maintaining consistent attendance. It is recommended that group members be called and reminded of the time and place of the group between 24 to 48 hours prior to the scheduled meeting time. In addition, group coordinators need to do their best to accommodate the complex schedules of the majority of their group members when meeting times are set. Based on group coordinators' responses, helping women find reliable, accessible transportation is another key to success. There is a variety of ways this can be accomplished. For instance, one group represented in this research was lucky enough to have funding to pay for transportation to and from the group. Another group coordinator reported that she helped the women learn how to use public and paratransit services successfully. Both of these groups had thriving attendance. If there is

not reliable, accessible transportation in the area, it might be more practical to pursue an online support group format.

Once a core group membership has been established, data from the present study revealed there are a number of strategies that will help in maintaining a successful in-person group. Group coordinators resoundingly said that giving group members ownership over the group is essential. Thus, future in-person support groups for young disabled women would be well advised to let their members guide the way. Still, group coordinators did report that group members were hesitant to take the lead when it came to planning and maintaining the group. This was a source of frustration for many group coordinators. It is important to recognize that the group members' passivity may be an unfortunate consequence of disability oppression. For some of the young women their involvement in the group may mark the first time they have ever had permission to discuss topics such as disability and sexuality, let alone have permission to take charge of these discussions and group activities. Thus, it is essential that the group member has an opportunity to build a strong knowledge base and relationships with other group members before being asked to take charge of their own group. Instituting activities geared towards increasing leadership skills and confidence of group members may also be necessary. The coordinators indicated that caring and gentle leadership was needed to keep the group members on-topic and productive during group time. Relatedly, coordinators also mentioned having to use creative conflict resolution strategies when moderating their face-to-face groups. Some helpful strategies included taking votes on when and where to do activities and teaching the women about healthy and respectful boundaries. Setting manageable goals to be accomplished in face-to-face meetings was also reported to be helpful. Prospective group

coordinators might find it beneficial to come up with long-term and short-term goals for their group. The short-term goals could be mapped out for each group session and concretely related back to the long-term goals. It is important that adequate staff and resources are available to meet these objectives. If resources are lacking, the group goals need to be reexamined and edited to be compatible with available resources. This will set the group up for success moving forward.

During face-to-face meetings it is essential that a safe haven be created where women feel comfortable to express their emotions and talk about important issues in their life. Thus, it is vital that confidentiality of group members be a priority within the group space. Members should be encouraged to help each other, and each member given the opportunity to demonstrate and utilize their strengths, whatever those may be. This will help foster a culture of collective mentoring, similar to the ones reported in this research. All of the face-to-face support groups represented in this research went beyond merely giving members a space to share emotions and stories with one another. They took field trips out in the community and aimed to teach the women about disability justice and sexuality. All of these components worked together to help group members build a healthy and holistic self-perception. Support group spaces for young disabled women should aim to teach them about different models of disability and provide them with opportunities to gain knowledge about disability rights and sexuality. This will empower them to see themselves and the world around them in new and different ways.

#### H. **Blending Face-To-Face and Online Formats**

As we move forward into the next generation of support group models, it is important to keep in mind that online and in-person formats do not have to be mutually

exclusive. The two models can potentially be blended to compensate for the shortcomings of each. In-person get-togethers could be planned and advertised within the virtual support group space and be available to those who can attend. Given the advent of live video streaming, it may be possible to stream the get-together within the closed virtual community for those who are unable to be there in person.

In a similar vein, video chat could be scheduled within online groups to give members some valuable face time with one another. This would foster opportunities to see the emotions and intonation that often are absent in written online communication. The results of this research indicate that both formats offer promise for young disabled women and help them achieve a new confident sense of self. It is possible that blending these two formats could create an even more powerful stimulus to positive self-concept.

The empowered consciousness that emerged among many of the women in the present study extended beyond the confines of the individual woman. The women recognized their responsibilities and rights as members of the disabled women's community collectively. Elizabeth, a participant of an in-person support group poignantly expressed, "The group's message just makes me feel stronger and deeply about wanting to help solve the struggles that we face. It makes me just push harder for us to be known, valued and respected." Members of online support groups also articulated similar feelings indicative of the emergence of a collective consciousness. Further research is needed to determine if and how blending the in-person and online support formats will help transform disabled women's thinking from "I" to "we." In order for a successful cognitive shift such as this to take place it may be advantageous to make groups available to pre-adolescent girls as well as those entering emerging adulthood. The sooner women are exposed to new and

empowering ideas about disability, the less likely they are to be detrimentally affected by the harmful and pervasive instances of stigma within our society. Empowerment programs for pre-adolescent girls with disabilities have been successfully created in the past (e.g., Rousso, 2001) and offer promise in the future.



## VI. CONCLUSION

This research illuminates how peer group support influences the self-concept of young disabled women. Joanna's words poignantly sum up the benefits of being able to engage in peer support with women who share the disability experience:

Meeting others, I have to say, I think will help them a lot to find out who they are and what they want to be in life. Because it comes down to if you're comfortable who you are in your own skin you're not going to let your disability limit what you can do in life. When you see other women with disabilities doing things in life you become more empowered and believe that you can do it too!

Contrary to the isolation and loneliness encountered by women in other aspects of their lives, their peer support group was a space where they felt they belonged. The women were able to cultivate unique and supportive relationships with fellow group members. The members relished the opportunity to give and receive unconditional and engaged support from other women who had first-hand knowledge of the disability experience. These aspects of the support group process were used as tools on their journey to reimagining possibilities for their future and becoming secure and comfortable with themselves.

Belonging to a support community that had a strong social justice orientation empowered the women to advocate for issues relevant to their lives. Relatedly, the group space gave rise to opportunities to be a leader and be perceived as an authority figure. As a result, the women felt a newfound sense of usefulness, respect, and value. Some women began to perceive themselves as part of the disability community at large and realize that disability issues do not occur in isolation, but rather require the attention of us *all*.

In developing future support groups for young disabled women it is important to recognize that both online and in-person groups appear to operate through a comparable support process and produce similar beneficial results. However, as the participants in this research revealed, the in-person support group format presents a myriad of barriers to the

participation of young disabled women. The online support group format provides a promising avenue for circumventing some of the challenges encountered with in-person support, but this format poses accessibility issues for some individuals. As advances in technology and comprehensive policies regarding web accessibility are written it is hoped that one day all disabled women will have access to the empowering support process demonstrated in this research.

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## APPENDIX C

### Individual Interview Guide (In-Person Group Member)

#### Exploring the Experiences of Women with Disabilities in Support Groups

##### Interview Guide for Initial Individual Interview with Group Member

##### Opening Question

Thank you so much for agreeing to talk with me today. From what I have learned about (GROUP NAME), it seems like a great group of women. Each individual is different and the type of things the group does is likely to affect each group member differently. Think about the meetings and the types of activities that the group does together. Can you tell me about some of the things within the group that you find to be the most helpful?

*Probe: What types of things have you learned in the group that you find helpful?*

*Probe: What types of activities does the group do together that you find helpful?*

##### Main Topic: Group Process

**Key Question:** Think about before you joined the group. How would you have described yourself before joining the group?

*Probe: How did you feel about yourself before joining the group?*

*Probe: Tell me about some aspects of yourself that you felt good about.*

*Probe: Tell me about some aspects about yourself that you did not feel good about.*

## APPENDIX C (continued)

**Key Question:** Now, after you joined the group, how, if at all, do you feel differently about yourself?

*Probe: What new things have you discovered about yourself since joining the group?*

*Probe: How, if at all, has the way you feel about yourself changed since joining the group?*

*Probe: How, if at all, has the way you feel about your disability changed since joining the group?*

*(Ask following question if feelings have changed.)*

**Key Question:** What about the group experience has helped you to feel good about yourself?

*Probe: How have group discussions influenced the way that you feel about yourself?*

*Probe: Tell me a little bit about group field trips and outings. How, if at all, do you think they have influenced the way you see yourself?*

*Probe: What types of activities does the group do together that help you to feel good about yourself?*

**Main Topic: Mission/Philosophy of the Group**

**APPENDIX C (continued)**

**Key Question:** As part of this project, I am talking with members of several different groups who are women with disabilities. Each group has a unique message that is conveyed to group members and to the outside world. Tell me a little bit about the message of your group.

