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**I, Diane E Clouse , hereby submit this original work as part of the requirements for the degree of Doctor of Education in Special Education.**

It is entitled:

**Visualize Our Perspective: Using Photovoice to Document Students' College Experiences**

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# Visualize Our Perspective: Using Photovoice to Document Students' College Experiences

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by

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# Abstract

This case study describes the perceptions of seven diverse adults with intellectual disability enrolled in an inclusive post-secondary program and engaged in a collaborative group approach to inclusive research. The study documents, describes, and analyzes the perceptions of these adults' post-secondary educational experiences and the impact of their participation in the research processes. Multiple methods documenting participants' viewpoints included focus groups, photovoice, semi-structured interviews, and questionnaires. Objectives were to: (a) provide participants with intellectual disability with the opportunities to document and critically discuss their post-secondary educational program in order to evaluate its effectiveness; (b) share their results with peers, policymakers, and other potential stakeholders; and (c) document the inclusive research practices utilized to achieve these objectives and how they influenced participants. Results reveal participation in this inclusive college program is providing participants with opportunities for personal and relational development including: recognizing college as their preferred option; defining themselves; adapting to challenges; exceeding others' expectations; developing friendships and close personal bonds; belonging to the college community; and other positive social experiences. Data supports common themes across their perspectives, while highlighting the uniqueness of each individual. Further inclusive research with adults with intellectual disability is needed to begin to comprehend the impact of inclusive post-secondary educational programs and document their abilities to advocate for themselves, critically reflect on experiences, and effectively contribute to research processes. Such research supports the notion "Nothing about us, without us."

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Table of Contents

# List of Tables and Figures

**Tables** **Page**

**Figures**

# Chapter I. Introduction

Adults with intellectual disability (ID) have had somewhat limited and segregated roles in society via adult day care centers and sheltered employment workshops (Grigal & Hart, 2013). As advocates push for a more inclusive society, adults with ID need to develop necessary skills to manage their own lives (Browder & Shapiro, 1985; Taber-Doughty, Miller, Shurr, & Wiles, 2013; Wehman, Shutz, Bates, Renzaglia, & Karan, 1978). All young adults struggle with independently making decisions about their behavior, learning, and careers; however, the challenge for young adults with ID is even greater. This is evident as young adults with ID continue to exit our educational systems with limited self-management skills (Shogren & Broussard, 2011). For young adults who are typically developing self-management skills are honed during their post-secondary educational experiences when most first experience life independent of their families. Unfortunately, post-secondary educational opportunities have been limited for adults with ID (Tatnall, 2014).

Zafft, Hart, and Zimbrich (2004) among other researchers (Benz, Lindstrom, Yovanoff, 2000; Gilmore, Schuster, Zafft, & Hart, 2001) recognized the positive correlation between the level of education and employment opportunities for people with ID. This has led to an increase in post-secondary educational opportunities for adults with ID; there are currently nearly 240 programs available (http://www.thinkcollege.net/about-us). Inclusive post-secondary options are growing and replacing segregated life skills or community-based transitions programs; they offer great potential for improved quality of life for adults with ID (Zafft et al., 2004). As the number of post-secondary educational programs for adults with ID increases, so does the need for further research on the impact of these programs, specifically from the perspective of the participants themselves. The majorities of the data collected have been via surveys (Hart, Mele-McCarthy, Pasternack, Zimbrich, & Parker, 2004; Papay & Bambara, 2011; Stodden, Whelley, Chang, & Harding, T. 2001) or program reviews (Getzel, 2008; Hafner, 2011; Neubert & Moon, 2006; Zafft, Hart, & Zimbrich, 2004) from faculty or staff. Little evidence has been collected from adults with ID documenting the impact of post-secondary educational experiences on their lives (Fuller, M., Healey, M., Bradley, A., & Hall, T., 2004; Hafner, Moffatt, & Kisa, 2011; O'Brien et al., 2009; Paiewonsky, 2011).

In the current literature adults with ID have not fully participated in research processes that were designed to improve their behaviors and, presumably, sought to improve their quality of life (Clouse, Bauer, & Oettinger, 2015). Such approaches reveal researcher attitudes of low expectations toward participants' abilities and deny them the opportunity to attempt to manage their own behaviors and make choices in their lives. Individuals with ID are rightful participants in research about their lives (Conder, Milner, & Mirfin-Veitch, 2011; Povee, Bishop, & Roberts, 2014). Inclusive research practices provide a voice for vulnerable populations such as individuals with ID in (a) encouraging their input throughout the research process, and (b) actuating their role as research partner acting with other researchers rather than a subject being acted upon by researchers (Aldridge, 2014; Gilbert, 2004; Knox, Mok, & Parmenter, 2000; Povee et al., 2014). Although inclusive research involving participants with ID is increasing, the term "inclusive" or "participatory" research can be vague (Chapman & McNulty, 2004) and research describing specific inclusive methods with participants with ID is rare (Burke et al, 2003; Jurkowski, 2008). This study expands the literature by authenticating the seldom-documented perspectives of participants with ID regarding their post secondary educational (PSE) experience and records how engagement in inclusive research processes impacts adults with ID.