*Probe: What is the group's message with regards to disability?*

*Probe: What is the group's message with regards to women?*

*Probe: What other issues does the group's message address?*

**Key Question:** How, if at all, does the group's message influence the way you feel about yourself?

*Probe: How, if at all, does the group's message influence the way that you feel about yourself as a woman?*

*Probe: How, if at all, does the group's message influence the way that you feel about your disability?*

*Probe: In what ways has the group's message changed the way that you feel about your body?*

## APPENDIX C (continued)

### Main Topic: Relationships with Other Group Members

**Key Question:** Tell me about your relationship with other group members.

*Probe: How, if at all, have these relationships influenced the way that you see yourself?*

*Probe: What, if anything, do the other women say that changes the way that you see yourself?*

*Probe: What do the other women do that changes the way that you see yourself?*

*Probe: Tell me about the interactions that you have with your fellow group members outside of group meetings.*

**Key Question:** Often times mentor/mentee relationships develop in these types of groups this takes place when veteran or older member(s) provides guidance and support to newer or younger member (s). If you've been involved in a mentor/mentee relationship within the group, what about this relationship has been helpful to you? (And/ or how your mentee felt about themselves, if applicable?)

*Probe: Think about memorable time you spent with your mentee/ mentor. What made it memorable? How was it helpful to you?*

*Probe: What ~~type of things help~~ create a strong bond between newer or younger members and the veteran or older members?*

## APPENDIX C (continued)

*Probe: Describe types of information the older or veteran members share with the newer or younger members. How, if at all, do you think this information makes a difference in the way people view themselves?*

**Key Question:** How has your relationship with the group coordinator influenced the way you think about yourself?

*Probe: What, if anything, has the group coordinator done or said that changed the way you feel about yourself?*

*Probe: Each group coordinator has a different style of leadership. Can you describe the ways in which your group coordinator leads the group?*

*Probe: What about this leadership is most important to you?*

### **Main Topic: Group Process and Identification with the Women's Community**

**Key Question:** It's been said that women with disabilities sometimes have goals, unique situations and/or face challenges that men with disabilities do not encounter. What are the types of things that are important to you as a woman with a disability?

*Probe: Tell me about the goals that you have set for yourself that are important to the way you feel about yourself as a woman.*

*Probe: Tell me about the needs you have as a woman with a disability.*

## APPENDIX C (continued)

**Key Question:** How is it important that the group is made up of women only, if it is important?

*Probe: In what ways do you think the group would be different if it included men as well as women?*

*Probe: In what ways, if it at all, does being in a group made up of only women with disabilities affect the bond and/or interactions among group members?*

*Probe: What types of information pertaining to women's issues (e.g. information on birth control, women's reproductive health, dating, LBGT issues, gender discrimination etc.) does the group address? (Pause for response)*  
*How, if at all, has learning this information influenced the way you feel about yourself?*

*Probe: Tell me about the types of activities that the group does together that focus on women's issues (pause for response). In what ways did participating in these activities influence the way you feel about yourself?*

*Probe: Tell me about any guest lecturers who spoke on issues specifically about women with disabilities (pause for response). In what ways was this helpful to you?*

### **Main Topic: Group Process and Transition to Adulthood**

## APPENDIX C (continued)

**Key Question (asked to women 18-35):** In the next portion of the interview, I'd like to discuss how, if at all, being part of the group has helped you transition or become an adult. What do you feel makes somebody an adult?

**Key Question (asked to women 36-45):** In the next portion of the interview, I'd like to discuss how, if at all, being part of your current group would have helped you during this transition. Think back to the years when you were transitioning into adulthood, i.e. ages 18-35. What do you feel makes somebody an adult?

*Probe: There are different events in people's lives that oftentimes mark passage into adulthood. Can you tell me about some events in your life that you felt marked your passage into adulthood?*

*Probe: What types of obstacles make it difficult for people to enter adulthood?*

**Key Question (asked to women 18-35):** In what ways, if at all, do you think being a part of the group has helped you transition into adulthood?

**Key Question (asked to women 36-45):** In what ways, if at all, do you think being a part of the group would have helped you transition into adulthood?

*Probe: How has the group/how would the group have helped you meet goals that are/were important to you in your transition to adulthood?*

*Probe: In what ways do the activities the group does help/how do you think they may have helped you transition into adulthood?*

## APPENDIX C (continued)

*Probe: In what ways do the discussions that the group has together help/how do you think they may have helped you transition to adulthood?*

*Probe: In what ways does the group coordinator help/how do you think they may have helped you transition into adulthood?*

### **Main Topic: Format of the Group**

**Key Question:** Over the course of conducting this research I have discovered that younger women (ages 18-35) do not participate in/regularly attend the meetings of in-person peer support groups for women with disabilities. What do you think some of the reasons are for this?

*Probe: What are some of the barriers women with disabilities may face in attempting to participate in an in-person support group?*

**Key Question:** In the last decade, there has been an increase in online support options available. What are your thoughts on the online peer-support format?

*Probe: What are some advantages of an in-person support group?*

*Probe: What are some disadvantages of the in-person format for a support group?*



**APPENDIX C (continued)**

**Key Question:** How, if at all, do you think online support forums encourage the participation of younger women?

**Closing Question:** We have discussed a lot of things about the group and the way it has influenced how you feel about yourself. Is there anything else that we have not talked about which you would like me to know about the way that the group has influenced you?

**Background Questions:** The following are demographic and background questions, which will be helpful when analyzing the data:

1. How long have you been part of the group?
2. How old are you?
3. What is your race and/or ethnicity?
4. What type of disability do you have?
5. When was the onset of your disability?

## APPENDIX D

### Individual Interview Guide (Online Group Member)

#### Exploring the Experiences of Women with Disabilities in Support Groups

##### Individual Interview Guide with Online Group Member

##### Opening Question

Thank you so much for agreeing to talk with me today. From what I have learned about (GROUP NAME), it seems like a great online community. When you think about your involvement in the group, what are some things that immediately come to mind about your participation?

*Probe: What types of things have you learned in the group that you find helpful?*

*Probe: What types of discussions does the group have that you find helpful?*

##### Main Topic: Group Process

**Key Question:** Think about before you joined the group. How would you have described yourself before joining the group?

*Probe: How did you feel about yourself before joining the group?*

*Probe: Tell me about some aspects of yourself that you felt good about.*

*Probe: Tell me about some aspects about yourself that you did not feel good about.*

**Key Question:** Now, after you began participating in the group/forum, how, if at all, do you feel differently about yourself?

## APPENDIX D (continued)

*Probe: What new things have you discovered about yourself since joining the group?*

*Probe: How, if at all, has the way you feel about yourself changed since joining the group?*

*Probe: How, if at all, has the way you feel about your disability changed since joining the group?*

*(Ask following question if feelings have changed.)*

**Key Question:** What about the group experience has helped you to feel good about yourself?

*Probe: How have group discussions influenced the way that you feel about yourself?*

*Probe: What resources (articles, videos, other pages, information about in-person events, etc.) shared on the forum have influenced how you feel about yourself?*

### **Main Topic: Mission/Philosophy of the Group**

**Key Question:** As part of this project, I am talking with members of several different groups for women with disabilities. Each group has a unique message that is conveyed to group members and to the outside world. If identifiable, tell

## APPENDIX D (continued)

me a little bit about the themes that are present in the forums/message boards/chat rooms etc.?

*Probe: What are some of the online group's perspective on disability?*

*Probe: What are some of the group's perspectives specifically regarding women with disabilities?*

**Key Question:** How, if at all, do the group's perspectives influence the way you feel about yourself?

*Probe: How, if at all, do they influence the way that you feel about yourself as a woman?*

*Probe: How, if at all, do they influence the way that you feel about your disability?*

*Probe: In what ways have they changed the way that you feel about your body?*

### **Main Topic: Relationships with Other Group Members**

**Key Question:** Tell me about your relationship with other group members.

*Probe: How, if at all, have these relationships influenced the way that you see yourself?*

*Probe: What, if anything, do other women on the forum say that changes the way that you see yourself?*

*Probe: Tell me about the interactions that you have with your fellow group members outside of the forum, if any.*

## APPENDIX D (continued)

**Key Question:** Often times, mentor/mentee relationships develop in these types of groups. This takes place when veteran or older member(s) provides guidance and support to newer or younger member (s). If you've been involved in a mentor/mentee relationship within the group, what about this relationship has been helpful to you? (And/ or how your mentee felt about themselves, if applicable?)