## Theoretical Underpinnings and Methodological Choices

Crotty's (1998) first element of the research process is identifying epistemology (see Figure 1). As a social constructionist I recognized that we define ourselves, and our realities, through social interactions, culture, and personal and group history. This study aimed to document the perspectives of the participants with ID regarding their PSE program, reflecting on the influences of the social interactions and experiences made possible by the opportunity to participate in this program. Documenting the participants' viewpoints provided the opportunity to highlight their individually constructed realities, while recognizing the influence of our interactions as this knowledge was generated (Cunliffe, 2004). Following Vygotsky's developmental theory, which contends knowledge construction is a social process mediated by signs and symbols of individuals' culture, I realized that I needed to recognize my own worldviews and cultural assumptions and how they might influence my research practices. As a former k-12 intervention specialist and staff member of the PSE program involved, I approached this study with the belief that individuals with ID have valuable perceptions and insights about their own experiences that needed to be captured. I acknowledged that my presence in this research process was not neutral and the data collected social constructs influenced by the interactions between the participants and myself (Smagorinsky, 1995).

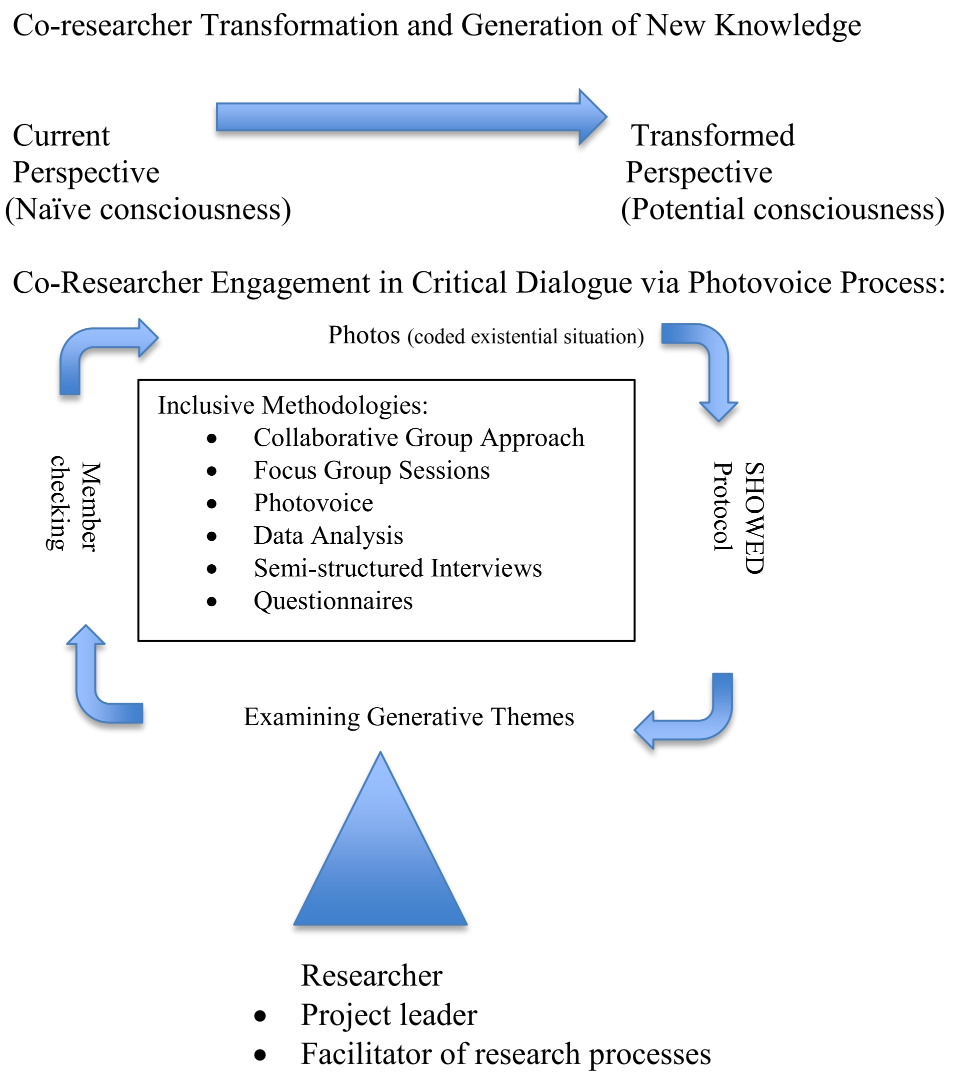
Figure 1. Four Elements of Research Process (Crotty, 1998)