*Probe: What ~~type of things help~~ create a strong bond between newer or younger members and the veteran or older members?*

*Probe: Describe types of information the older or veteran members share with the newer or younger members. How, if at all, do you think this information makes a difference in the way people view ~~themselves~~?*

### **Main Topic: Group Process and Identification with the Women's Community**

**Key Question:** It's been said that women with disabilities sometimes have goals, unique situations and/or face challenges that men with disabilities do not encounter. What are the types of things that are important to you as a woman with a disability?

*Probe: Tell me about the goals that you have you set for yourself that are important to the way you feel about yourself as a woman.*

*Probe: Tell me about the needs you have as a woman with a disability.*

## APPENDIX D (continued)

### **If forum is made up entirely of women with disabilities-**

**Key Question:** How is it important that the group is made up of women only, if it is important?

*Probe: In what ways do you think the group would be different if it included men as well as women?*

*Probe: In what ways, if it at all, does being in a group made up of only women with disabilities affect the bond and/or interactions among group members?*

*Probe: What types of information pertaining to women's issues (e.g. information on birth control, women's reproductive health, dating, LGBT issues, gender discrimination etc.) does the group address? (Pause for response)*

*How, if at all, has learning this information influenced the way you feel about yourself?*

### **If forum is comprised of men and women with disabilities-**

**Key Question:** How do you think this forum would be different if it were exclusively for women with disabilities?

*Probe: What are some advantages of having male and female participation?*

*Probe: What do you think some advantages of having a women's-only group could be?*

## APPENDIX D (continued)

*Probe: What are some disadvantages to having both male and female participation in the forum?*

### **Main Topic: Group Process and Transition to Adulthood**

**Key Question (asked to women 18-35):** In the next portion of the interview, I'd like to discuss how, if at all, being part of the group has helped you transition or become an adult. What do you feel makes somebody an adult?

**Key Question (asked to women 36-45):** In the next portion of the interview, I'd like to discuss how, if at all, being part of your current group would have helped you during this transition. Think back to the years when you were transitioning into adulthood, i.e. ages 18-35. What do you feel makes somebody an adult?

*Probe: There are different events in people's lives that oftentimes mark passage into adulthood. Can you tell me about some events in your life [that](#) you felt marked your passage into adulthood?*

*Probe: What types of obstacles make it difficult for people to enter adulthood?*

**Key Question (asked to women 18-35):** In what ways, if at all, do you think being a part of the group has helped you transition into adulthood?

**Key Question (asked to women 36-45):** In what ways, if at all, do you think being a part of the group would have helped you transition into adulthood?

## APPENDIX D (continued)

*Probe: How has the group/how would the group have helped you meet goals that are/were important to you in your transition to adulthood?*

*Probe: In what ways do the discussions that the group has together help/how do you think they may have helped you transition to adulthood?*

*Probe: What resources (articles, videos, other pages, information about in-person events, etc.) are shared on the forum and are helpful in this transition into adulthood?*

### **Main Topic: Format of the Group**

**Key Question:** Tell me about your experience with the online format.

*Probe: What are some advantages of the online format for a support group?*

*Probe: What are some disadvantages of the online format for a support group?*

*Probe: If anything, what would you change about the format (i.e. elements of the chat rooms, message boards, website, etc.) of the group?*

**Key Question:** Over the course of conducting this research I have discovered that younger women (ages 18-35) do not participate in/regularly attend the meetings of in-person peer support groups for women with disabilities.

What do you think some of the reasons are for this?

*Probe: What are some of the barriers women with disabilities may face in attempting to participate in an in-person support group?*



**APPENDIX D (continued)**

**Key Question:** How, if at all, do online support forums encourage the participation of younger women?

*Probe: If anything, what about the online format do you think makes it an appealing peer-support option for younger women with disabilities?*

**Closing Question:** We have discussed a lot of things about the online group and the way it has influenced how you feel about yourself. Is there anything else that we have not talked about which you would like me to know about the way that the group has influenced you?

**Background Questions:** The following are demographic and background questions, which will be helpful when analyzing the data:

1. How long have you been part of the group?
2. How old are you?
3. What is your race and/or ethnicity?
4. What type of disability do you have?
5. When was the onset of your disability?

## APPENDIX E

### Screening Documents for In-Person Group Members

#### Screening Questions for Participation in Individual Interviews



“Exploring Experiences of Women with Disabilities in Support Groups”

1. Are you between the ages of 18-45?
2. Did you become disabled at age 21 or younger?
3. Do you act as your own legal guardian?
4. How long have you been a member of your support group?

## APPENDIX F

### Screening Documents for Online Group Members

#### Screening Questions for Interview with Online Group Members



#### “Exploring Experiences of Women with Disabilities in Support Groups”

1. Are you between the ages of 18-45?
2. What was your age of onset of disability?
3. Do you act as your own legal guardian?
4. How long have you been a part of the online support group?
5. How often do you participate in the online community (i.e. posting, discussions, reading and browsing posts and event calendars, etc.)?

## APPENDIX G

### Conversational Interview Guide for Interview with Current Group Coordinator

#### **Exploring the Experiences of Women with Disabilities in Support Groups**

#### **Conversational Interview Guide for Interview with Group Coordinators**

1. Tell me about your experience as a group coordinator for *(insert group name here)*.
  
2. What are your objectives when leading the group?
  
3. What challenges, if any, did you experience in starting the group?
  
4. What challenges, if any, have you experienced in maintaining the group?
  
5. (If challenges are noted) How have the challenges you've faced as group coordinator been addressed?
  
6. What additional resources and/or solutions do you think would be helpful in addressing challenges that you face in maintaining the group?

*Follow-up (add any information if you'd like to elaborate):* Why do you think some women with disabilities come to participate in the group, while others don't?

**APPENDIX G (continued)**

7. In general, tell me about your observations of how the members' self-concepts have changed and developed through being part of the group.

8. What kinds of peer support do you think women with disabilities need for self-development?

Probe: If you could create the ideal support group for this purpose, what would it be like?

9. To the best of your knowledge, when was the group first founded?

10. How long have you been acting as the group coordinator?

|

## APPENDIX H

### Conversational Interview Guide with Group Coordinators of Past/Inactive Groups

**|Exploring the Experiences of Women with Disabilities in Support Groups**

**Conversational Interview Guide for Interview with Group Coordinators of  
Past/Inactive Groups**

1. Tell me about your experience as a group coordinator for *(insert group name here)*.
  
2. What were your objectives when leading the group?
  
3. In general, tell me about your observations of how the members' self-concepts changed and developed through being part of the group.
  
4. To the best of your knowledge, what were the reasons for discontinuing the group?
  
5. What challenges, if any, did you experience in starting the group?
  
6. What challenges, if any, did you experience in maintaining the group?
  
7. (If challenges are noted) How were the challenges you've faced as group coordinator addressed?
  
8. What additional resources and/or solutions do you think would have been helpful in addressing challenges that you faced in trying to maintain the group?

**APPENDIX H (continued)**

(To help provide further elaboration, if necessary): Why do you think some women with disabilities come to participate in the group but others don't?

9. What kinds of peer support do you think women with disabilities need for self-development?

(To help provide further elaboration, if necessary): If you could create the ideal support group for this purpose, what would it be like?

10. How long was the group active?

11. For how long did you act as group coordinator?

## APPENDIX I

### Email Recruitment Notice to Group Coordinators



**University of Illinois-Chicago Research**  
**Email Recruitment for Group Participation in Research**  
*(sent to Group Coordinator)*

“Exploring the Experiences of Women With Disabilities in Support Groups”

**Protocol Number: 2015-0478**

Principal Investigator: Norma Jane Mejias (“Janie”), MS, Ph.D candidate  
 Department: Disability & Human Development, University of Illinois at Chicago  
 (703) 625-8849  
[nmejia2@uic.edu](mailto:nmejia2@uic.edu)

Advisor: Carol J. Gill, PhD., Professor  
 Dept. of Disability & Human Development, University of Illinois at Chicago, (M/C 626)  
 1640 W. Roosevelt Road  
 Chicago, Illinois 60608  
[cg16@uic.edu](mailto:cg16@uic.edu)  
 (312)-355-0550

**What is the purpose of this research?**

The purpose of this research is to explore the experiences of members of support groups for young women with disabilities. This research will also examine how, if at all, participation in the group helps members meet goals that are important to them as they enter adulthood.