**Empowerment education.** My theoretical paradigm was interpretive (Creswell, 2013; Denzin & Lincoln, 2013) and grounded in Freire's empowerment education theory (Freire, 1970). An interpretive approach considers a phenomenon in naturalistic settings as the researcher tries to "set aside" prior beliefs and knowledge in order capture the reality or perspective of participants. In this study, participants were individuals with ID whose role in society has generally been somewhat limited and, at times, segregated. Freire (1970) contended that in order to overcome the systems in society that serve to oppress certain members, the oppressed individuals need to play an active role in their "liberation" in order regain their sense of "humanity" (p.60). They must be willing and have the opportunity to view their world in a different way (Freire, 1970, p.60).

Through the various inclusive methodological choices, I embraced Freire's (1970) empowerment education theory as described by Wallerstein and Bernstein (1988). Utilizing the photovoice process (Wang & Burris, 1994) the participants and myself were "co-investigators" in this study exploring the topic and taking a dialogical approach using problem-posing methods. Considering Freire's (1970) critical pedagogy, this research project took on a more cooperative approach by recognizing the participants with ID as being able to reflect critically about their college experience. Such an approach sought to capture the participants' views of their world whereby themes were generated and "re-presented" to support engagement in on-going reflection and action (Freire, 1970; Wallerstein & Bernstein, 1988). Examining generative themes can help individuals begin the process of looking at their "world" (existential situation) critically, which can be a transforming activity (Freire, 1970, p.104). Figure 2 highlights the theoretical framework for this project as I worked with co-researchers to document their perspectives by engaging them in the transformative process of critical dialogue with the goal of generating new knowledge.

**Inclusive case study approach.** I took a replication approach to multiple-case design by documenting and analyzing multiple "cases" (Yin, 2014). Similar to the logic of conducting multiple experiments, each case follows duplication logic (Yin, 2014); in this study a "case" was an adult participant with a documented intellectual disability. Selecting multiple cases enabled multiple perspectives to be revealed and provided the opportunity to conduct cross-case analysis including exploring variances and similarities both within and between cases regarding the perceptions of the participants (Baxter & Jack, 2008; Miles, Huberman, & Saldana, 2013;

Figure 2. Empowerment Education (Freire, 1970): A Framework for Inclusive Research



Yin, 2014). This case study took a collaborative group approach as described by Bigby, Frawley, and Ramcharan (2014) utilizing inclusive methods. Such an approach engaged researchers and participants with ID, working together towards common, yet distinct objectives.

Table 1 provides further details regarding what a collaborative group approach to inclusive research involves and how it was applied in this study.

I refer to the participants with ID as “co-researchers” throughout this study based on their role in this collaborative group approach. My operational definition of “co-researcher” in this study is a participant with an ID who: was engaged collaboratively in the research process; was considered equally valued and included in decision-making processes; had shared control of research process, even though the role of leadership remained with the researcher; had skills and experiences that were utilized to produce new knowledge; and may have an understanding of the study, but were not necessarily involved in every aspect of it.

Table 1
*Collaborative Group Approach to Inclusive Research*

| Characteristic according to Bigby et al. (2014) | Application to current study |
|---|---|
| Characteristics of participants included are people with ID who have experience in the area of the specific research study. | Co-researchers are adults with ID who are part of a post-secondary educational program; the researcher sought to document their perceptions of their program. |
| Aim of the research is knowledge for social change. | Aim of this study was to promote the self-advocacy movement for adults with ID, expanding the literature by authenticating the seldom-documented perspectives of co-researchers regarding their post-secondary educational experience and engagement in the research processes. |
| Extent of inclusion involves people with and without ID. | Researcher and participants who typically developing worked with co-researchers who had an ID. |
| People with ID have sole or joint involvement in the initiation of the inclusion in the research process. | Co-researchers were invited to participate in the study based on the understanding that they will be engaged in the data collection and analysis phases of the research process. |
| People with and without disabilities collaborating together with shared, yet distinct purposes. | Researcher had specific objectives of answering research questions.<br>Co-researchers had unique personal goals, objectives, and interests. |