**Who is eligible to participate in this research?**

- Support groups that serve women with disabilities 18 years of age or older;
- Support groups that include only women with disabilities;
- Support groups who serve only women who act as their own legal guardian.

**What research activities are involved?**



**APPENDIX I (continued)**

- Janie Mejias will visit one to two group meetings to get an idea of the types of activities the group does together (if travel arrangements are feasible). The number of times the group is observed will depend upon frequency and location of meetings. All members age 18 years or older and act as their own legal guardian are eligible to participate in the group meeting observation(s).
- During the meeting observation, Janie Mejias will take notes on the types of activities the group does together, as well as group dynamics and interactions. Group members will not be asked to do anything outside of what they normally do in their support groups. No identifying information will be collected during the observation.
- An interview with the group coordinator will be conducted in-person, over the phone, or through email. People who have previously acted as a group coordinator for a support group specifically for women with disabilities are also eligible to participate in a group coordinator interview, even if the group is currently inactive.
- All group members, ages 18-45 with an age of onset of disability at 21 years or younger, may be eligible to participate in an individual interview. For those who do participate, the newer members will be asked to do follow-up interviews at three months and six months, following their original interview date. Please note that a support group does not have to participate in the observation portion for individual interviews to be held with interested and eligible group members. As compensation for their time, all who participate in individual interviews, including the group coordinator, will receive an Amazon gift card valued at \$20.00

If you and your group are interested in participating, or if there are any questions, please contact Janie Mejias using information provided above.

## APPENDIX J

### Research Information Sheet



**University of Illinois-Chicago**  
**Research Information Sheet**  
*(to all Group Members)*

**“Exploring the Experiences of Women With Disabilities in Support Groups”**

**Protocol Number: 2015-0478**

Principal Investigator: Norma Jane Mejias (“Janie”), MS, Ph.D candidate  
 Department: Disability & Human Development, University of Illinois at Chicago  
 (703) 625-8849  
[nmejia2@uic.edu](mailto:nmejia2@uic.edu)

Advisor: Carol J. Gill, PhD., Professor  
 Dept. of Disability & Human Development, University of Illinois at Chicago, (M/C 626)  
 1640 W. Roosevelt Road  
 Chicago, Illinois 60608  
[cgl6@uic.edu](mailto:cgl6@uic.edu)  
 (312)-355-0550

**What is the purpose of this research?**

The purpose of this research is to explore the experiences of members of support groups for young women with disabilities. This research will also examine how, if at all, participation in the group helps members meet goals that are important to them as they enter adulthood.

**APPENDIX J (continued)****Who is eligible to participate in this research?**

Support group members who are 18 years or older, who also act as their own legal guardians

**What research activities are involved?**

- Janie Mejias will visit one to two group meetings to get an idea of the types of activities the group does together.
- Group members ages 18-45, with an age of onset of disability at 21 years or younger, may be eligible to participate in an individual interview. For those who do participate, the newer members will be asked to do follow-up interviews at three months and six months, following their original interview date. Please note that a support group does not have to participate in the observation portion for individual interviews to be held with interested and eligible group members. As compensation for their time, all group members who participate in individual interviews will receive an Amazon gift card valued at \$20.00.

If you have any questions or would like further information, please contact the principal investigator of this research, Janie Mejias, at (703) 625-8849, or [nmejia2@uic.edu](mailto:nmejia2@uic.edu)

## APPENDIX K

### Recruitment Notice for Individual Interviews In-Person Group Members



### **Recruitment Document for Participation in Individual Interviews** (to Group Members ages 18-45)

### **“Exploring the Experiences of Women with Disabilities in Support Groups”**

**Protocol Number:** 2015-0478

Principal Investigator: Norma Jane Mejias (“Janie”), MS, Ph.D candidate  
Department: Disability & Human Development, University of Illinois at Chicago  
(703) 625-8849  
[nmejia2@uic.edu](mailto:nmejia2@uic.edu)

Advisor: Carol J. Gill, PhD., Associate Professor  
Dept. of Disability & Human Development, University of Illinois at Chicago, (M/C 626)  
1640 W. Roosevelt Road  
Chicago, Illinois 60608  
[cgl6@uic.edu](mailto:cgl6@uic.edu)  
(312)-355-0550

Dear Group Member,

You may be eligible to participate in the individual interview portion of the research project “Exploring the Experiences of Women With Disabilities in Support Groups.” This research is being done by Norma Jane Mejias (“Janie”),

**APPENDIX K (continued)**

a Ph.D student in the Department of Disability and Human Development at the University of Illinois at Chicago. Dr. Carol Gill, a professor in the Department of Disability and Human Development at the University of Illinois Chicago, is supervising this research.

**What is the purpose of this research?**

The purpose of this research is to explore the experiences of members of support groups for young women with disabilities. This research will also examine how, if at all, participation in the group helps members meet goals that are important to them as they enter adulthood.

**In order to participate in the individual portion of this research you must meet the following requirements:**

- You are between the ages of 18-45 with an age of onset of disability at 21 years or younger
- You act as your own legal guardian
- You are a member of a support group for women with disabilities taking part in this study

## APPENDIX L

### Recruitment Notice for Participation for Individual Interviews with Online Group Members



**University of Illinois-Chicago  
Research Recruitment Notice:  
Seeking Participants for Research Exploring the Experiences of Women with  
Disabilities in Online Support Groups**

**What is the purpose of this research?**

The study will explore the experiences of women with disabilities in support groups. The benefits and drawbacks to the online peer support format for women with disabilities are also being explored. Additionally, the research aims to examine how, if at all, participation in the group helps you meet goals that are important to you as you enter adulthood.

**Who is eligible to participate in this research?**

- Women between the ages of 18-45
- Who act as their own legal guardians
- And who have been participating in an online support group for people with disabilities

**What research activities are involved?**

Participation in this research involves an individual interview conducted either over the phone or through email. The interview should last approximately an hour to an hour and a half. As compensation for their time, all participants will receive an Amazon gift card valued at \$20.00.

If you would like to participate, would like further information, or have any questions, please contact the principal investigator of this research, Janie Mejias, at (703) 625-8849, or [nmejia2@uic.edu](mailto:nmejia2@uic.edu)

**Protocol Number: 2015-0478**

Principal Investigator: Norma Jane Mejias ("Janie"), MS, Ph.D candidate  
Department: Disability & Human Development, University of Illinois at Chicago  
(703) 625-8849  
[nmejia2@uic.edu](mailto:nmejia2@uic.edu)

Advisor: Carol J. Gill, PhD., Professor  
Dept. of Disability & Human Development, University of Illinois at Chicago, (M/C 626)  
1640 W. Roosevelt Road  
Chicago, Illinois 60608  
[cgl16@uic.edu](mailto:cgl16@uic.edu)  
(312)-355-0550

**APPENDIX L (continued)**

Up to eight qualified volunteers from your support group will be chosen for the individual interviews. Preference will be given to members who have participated in the support group for the longest and shortest amounts of time.

During the individual interview, you will be asked questions about your experiences in the support group. The interview will also examine how, if at all, your participation in the group helps you meet goals that are important to you as you enter adulthood. This initial interview will take about an hour to an hour and a half to complete. Individual interviews may be conducted in-person, via phone or email. If you have recently joined the group, you will be contacted for follow-up telephone or email interviews at three months and six months, following your original interview date. Each follow up interview should take approximately 30 minutes to complete.

Please note that your interview responses will not be linked to your real name, your identity will be kept private. Also, participation in this

**APPENDIX L (continued)**

research project is completely voluntary, and your decision whether or not to participate will not affect your relationship with the group in any way.

Should you choose to participate in the individual interview, you will be compensated for your time with an Amazon gift card valued at 20.00. This gift card will be distributed upon conclusion of the initial interview. Should you choose to withdraw from the study after the interview has begun, you will still receive this compensation. If you choose to take part in an email or phone interview, the gift card will be sent to you via USPS. Additionally, you will be reimbursed up to twenty dollars for your travel expenses to and from the individual interview site, *if applicable*. You will be given this payment upon your arrival at the interview site.



**APPENDIX L (continued)**

If you are interested in participating in the individual interview portion of this research, please read the statement below, check the box and sign on the lines, then return this letter to your group coordinator. You may also contact the principal investigator Janie Mejias directly at [nmejia2@uic.edu](mailto:nmejia2@uic.edu) or by phone at (312) 526-3241 or (703) 625-8849.

Sincerely,

Janie Mejias

☐ I am interested in learning more about participating in an individual interview. By checking this box and signing on the line below, I give my group coordinator permission to give Janie Mejias my contact information.

**Printed Name:** \_\_\_\_\_

**Signature:** \_\_\_\_\_

## APPENDIX M

### IRB Initial Approval Letter

#### UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)  
Office of the Vice Chancellor for Research (MC 672)  
203 Administrative Office Building  
1737 West Polk Street  
Chicago, Illinois 60612-7227

#### **Approval Notice Initial Review (Response to Modifications)**

September 3, 2015

Norma Mejias  
Disability and Human Development  
1524 S Sangamon Street, Unit 303  
Chicago, IL 60608  
Phone: (703) 625-8849

RE: **Protocol # 2015-0478**  
**“The Role of Support Group Involvement in the Self-Concept of Women with Disabilities”**

Dear Ms. Mejias:

Your Initial Review application (Response to Modifications) was reviewed and approved by the Expedited review process on August 31, 2015. You may now begin your research.

Please note the following information about your approved research protocol:

**Please remember to submit a copy of the completed transcription agreement when available. The agreement must be accompanied by an Amendment form when submitted to the UIC IRB.**

**Protocol Approval Period:** August 31, 2015 - August 30, 2016  
**Approved Subject Enrollment #:** 60  
**Additional Determinations for Research Involving Minors:** These determinations have not been made for this study since it has not been approved for enrollment of minors.  
**Performance Site:** UIC  
**Sponsor:** None  
**Research Protocol:**  
a) The Role of Support Group Involvement; Version 3; 08/20/2015  
**Recruitment Materials:**  
a) Recruitment Document (large and regular print); Version 1; 03/14/2015  
b) Invitation (large and regular print); Version 1; 04/12/2015  
c) Screening for Observation of Meeting; Version 1; 07/20/2015  
d) Screening for Individual Interviews; Version 1; 07/20/2015  
e) Study Information for Group Members; Version 2; 07/20/2015  
f) Group Recruitment Email to Group Coordinator; Version 2; 07/20/2015

Phone: 312-996-1711

<http://www.uic.edu/depts/ovcr/oprs/>

FAX: 312-413-2929

## APPENDIX M (continued)

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- g) Recruitment for Individual Interviews; Version 2; 07/20/2015
- h) Email Interview Reminder Notice; Version 1; 08/20/2015

**Informed Consents:**

- a) Consent Comprehension Questions for Individual Interviews; Version 1; 07/20/2015
- b) Consent for Group Observation; Version 2; 07/20/2015
- c) Consent Comprehension Questions for Group Observations; Version 1; 07/20/2015
- d) Consent for Interview with Group Coordinator; Version 3; 08/20/2015
- e) Consent for Individual Interviews with Group Members; Version 3; 08/20/2015
- f) A waiver of documentation (verbal consent, no signature obtained) and an alteration of consent have been granted for eligibility screening only under 45 CFR 46.117(c)(2) and 45 CFR 46.116(d) (minimal risk; information for ineligible or declining subjects will be immediately destroyed)

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

- (6) Collection of data from voice, video, digital, or image recordings made for research purposes.,
- (7) 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 social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

**Please note the Review History of this submission:**

Receipt Date	Submission Type	Review Process	Review Date	Review Action
04/24/2015	Initial Review	Expedited	04/28/2015	Modifications Required
07/20/2015	Response To Modifications	Expedited	07/27/2015	Modifications Required
08/28/2015	Response To Modifications	Expedited	08/31/2015	Approved

Please remember to:

→ Use your **research protocol number** (2015-0478) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the OPRS website under:

**"UIC Investigator Responsibilities, Protection of Human Research Subjects"**

(<http://tiger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf>)

**Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.**

**Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.**

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-2014. Please send any

**APPENDIX M (continued)**

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correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sandra Costello  
Assistant Director, IRB # 2  
Office for the Protection of Research Subjects

Enclosures:

**1. UIC Investigator Responsibilities, Protection of Human Research Subjects**

**2. Informed Consent Documents:**

- a) Consent Comprehension Questions for Individual Interviews; Version 1; 07/20/2015
- b) Consent for Group Observation; Version 2; 07/20/2015
- c) Consent Comprehension Questions for Group Observations; Version 1; 07/20/2015
- d) Consent for Interview with Group Coordinator; Version 3; 08/20/2015
- e) Consent for Individual Interviews with Group Members; Version 3; 08/20/2015

**3. Recruiting Materials:**

- a) Recruitment Document (large and regular print); Version 1; 03/14/2015
- b) Invitation (large and regular print); Version 1; 04/12/2015
- c) Screening for Observation of Meeting; Version 1; 07/20/2015
- d) Screening for Individual Interviews; Version 1; 07/20/2015
- e) Study Information for Group Members; Version 2; 07/20/2015
- f) Group Recruitment Email to Group Coordinator; Version 2; 07/20/2015
- g) Recruitment for Individual Interviews; Version 2; 07/20/2015
- h) Email Interview Reminder Notice; Version 1; 08/20/2015

cc: Tamar Heller, Disability and Human Development, M/C 626  
Carol J. Gill (faculty advisor), Disability and Human Development, M/C 626

## APPENDIX N

### Consent for Individual Interview (In-Person Group Member)



**University of Illinois at Chicago  
Consent for Participation in Social Behavioral Research  
Individual Interview With Group Member**

**“Exploring the Experiences of Women with Disabilities  
In Support Groups”**

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator: Norma Jane Mejias (“Janie”), MS, Ph.D Candidate  
Department: Disability & Human Development, University of Illinois at Chicago  
(703) 625-8849  
[nmejia2@uic.edu](mailto:nmejia2@uic.edu)

Faculty Advisor: Carol J. Gill, PhD., Professor  
Dept. of Disability & Human Development, University of Illinois at Chicago, (M/C 626)  
1640 W. Roosevelt Road  
Chicago, Illinois 60608  
[cgl16@uic.edu](mailto:cgl16@uic.edu)  
(312)-355-0550

**Why am I being asked to participate?**

You are being asked to be a subject in a research study about support groups for women with disabilities.

## APPENDIX N (continued)

You have been asked to participate in the research because you are over 18 years of age, you are your own legal guardian, and you have either recently joined or are a long-time member of a support group for women with disabilities that meets the requirements for this study.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Chicago or your support group. **If you decide to participate, you are free to withdraw at any time without affecting those relationships.**

Approximately 60 subjects may be involved in this research at UIC.

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

The study will explore the experiences of women with disabilities in support groups. Also, the research aims to examine how, if at all, participation in the group helps you meet goals that are important to you as you enter adulthood.

### **What procedures are involved?**

The individual interview portion of this research will be conducted either in-person (at the location where the group meets, or a location convenient for the participant), over the phone, or through email. Please let the Principal Investigator know which interview method you prefer. Every effort will be made to accommodate in-person interview requests. However, if your group is located outside of the Chicago area, it may not be possible for the Principal Investigator to travel to you.

All in-person and telephone interviews will be audio-recorded and transcribed. This is important to ensure the accuracy of data collection, and is a requirement of your participation in the individual interview(s). If you decline to be audio recorded, you are not eligible to participate in the interview portion of the research.

## APPENDIX N (continued)

If you are a newer group member, you may be contacted for a shorter follow-up telephone or email interview. The follow-ups will take place at both three months after the original interview and six months after the original interview.