| Characteristic according to Bigby et al. (2014) | Application to current study |
|---|---|
| Combining resources (skills and experiences) of researcher and participants with ID to produce new knowledge, which could not necessarily be generated by either group individually. | Use of participatory, collaborative qualitative methods of data collection and analysis (photovoice, focus groups, interviews, and questionnaires) provided rich data for researcher from the perspective of the co-researchers that would not have otherwise been generated via solely a survey or other more positivistic approaches.<br>Co-researchers were engaged in activities and opportunities that most likely would not have occurred without the support of the researcher or their peer participants who are typically developing, or had they not been involved in the study. |
| Everyone involved has an understanding of the project, but may not necessarily be involved in every aspect of it. | Researcher provided an overview of project and purpose, but researcher and participants with and without disabilities had distinct roles in the project. |
| Each person's contribution is considered equally valued. | Group protocols for decision-making were developed. Data collection and analysis was designed to value, as much as possible, each person's input (via photovoice, focus groups, interviews, and questionnaires). Feedback was solicited from co-researchers via weekly reflection checklist during focus group sessions (see Appendix A). |
| Even though control of research process is shared, the role of leadership remains the responsibility of the researcher. | Researcher designed the study and facilitated data collection and analysis; however, input from co-researchers was solicited throughout data collection and analysis processes. |
| Qualitative methods are utilized; however, they may be modified to be group-based involving input from all members | Weekly focus groups involved all co-researchers' input in data analysis and on-going research process design. |
| Knowledge generated has been derived from multiple perspectives and collaborative efforts. | Data collection and analysis was designed as a collaborative effort that values each person's input (via photovoice, focus groups, interviews, and questionnaires). |
| Acknowledgement that "non-accessible space" (researchers working without participants with ID in order to prepare or provide accessibility to work inclusively with them) is acceptable and necessary. | Researcher designed the study (without co-researcher input) in order to incorporate principles of universal design for learning into the data collection and data analysis processes and prepared to provide accommodations as necessary to support co-researcher contribution to the best of each of their abilities. |
| Additional resources (time, money, personal commitment to project) may be necessary, compared to traditional methods including development of trusting relationships between research and participants with ID and potential ethical challenges. | Researcher had previously established a rapport with the second and third year program through her involvement in the PSE program. Researcher attended PSE program functions prior to start of study to develop a rapport with first year cohorts. Researcher reviewed literature regarding ethical considerations when working with participants with ID and included suggested accommodations in the research design. Ongoing reflection and adjustments were made as ethical deliberations occurred. |

**Inclusive Methodological Choices.** Given my conceptual framework and positionality, I planned multiple methods to capture my co-researchers' perspectives and provided them with opportunities to partake in decision-making regarding the project design and their level of participation as the project unfolded. These methods included focus group sessions, photovoice, semi-structured interviews and questionnaires. Additionally, I chose procedures, including video recording, field notes and analytic memos, to record the details of the data as it was collected.

***Focus group sessions.*** As Bigby and colleagues (2014) indicate, in a collaborative group approach I had a role of leadership in this project and completed some work without the co-researchers' input. In the initial planning of research processes I chose weekly focus group sessions as the most appropriate means to meet with my co-researchers and their peer supporters. Typically, focus groups are used as a means of group interviews in qualitative research (Creswell, 2012; Yin, 2014). Focus group sessions in this study served multiple purposes and are defined by five phases: (a) Phase I: Introduction and training; (b) Phase II: Photovoice process; (c) Phase III: Co-researcher engagement in data analysis; (d) Phase IV: Dissemination; and (e) Phase V: Wrap up. These weekly one-hour sessions were held on a consistent day and time in a conference room on campus that was in a convenient location for co-researchers. Snacks were provided for each session. Stalker (1996) noted the importance of supplying refreshments during focus group sessions as well as minimizing the use of jargon during discussions. Focus group sessions were audiotaped and transcribed for data analysis.

***Field notes.*** In order to assist in the documentation of critical dialogue and subsequent generative themes, undergraduate participants who are typically developing took observational field notes (Yin, 2014) during focus group sessions as co-researchers presented and discussed their photos (see Table 2). Field notes included a descriptive code (consisting of a few words) that summarized the photo (Miles et al, 2014) to provide a point of reference. Setting and conditions included recording details of the contextual factors like environmental elements and co-researchers' emotional dispositions. Various comments, reflections, and responses were documented and saved in Microsoft word files. The use of observational field notes in addition to transcriptions of audio-taped focus group sessions involving data analysis with co-researchers assisted in documenting and interpreting the inclusive data analysis practices (Creswell, 2012; Kramer, Kramer, Garcia-Iriarte, & Hammel 2011; Paiewonsky, 2005).

Table 2
*Field Notes Form*

| Date | Participant who took photo | Descriptive Code of Photo (what was the picture of) | Setting and Conditions | Comments, reflections, generative themes discussed regarding photo taken ***from participants*** during critical dialogue |
|---|---|---|---|---|
| | | | | |

***Analytic Memos.*** I engaged in documenting my thoughts through research memos. Memos are an important part of the analysis process in qualitative research (Corbin & Strauss, 2008). Immediately following each focus group session I wrote memos capturing my reflections of analytic thoughts regarding the process, co-researchers' experiences or comments, and any other insights that occurred (Corbin & Strauss, 2008; Maxwell, 2013; Miles et al., 2013). Additionally, my memos systematically documented my reflections regarding incidental observations, conversations, or general thoughts about the data and the data collection process (Maxwell, 2013; Miles et al., 2013). The memos were analytical, recording my immediate ideas following a session, conversation, or other incidental, yet potentially pivotal, data that may have otherwise been not been recorded. Freire (1970, p.112) noted the importance of not dismissing any activity when investigating a situation. Corbin and Strauss (2008) recommended that memos be conceptual versus descriptive in nature in order to support the advancement of data analysis throughout the research process. Memos were typed and saved in Microsoft Word using a table format (see Table 3). I found it beneficial to keep the memo description in the blank memo file so that I could review function of the memos before I recorded them.

Table 3
*Analytic Memo Form*

| | |
|---|---|
| Date: | Raw Data (observation, focus group, etc. from which memo is based): |
| Memo:<br>• Reflections of analytic thoughts regarding the process, participants' experiences or comments, and any other insights that occurred (Corbin & Strauss, 2008; Maxwell, 2013; Miles et al., 2013).<br>• Reflections regarding incidental observations, conversations, or general thoughts about the data or data collection process (Maxwell, 2013; Miles et al., 2013).<br>• Memos should be analytical, recording my immediate ideas following a session, conversation, or other incidental, yet potentially pivotal, data that may have otherwise been not been recorded.<br>• Corbin and Strauss (2008) recommend that memos be conceptual versus descriptive in nature in order to support the advancement of data analysis throughout the research process. | |

***Photovoice.*** Photovoice methodology is grounded on documentary photography, empowerment education (Freire, 1970), and feminist theory (Wang & Burris, 1997). Photovoice is a type of participatory action research tool employed as an empowerment tool where participants, often part of vulnerable populations with limited power (e.g. youth or people who are homeless), utilize photographs to record their experiences and then engage in critical reflection with the goal of informing policymakers (Wang & Burris, 1994; Wang & Burris, 1997; Wang, Morrel-Samuels, Hutchison, Bell, & Pestronk, 2004). Co-researchers in this study were individuals with ID whose role in society has generally been somewhat limited and, at times, segregated, often with restricted autonomy. Accordingly, participatory tools, which provide the opportunity for these co-researchers to express and share their ideas, were a logical choice (Jurkowski, 2008; Jurkowski & Paul-Ward, 2007; Paiewonsky, 2011). Moreover, photovoice has been identified as an effective research tool for engaging and empowering participants with ID (Jurkowski, 2008).

Co-researchers in this study took photos to document their college experience. These photos acted as “codes” that represented the co-researchers’ descriptions of their experiences or what Freire (1970, p.105) referred to as their “coded existential situation.” According to Freire (1970), the photographs provide a concrete representation of each of the participant’s existential reality, their “part” of the “whole” situation. Freire suggests that the “coded existential situation,” or photograph in this case, supports participants in recognizing their perspective as a concrete part of a larger experience that is shared with others (Freire, 1970, p.105). When people only recognize pieces of the “whole” situation, they do not comprehend the accurate “reality” (Freire, 1970, p.104).