The individual interviews will take about an hour to an hour and a half to complete. Follow-up interviews will take approximately twenty to thirty minutes to complete.

During the individual interview, the Principal Investigator will ask you questions about your experiences in the group and how the group has influenced you. The Principal Investigator will also ask questions related to any goals you may have as you transition into adulthood, and how, if at all, the group has or could have helped you meet these goals. Once data collection is complete and a report has been drafted, participants will be asked to read and provide feedback on a draft of the research results.

### **What are the potential risks and discomforts?**

This research is not expected to present risk beyond any possible emotional discomfort of describing your personal views about your participation in the group and how it has influenced you. However, there is the potential risk that others may find out that you are participating, or that others may find out identifiable information about you disclosed during the research.

If you are uncomfortable with any aspects of the interview, just let the Principal Investigator know, and you may choose not to answer specific questions. At any time, you may also choose to end your participation in this research entirely.



## APPENDIX N (continued)

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

Taking part in this research study may not benefit you personally. By participating in this research, you will help the investigator discover important aspects of the support group process. The information learned may also be helpful to others in similar circumstances.

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

This is not a treatment study. Your alternative is not to participate in this study.

### **What about privacy and confidentiality?**

The only people who will know that you are a research subject are members of the research team. Otherwise information about you will only be disclosed to others with your written permission, or if necessary to protect your rights or welfare (for example, when the UIC Office for the Protection of Research Subjects monitors the research or consent process) or if required by law.

A possible risk of the research is that your participation, or information about you, might become known to individuals outside the research. However, several measures will be taken to protect your privacy and confidentiality. Study information which identifies you, including actual name, email address, phone number, and mailing address, as well as the consent form signed by you, will be stored in a locked cabinet that only Norma Jane Mejias (Janie), the Principal Investigator, has access to. Portions of your responses to interview questions may be used when reporting the results of this study, but your name will be replaced with a code name and all other identifying information will be excluded.

The in-person and telephone interviews will be audiotape recorded. You will be given a code name before the audio recording begins. You will only be referred to by this code name on the audiotape. If you do an interview via email, the email will be stripped of your email address and real name. The email will be stored using your code name. All identifiers, contact information and research data, including



## APPENDIX N (continued)

audiotape recordings, transcriptions of audiotape recordings, and emails will be destroyed within one year of soliciting your feedback on the draft research report.

Your contact information will be stored in a password-protected Microsoft Word document that only the principal investigator will have access to. Hardcopies of your contact information will be stored in a locked filing cabinet that only the principal investigator will have access to.

If you disclose actual or suspected abuse, neglect, or exploitation of a child, or disabled or elderly adult, the researcher or any member of the study staff must, and will, report this to Child Protective Services (i.e. Department of Family and Human Services), Adult Protective Services, and/or the nearest law enforcement agency.

### **What are the costs for participating in this research?**

There are no costs to you for participating in this research.

### **Will I be reimbursed for any of my expenses or paid for my participation in this research?**

You will be compensated for your time with an Amazon gift card valued at 20.00USD. This gift card will be distributed upon conclusion of the initial interview. Should you choose to withdraw from the study after the interview has begun, you will still receive this compensation. If you choose to take part in an email or phone interview, the gift card will be sent to you via USPS. If you are an international participant, you will receive the 20.00 gift card via email.

Additionally, you will be reimbursed up to twenty dollars for your travel expenses to and from the individual interview site, *if applicable*. You will be given this payment upon your arrival at the interview site.

**APPENDIX N (continued)****Can I withdraw or be removed from the study?**

You can choose whether or not to participate in this study. If you volunteer to participate, you have the right to leave a study at any time without penalty. If you would like to withdraw from the study, please let the Principal Investigator know.

The Principal Investigator may withdraw you if certain situations arise. For instance, you may be withdrawn if the Principal Investigator cannot continue the study due to equipment failure, illness, scheduling problems, etc. You may also be withdrawn if you are unable to complete the tasks presented to you or if the Principal Investigator learns that you do not meet the requirements for participation.

**Who should I contact if I have questions?**

Contact the Principal Investigator Norma Jane Mejias (Janie) at (312) 526-3241 or (703) 625-8849, or email at [nmejia2@uic.edu](mailto:nmejia2@uic.edu)

Or contact her faculty supervisor, Carol Gill, at (312)-355-0550 or email at [cgl16@uic.edu](mailto:cgl16@uic.edu)

- If you have any questions about this study or your part in it
- If you have questions, concerns or complaints about the research

**What are my rights as a research subject?**

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at [uicirb@uic.edu](mailto:uicirb@uic.edu).

## APPENDIX N (continued)

### **Remember:**

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University or your support group. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

### **Signature of Subject**

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Signature of Person Obtaining Consent

\_\_\_\_\_  
Date (must be same as subject's)

\_\_\_\_\_  
Printed Name of Person Obtaining Consent

## APPENDIX O

### Consent for Individual Interview (Online Group Member)



**University of Illinois at Chicago  
Consent for Participation in Social Behavioral Research  
Individual Interview With Online Group Member**

**“Exploring the Experiences of Women with Disabilities  
In Support Groups”**

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator: Norma Jane Mejias (“Janie”), MS, Ph.D Candidate  
Department: Disability & Human Development, University of Illinois at Chicago  
(703) 625-8849  
[nmejia2@uic.edu](mailto:nmejia2@uic.edu)

Faculty Advisor: Carol J. Gill, PhD., Professor  
Dept. of Disability & Human Development, University of Illinois at Chicago, (M/C 626)  
1640 W. Roosevelt Road  
Chicago, Illinois 60608  
[cg16@uic.edu](mailto:cg16@uic.edu)  
(312)-355-0550

**Why am I being asked to participate?**

You are being asked to be a subject in a research study about support groups for women with disabilities.

## APPENDIX O (continued)

You have been asked to participate in the research because you are a woman between the ages of 18-45, you are your own legal guardian, and you are an active participant of an online support group or community for people with disabilities.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Chicago or your support group. **If you decide to participate, you are free to withdraw at any time without affecting those relationships.**

Approximately 60 subjects may be involved in this research at UIC.

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

The study will explore the experiences of women with disabilities in support groups. The benefits and drawbacks to the online peer support format for women with disabilities are also being explored. Additionally, the research aims to examine how, if at all, participation in the group helps you meet goals that are important to you as you enter adulthood.

### **What procedures are involved?**

The individual interview will be conducted either over the phone or through email. Please let the Principal Investigator know which interview method you prefer. The individual interview should take about an hour to an hour and a half to complete.

All telephone interviews will be audio-recorded and transcribed. This is important to ensure the accuracy of data collection, and is a requirement of your participation in the individual interview. If you decline to be audio recorded, you are not eligible to participate in the research.

During the individual interview, the Principal Investigator will ask you questions about your experiences in the group and how the group has influenced you. The Principal Investigator will also ask questions related to any goals you may have as you transition into adulthood, and how, if at all, the group has or could have helped

**APPENDIX O (continued)**

you meet these goals. You will also answer questions related to the benefits and drawbacks of the online support group format. Once data collection is complete and a report has been drafted, participants will be asked to read and provide feedback on a draft of the research results.

**What are the potential risks and discomforts?**

This research is not expected to present risk beyond any possible emotional discomfort of describing your personal views about your participation in the group and how it has influenced you.

If you are uncomfortable with any aspects of the interview, just let the Principal Investigator know, and you may choose not to answer specific questions. At any time, you may also choose to end your participation in this research entirely.

**Are there benefits to taking part in the research?**

Taking part in this research study may not benefit you personally. By participating in this research, you will help the investigator discover important aspects of the support group process. The information learned may also be helpful to others in similar circumstances.

**What other options are there?**

This is not a treatment study. Your alternative is not to participate in this study.

**What about privacy and confidentiality?**

The only people who will know that you are a research subject are members of the research team. Otherwise information about you will only be disclosed to others

## APPENDIX O (continued)

with your written permission, or if necessary to protect your rights or welfare (for example, when the UIC Office for the Protection of Research Subjects monitors the research or consent process) or if required by law.