In order to support co-researchers in transforming their perception of reality to include all of the “parts” that make up the “whole” (Freire, 1970, p.104) of their experience, co-researchers were asked to select and share their unique photos. Co-researchers met as a group and engaged in critical dialogue and reflection regarding their selected photos (Wang & Burris, 1997). This was facilitated using an adapted SHOWED protocol (Wallerstein, & Bernstein, 1988; Wang et al, 1998; Wang, et al., 2004). The mnemonic SHOWED stands for: What do you See here?; What is really Happening?; How does this relate to Our lives? Why does this problem or strength exist? How could this image **E**ducate others? What can we Do about it? Following Paiewonsky's 2005 model, alternative question options were utilized to support co-researcher comprehension and participation in critical dialogue (see Appendix A). Additional options were also considered if co-researchers struggled engaging in critical dialogue via the SHOWED protocol. For example, in a review of literature of the use of photovoice as a CBPR tool Hergenrather and colleagues (2009) highlight another option using the PHOTO mnemonic (Describe your **P**icture; What is **H**appening in your picture?; Why did you take a picture **O**f this?; What does this picture **T**ell us about your life?; How can this picture provide **O**pportunities for us to improve life?) (Graziano, 2004; Hussey, 2006; Mamary, McCright, & Roe, 2007). Other, similar questions have also effectively used to facilitate critical dialogue in a study by Rhodes & Hergenrather (2007). These questions include: (a) What do you see in this photograph; (b) How does this photograph make you feel; (c) What do you think about this; (d) What can we do about it.

Critical dialogue can loosely be defined as individuals engaging in discourse concerning the discovery of the contradictions that exist in the interaction of the parts of their whole situation. Facilitating critical dialogue using the adapted SHOWED protocol (see Appendix A) engaged co-researchers in the analysis of their coded situations (the photos). This process was designed to lead them from a naïve consciousness, which Freire (1970, p.113) denotes as

Goldman's "real consciousness," or one that may not perceive reality beyond the current "limit-situations," to a critical perception of their reality or "potential consciousness." Goldmans's concept of "potential consciousness" as referred to by Freire (1970, p.113) expands their "praxis" or view of the world and how they act upon it (Freire, 1970, p.106).

According to Freire (1970, p.103), critical insight is achieved through the identification of "generative themes." Exploring generative themes is the same as exploring individuals' praxis (Freire, 1970, p.106). Themes are labeled as "generative" since they have the potential of expanding into even more themes (Freire, 1970, p.102). Freire (1970) described generative themes as existing in "concentric circles, moving from the general to the particular" (p.103) and noted that they are found in the ways people talk about and react to their world, the "thought-language with which men and women refer to reality" (p.97).

Establishing generative themes requires the researcher or facilitator and the participants to engage with one another as "co-investigators" to identify themes based on the participants' view of reality using a dialogical problem-posing methods (Freire, 1970, p.108). This requires the researcher or facilitator to engage in dialogue that "re-presents" the themes back to the participants as a "problem" in order to support them in viewing their world critically. This process potentially generates more themes (Freire, 1970, p.104). Barnes (1992) discussed the importance of establishing a practical "dialogue" between the researcher and participants with disabilities, where the researcher uses their expertise to support the empowerment of participants. Freire (1970) warned facilitators to be careful not to dismiss any "themes" posed or fail to engage in critical dialogue regarding them. The process should also look for connections among themes and consider the historical-cultural context from which they may have emerged (Freire, 1970, p.108). Examining generative themes can help individuals begin the process of looking at their "world" (existential situation) critically, which is a transforming activity (Freire, 1970, p.104).

***Questionnaires.*** Co-researchers were given weekly research reflection checklists, or questionnaires, as well as final questionnaires to document their perspective on participating in the study to be used for data analysis and social validity (see Appendix B and C, respectively). Jurkowski (2008) suggested the use of a more formal evaluation tool in order to document participants' with ID perceptions regarding their participation in the research process. Guests who attended the final disseminations were invited to complete a questionnaire (see Appendix D and E) to document their interpretations and perceptions of the value of the photovoice data. These guests were peers, program staff, university faculty members, friends and family members, or other program stakeholders.

***Semi-structured Interviews.*** Individual semi-structured interviews were scheduled with each co-researcher after the final dissemination. The purpose of the individual interviews was to provide: (a) an additional opportunity for participants to express their individual viewpoints. Some co-researchers may not be as comfortable expressing themselves in the focus group setting, so the interview provides an one-on-one opportunity to them to share what they think about their college experience (Booth & Booth, 2003; Conder et al., 2011); (b) an additional opportunity for participants to express what they thought about being part of the research process; and (c) additional data for triangulation (Miles et al., 2013). The utilization of photovoice in combination with semi-structured interviews has been identified as an effective way of documenting the perspectives of people with disabilities and the use of semi-structured interviews is considered useful methodology in contextual approaches such as this (Ottmann & Crosbie, 2013).