A possible risk of the research is that your participation, or information about you, might become known to individuals outside the research. However, several measures will be taken to protect your privacy and confidentiality. Study information which identifies you, including actual name, email address, phone number, and mailing address, as well as the consent form signed by you, will be stored in a locked cabinet that only Norma Jane Mejias (Janie), the Principal Investigator, has access to. Portions of your responses to interview questions may be used when reporting the results of this study, but your name will be replaced with a code name and all other identifying information will be excluded.

The telephone interviews will be audiotape recorded. You will be given a code name before the audio recording begins. You will only be referred to by this code name on the audiotape. If you do an interview via email, the email will be stripped of your email address and real name. The email will be stored using your code name. All identifiers, contact information and research data, including audiotape recordings, transcriptions of audiotape recordings, and emails will be destroyed within one year of soliciting your feedback on the draft research report.

Your contact information will be stored in a password-protected Microsoft Word document that only the principal investigator will have access to. Hardcopies of your contact information will be stored in a locked filing cabinet that only the principal investigator will have access to.

If you disclose actual or suspected abuse, neglect, or exploitation of a child, or disabled or elderly adult, the researcher or any member of the study staff must, and will, report this to Child Protective Services (i.e. Department of Family and Human Services), Adult Protective Services, and/or the nearest law enforcement agency.

### **What are the costs for participating in this research?**



**APPENDIX O (continued)**

There are no costs to you for participating in this research.

**Will I be reimbursed for any of my expenses or paid for my participation in this research?**

You will be compensated for your time with an Amazon gift card valued at 20.00USD. This gift card will be mailed to you upon conclusion of the interview. Should you choose to withdraw from the study after the interview has begun, you will still receive this compensation. If you are an international participant, you will receive the 20.00 gift card via email.

**Can I withdraw or be removed from the study?**

You can choose whether or not to participate in this study. If you volunteer to participate, you have the right to leave a study at any time without penalty. If you would like to withdraw from the study, please let the Principal Investigator know.

The Principal Investigator may withdraw you if certain situations arise. For instance, you may be withdrawn if the Principal Investigator cannot continue the study due to equipment failure, illness, scheduling problems, etc. You may also be withdrawn if you are unable to complete the tasks presented to you or if the Principal Investigator learns that you do not meet the requirements for participation.

**Who should I contact if I have questions?**

Contact the Principal Investigator Norma Jane Mejias (Janie) at (703) 625-8849, or email at [nmejia2@uic.edu](mailto:nmejia2@uic.edu)

Alternatively, you may contact her faculty supervisor, Carol Gill, at (312)-355-0550 or email at [cgl6@uic.edu](mailto:cgl6@uic.edu)

- If you have any questions about this study or your part in it
- If you have questions, concerns or complaints about the research



## APPENDIX O (continued)

### **What are my rights as a research subject?**

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at [uicirb@uic.edu](mailto:uicirb@uic.edu).

### **Remember:**

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University or your support group. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

### **Signature of Subject**

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Signature of Person Obtaining Consent

\_\_\_\_\_  
Date (must be same as subject's)

## APPENDIX P

### Consent for Conversational Interview (Group Coordinator)



**University of Illinois at Chicago**  
**Consent for Participation in Social Behavioral Research**  
**Conversational Interview With Group Coordinator**

“Exploring the Experiences of Women With Disabilities  
 In Support Groups”

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator: Norma Jane Mejias (“Janie”), MS, Ph.D Candidate  
 Department: Disability & Human Development, University of Illinois at Chicago  
 (703) 625-8849  
[nmejia2@uic.edu](mailto:nmejia2@uic.edu)

Faculty Advisor: Carol J. Gill, PhD., Professor  
 Dept. of Disability & Human Development, University of Illinois at Chicago, (M/C 626)  
 1640 W. Roosevelt Road  
 Chicago, Illinois 60608  
[cgl6@uic.edu](mailto:cgl6@uic.edu)  
 (312)-355-0550

**Why am I being asked to participate?**

You are being asked to be a subject in a research study about support groups for women with disabilities.

## APPENDIX P (continued)

You have been asked to participate in the research because you are over 18 years of age, you are your own legal guardian, and facilitate or have previously facilitated a support group for women with disabilities.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Chicago or your support group. **If you decide to participate, you are free to withdraw at any time without affecting those relationships.**

Approximately 60 subjects may be involved in this research at UIC.

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

The study will explore the experiences of women with disabilities in support groups. Also, the research aims to examine how, if at all, participation in the group helps its members meet goals that are important to them as they enter adulthood.

### **What procedures are involved?**

The individual interview with the group coordinators will be conducted in-person (at the location where the group meets, or a location convenient for the participant), over the phone, or through email. Please let the Principal Investigator know which interview method you prefer. Every effort will be made to accommodate in-person interview requests. However, if your group is located outside of the Chicago area, it may not be possible for the Principal Investigator to travel to you.

All in-person and telephone interviews will be audio-recorded and transcribed. This is important to ensure the accuracy of data collection, and is a requirement of your participation in the individual interview(s). If you decline

**APPENDIX P (continued)**

to be audio recorded, you are not eligible to participate in the interview portion of the research.

During the interview, the Principal Investigator will ask questions about your experiences facilitating the group, the objectives of the group, and your observations regarding how the group influences its members. The interview will take approximately twenty to thirty minutes to complete.

Once data collection is complete and a report has been drafted, participants will be asked to read and provide feedback on a draft of the research results.

**What are the potential risks and discomforts?**

This research is not expected to present risk beyond any possible emotional discomfort of describing your personal views about your participation in the group and how it has influenced the group members. However, there is the potential risk that others may find out that you are participating, or that others may find out identifiable information about you disclosed during the research.

If you are uncomfortable with any aspects of the interview, just let the Principal Investigator know, and you may choose not to answer specific questions. At any time, you may also choose to end your participation in this research entirely.

**Are there benefits to taking part in the research?**

Taking part in this research study may not benefit you personally. By participating in this research, you will help the Principal Investigator discover important aspects of the support group process. The information learned may also be helpful to others in similar circumstances.

**APPENDIX P (continued)****What other options are there?**

This is not a treatment study. Your alternative is not to participate in this study.

**What about privacy and confidentiality?**

The only people who will know that you are a research subject are members of the research team. Otherwise information about you will only be disclosed to others with your written permission, or if necessary to protect your rights or welfare (for example, when the UIC Office for the Protection of Research Subjects monitors the research or consent process) or if required by law.

A possible risk of the research is that your participation, or information about you, might become known to individuals outside the research. However, several measures will be taken to protect your privacy and confidentiality. Study information which identifies you, including actual name, email address, phone number, and mailing address, as well as the consent form signed by you, will be stored in a locked cabinet that only Norma Jane Mejias (Janie), the Principal Investigator, has access to. Portions of your responses to interview questions may be used when reporting the results of this study, but your name will be replaced with a code name and all other identifying information will be excluded.

The in-person and telephone interviews will be audiotape recorded. You will be given a code name before the audio recording begins. You will only be referred to by your code name on the audiotape. If you do an interview via email, the email will be stripped of your email address and real name. The email will be stored using your code name. All identifiers, contact information and research data, including audiotape recordings, transcriptions of audiotape recordings, and emails will be destroyed within one year of soliciting your feedback on the draft research report.

Your contact information will be stored in a password-protected Microsoft Word document that only the principal investigator will have access to.

## APPENDIX P (continued)

Hardcopies of your contact information will be stored in a locked filing cabinet that only the principal investigator will have access to.

If you disclose actual or suspected abuse, neglect, or exploitation of a child, or disabled or elderly adult, the researcher or any member of the study staff must, and will, report this to Child Protective Services (i.e. Department of Family and Human Services), Adult Protective Services, and/or the nearest law enforcement agency.

### **What are the costs for participating in this research?**

There are no costs to you for participating in this research.

### **Will I be reimbursed for any of my expenses or paid for my participation in this research?**

You will be compensated for your time with an Amazon gift card valued at 20.00 USD. This gift card will be distributed upon conclusion of the interview. Should you choose to withdraw from the study after the interview has begun, you will still receive this compensation. If you choose to take part in an email or phone interview, the gift card will be sent to you via USPS. If you are an international participant, you will receive the 20.00 gift card via email.

Additionally, you will be reimbursed up to twenty dollars for your travel expenses to and from the individual interview site, *if applicable*. You will be given this payment upon your arrival at the interview site.

### **Can I withdraw or be removed from the study?**

**APPENDIX P (continued)**

You can choose whether or not to participate in this study. If you volunteer to participate, you have the right to leave a study at any time without penalty. If you would like to withdraw from the study, please let the Principal Investigator know.

The Principal Investigator may withdraw you if certain situations arise. For instance, you may be withdrawn if the investigator cannot continue the study due to equipment failure, illness, scheduling problems, etc. You may also be withdrawn if you are unable to complete the tasks presented to you, or if the Principal Investigator learns that you do not meet the requirements for participation.

**Who should I contact if I have questions?**

Contact the Principal Investigator Norma Jane Mejias (“Janie”) at (312) 526-3241 or (703) 625-8849, or email at [nmejia2@uic.edu](mailto:nmejia2@uic.edu)

Or contact her faculty supervisor, Carol Gill, at (312)-355-0550 or email at [cgl6@uic.edu](mailto:cgl6@uic.edu)

- If you have any questions about this study or your part in it
- If you have questions, concerns or complaints about the research

**What are my rights as a research subject?**

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at [uicirb@uic.edu](mailto:uicirb@uic.edu).

## APPENDIX P (continued)

### **Remember:**

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University or your support group. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

### **Signature of Subject**

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Signature of Person Obtaining Consent  
subject's)

\_\_\_\_\_  
Date (must be same as

\_\_\_\_\_  
Printed Name of Person Obtaining Consent



## APPENDIX Q

### Comprehension Questions for Participation in Individual Interview with Group Members



#### Questions to Assess Comprehension of the Consent Process For Participation in Individual Interview(s)

“Exploring the Experiences of Women with Disabilities in Support Groups”

##### **Purpose of this research study:**

- In your own words, what is the purpose of this research?

##### **Procedures involved in this research:**

- In your own words, what are you being asked to do for this portion of the research?

##### **Potential benefits, risks and discomforts:**

- In your own words, what are the potential risks and discomforts involved in this portion of the research?
- What are the benefits of participating in this research?

##### **Privacy and confidentiality:**

- In your own words, how will your privacy be protected, and what steps will be taken to protect the confidentiality of your interview responses?

##### **Payment and reimbursement:**

- Will you be paid for participating in this research?
- Will you be paid back for any of the expenses you incur while participating in this research?

##### **Withdrawal or removal from the research:**

- Can you choose whether or not to participate in this research?
- In your own words, what would happen if you chose not to participate in this research, or if you decided to stop your participation after the study had begun?
- What do you do if you want to skip a question, or if you want to quit the research activities?

**Contact information/rights as a research participant:** Who do you contact if you have questions regarding this research?

## VITA

### NORMA JANE MEJIAS

#### EDUCATION

- Doctorate in Disability Studies, University of Illinois, Chicago, Illinois, expected 2019. Dissertation Title: *Factors in Support Groups that Promote Positive Self-concept Development of Young Disabled Women*
- B.A., Psychology, St. Andrews Presbyterian College, Laurinburg, North Carolina, 2005
- M.S., Disability and Human Development, University of Illinois, Chicago, Illinois, 2009

#### HONORS AND AWARDS

- Anne Hopkins Scholarship 2017
- Alice J. Dan Dissertation Award 2014
- Ethel Louise Armstrong Fellowship 2010-2013
- Who's Who Among Students in Colleges and Universities Nominee 2005
- St. Andrews Bensons Fellow 2001

#### CONFERENCE/ PROFESSIONAL PRESENTATIONS

- Presented "Accommodating People with Disabilities in Healthcare Settings" at the Health Professions Student Council Collaborative Healthcare Series, September 2013, Chicago, Illinois
- Presented "Influence of a Support Group for Young Women with Disabilities on Sense of Belonging" at the Society for Disability Studies Conference, June 2013, Orlando, Florida

#### PUBLICATIONS

- Mejias, N. J. (2019). Service Animals. In T. Heller, S. P. Harris, C. J. Gill, & R. Gould (Eds.), *Disability in American life: An encyclopedia of concepts, policies, and controversies* (pp. 592-596). ABC-CLIO, an imprint of ABC-CLIO.
- Mejias, N. J., Gill, C. J., & Shpigelman, C. N. (2014). Influence of a support group for young women with disabilities on sense of belonging. *Journal of counseling psychology*, 61(2), 208-220.

#### TEACHING EXPERIENCE

Disability in U.S. Society (in-person) course at UIC

Teaching Assistant, Spring 2018, Fall 2018

- Graded and provided feedback on students' work
- Led a weekly discussion section
- Prepared and presented guest lecturers
- Tracked attendance using Excel

Disability, Health, and Society (in-person) course at UIC  
Teaching Assistant, Spring 2017, Fall 2017

- Graded and provided feedback on students' work
- Assisted with managing course content on Blackboard
- Wrote and presented guest lectures on course topics

Foundations Disability and Human Development (online version) course at UIC  
Instructor, Fall 2015, Fall 2016

- Created course syllabus
- Organized materials for students online
- Wrote and presented lectures in an online format
- Created and moderated discussions
- Graded student work and provided feedback

Disability in American Film (online version) course at UIC  
Teaching Assistant, Spring 2015, Summer 2015, Spring 2016

- Created discussion prompts
- Moderated discussions
- Graded coursework
- Provided weekly feedback to students, as well as clarifications and additional guidance when necessary

Foundations of Disability and Human Development (in-person) course at UIC  
Co-Instructor, Fall 2013 & Fall 2014

- Taught foundational concepts to first-year masters students
- Provided both written and oral feedback, as well as planned and presented lectures and course activities

## **RESEARCH EXPERIENCE**

Department of Disability and Human Development at UIC  
Research Assistant, Fall 2013–Summer 2014

- Assist with coding and auditing qualitative data
- Assist with literature reviews

DBTAC: Great Lakes ADA Center

Research Policy Analyst, July 2008–November 2008

- Created and analyzed an online survey to determine what ADA related topics would be most useful to patrons attending the center's audio conference series.
- Edited and collected resources for an online tool kit intended to help businesses and employers further their knowledge of their responsibilities under the ADA.
- Created domain specific resource sheets to help professionals working in a variety of different fields' best accommodate people with disabilities.

## **PROFESSIONAL AND SERVICE EXPERIENCE**

### **ADA25 Emerging Leaders**

Fellow, January 2017, March 2017

- Participated in a four day leadership retreat
- Learned about characteristics of effective leaders
- Learned leadership tactics and how to effectively work in groups
- Learned about leadership in connection to the disability rights movement
- Examined personal leadership style
- Created personal leadership plan

### **Canine Companions for Independence (North-Central region)**

Volunteer, 2013-present

- Assist with fundraising
- Participated in Team Training and graduated with an assistance dog
- Do demonstrations and community outreach
- Take part in event planning

### **Disability Justice Mentoring Project at Access Living, Chicago**

Mentor, Spring 2014-Spring 2016

- Spend a minimum of 3 hours per month with assigned mentee
- Provide guidance and worked to empower youth with disabilities to become effective self-advocates

### **Disability Studies Student Council at UIC**

Vice President, Fall 2013-Fall 2014

- Work as liaison between students and staff
- Assist with planning educational and social events for students

### **Access Living Young Professionals Council**

Membership and Recruitment Chairperson October, 2012-2014

- Help plan fundraising events for Access Living
- Educate Young people about access living mission and disability rights

### **Mobility International USA Cross Cultural Exchange**

Delegate, July 2004-August 2004

- Participated in a volunteer service project at Tokyo Wild Bird Park
- Participated in panel discussions with disability rights groups from Japan
- Learned about the status of disability rights in Japan
- Became familiar with Japanese culture and perspectives pertaining to disabilities.

American Association of People with Disabilities

Internship, May 2003-July 2004

- Attended several national conferences on Disability Rights.
- Composed a memo on the enforcement of IDEA.
- Composed a memo on different leadership programs for youth with disabilities.
- Wrote an article on IDEA reauthorization for their newsletter.

Office of Virginia Senator George Allen

Internship, August 2003

- Assisted in the front office
- Answered constituents questions and relayed comments to the Senator
- Researched and catalogued health care bills
- Gained overall knowledge of the legislative process