The individual interviews were audiotaped and transcribed; transcriptions were used for further data analysis and triangulation. Best practices and guidelines were followed to ensure co-researcher perspectives emerged from the interviews, minimizing any recency effects or acquiescence issues that can be common when interviewing individuals with intellectual disability (Ottmann & Crosbie, 2013).

# Chapter II. Literature Review

This literature review provides a brief history on the disability movement for individuals with ID stressing the importance of inclusive research practices that support the current self-advocacy movement. A review historical and social-cultural context from which advocacy evolved provides background for this study. This study, which used inclusive research methods to document adults with ID perspectives, engaged participants in empowering activities that support the self-advocacy movement. The principles of normalization, social role valorization, and the social model of disability, which are the foundation of the self-advocacy movement and driving force behind inclusive research practices, provide additional context. Ethical and procedural considerations for engaging in inclusive research with participants with ID have also been outlined. Finally, a review of current literature on PSE programs for adults with ID is provided to document the necessity of this study and the need to record inclusive research methods that support on-going evaluation processes for PSE programs for adults with ID.

## Historical Social-Cultural Context

Social-cultural attitudes towards disability are reflected in research approaches and methodological choices (Rioux, 1997). Wehmeyer, Bersani, and Gagne (2000) identified three "waves" or eras in the history of societal perceptions of disability, which have influenced the disability rights movement for people with ID. The first wave was professionalism in the early 1900s. People with ID were viewed as threats to a "civilized" society and had no civil rights; they were placed in segregated institutions due to perception that the best way to "handle" individuals with ID was to entrust them to "professionals" who were mostly physicians. In the late 1940's the parent movement emerged as perceptions of disability were evolving to be more positive, though still stereotypical; people with disabilities were no longer feared, but now pitied. Parents formed advocacy groups to fight for their rights and the rights of their children as professionals began to shift control back to them. Finally, during the 1970s and 1980s family members, as well as professionals, began to realize that people with ID could and should advocate for themselves, which led to the current self-advocacy movement.

**Self-advocacy.** This grassroots movement, which began with a small group of people with ID in Oregon who formed a self-advocacy group, has led to policy changes for adults with ID that focus on more personalized supports and inclusive community living. The intention is to empower adults with ID, to take on a more extensive role regarding making decisions in their own lives. Results of this movement include access to inclusive post-secondary educational programs as well as supported employment opportunities, which have begun to replace day habilitation centers and segregated sheltered workshops for adults with ID (Wehmeyer, Bersani, et al., 2000).

**Normalization principle**. The self-advocacy movement, based on the principle of "normalization" as originally defined by Nirje in 1972, has been (and continues to be) a challenge to the stereotypical perceptions of low expectations and struggle for respect, dignity, and confidence in the abilities of individuals with disabilities (Wehmeyer, Agran, & Hughes, 2000). The normalization principle argues that people with ID should live lives as close as possible to that of mainstream society including involvement in their community and interacting with families and friends (Dybwad & Bersani, 1996; Nirje, 1994).

**Social Role Valorization**. In 1983 Wolfensberger re-conceptualized the principle of normalization, referring to it as "social role valorization." He altered the focus from one of nonconformity to one of social devaluation. Lemay (1995) described Wolfensberger's interpretation of a devalued person as one who is:

> perceived by society to be of low value is apt to be treated in ways that reflect this perception: low-quality housing, poor schooling or no education at all, low-paying and low-prestige employment (if any employment at all), poverty, and poor-quality health care. The devalued person will be rejected, separated, and excluded, and the good things in life, which are taken for granted by valued persons, will be denied or taken from a devalued person, including supportive relationships, respect, autonomy, and participation in the activities of valued persons. (p.4)

More recently Wolfensberger (2011) stated that, since the goal of normalization was “to be the establishment, enhancement, or defense of the social role(s) of a person or group, via the enhancement of people’s social images and personal competencies” (p. 435), the term social role valorization (SRV) was a more appropriate term than “normalization.” The term valorization is derived from the French term *valorization* and refers to the valuing of a person (Lemay, 1995). Wolfensberger (2011) proposed that, in order to meet the goals of normalization or SRV, two things need to happen: (1) the perception or “social image” of people who are at risk for devaluation needs to be enhanced; and (2) their skills and/or abilities need to be improved. Wolfensberger outlines four conditions through which these can occur: (a) physical settings, (b) relationships and groupings, (c) appropriate programs and activities, (d) language and other symbols and images.

**Social model of disability.** Another model, the “social model of disability,” emerged in 1990, which holds that societal obstacles such as lack of accessibility to necessary services and supports, rather than the capabilities of people with intellectual disability, have resulted in their social and vocational exclusion (Chapman & McNulty, 2004; Gilbert, 2004; Mole, 2012; Walmsley, 2001). This theory has influenced the efforts towards more inclusive research practices and is specifically linked to emancipatory research, which seeks social justice and necessitates people with ID control every aspect of the research process (Chappell, Goodley, & Lawthom, 2001; Walmsley, 2001).

## Inclusive Research

Embracing the principles of normalization, SRV, and social model of disability, inclusive research engages participants with ID in the research process as partners with valuable insights and experiences. Inclusive research can foster empowerment (Atkinson, 2004, Burke, et al., 2003; Povee, et al., 2014) and supports self-advocacy as participants gain new skills and acquire new knowledge, which may empower them to act positively in their own lives (Walmsley, 2004). The term participatory research has been used interchangeably with inclusive research, but the level of involvement of participants in studies has varied (Chapman & McNulty, 2004). As previously described this study took a collaborative group approach to inclusive research (Bigby et al., 2014).

Bigby and colleagues (2014) described and conceptualized three approaches to inclusive research with people with ID in a review of literature from the United Kingdom, New Zealand, and Australia. They defined the three approaches (advisory, collaborative group, and leading and controlling) based on the role of the individuals with ID in the research process. In the 'advisory role' involvement was minimal as participants with ID provided limited data that informed the research. In the 'leading and controlling' role, participants with ID took on an emancipatory role by leading the research process, whereas the 'collaborative group' approach lies somewhere in the middle of this continuum. Research where participants with ID were in control of the entire research process has been referred to as emancipatory research and considered to be under the participatory "umbrella" (Walmsley, 2001).

Similar to emancipatory research, and also considered inclusive research (Kramer, et al, 2011; Sample, 1996), participatory action research (PAR) has involved participants in the research process with the goal of producing results pertinent to them (Walton, Schleien, Brake, Trovato, & Oakes, 2012). PAR is an approach that seeks to improve outcomes for those involved by providing realistic resolutions to problems and emphasizing the initiation of societal change, often utilizing qualitative data collection practices (Creswell, 2012; Reason & Bradbury, 2001). Finally, there are also community-based participatory research (CBPR) approaches. According to Hergenrather, Rhodes, Cowan, and Bardhoshi (2009), CBPR involves "community members and representatives working together to identify and explore health and disability disparities and identify priorities" (p. 687). Community based participatory research has typically involved collaborative processes that build "bridges" between communities and researchers incorporating knowledge gained into actions that positively influence those involved (Cornwall & Jewkes, 1995).

All of the inclusive research approaches are based on three principles according to Stalker (1998): (a) traditional role of researcher as expert and participant as "object" of research is unjust; (b) participants have the right to be included in research that can potentially influence their lives; (c) research is enhanced when participants are included. Inclusive research approaches have applied principles of normalization, SRV, and social model of disability providing people with ID the opportunity to advocate for themselves and take on a valued social role (Stone & Priestley, 1996; Walmsley, 2001). All of these approaches support the notion "nothing about us without us." After all, who can document a phenomenon better than those who actually experience it?

**Multiple methodologies.** Considering the social model of disability, researchers need to ensure the chosen methodologies do not limit participant participation in the research process**.** Inclusive research needs to involve qualitative methodological approaches that are flexible, accessible, and sensitive to the needs of people with ID (Aldridge, 2007; Aldridge, 2014; Goodley, 2005; Knox, Mok, & Parmenter, 2000; Walmsley, 2001). Although quantitative methodologies can be employed, limiting data collection to solely questionnaires or surveys can exclude adults with ID from participating in the research process. This is due to accessibility issues (difficulties with comprehension) or the inaccurate reflection of the perspectives of adults with ID because of their propensity towards acquiescence, or tendency to provide desired answers rather than their true viewpoints (Aldridge, 2014). Utilizing one universal approach is not always adequate; mixed methods employing more inclusive approaches are most appropriate with participants with ID (Aldridge, 2014; Ottman & Crosbie, 2013). Researchers need to recognize that some participants with ID, like those who are typically developing, may express themselves better in one format like one-on-one interviews versus another like focus groups (Conder et al., 2011). By limiting the modes of data collection, researchers may be creating barriers for participants with ID (Mole, 2012). Providing multiple forms of data collection enhances the opportunities for more accurately reflecting participants' with ID perspectives, thereby triangulating findings (Booth & Booth, 2003; Conder et al., 2011).

**Considering accessibility.** Initially an architectural construct, the principles of "universal design" integrate the social model of disability by designing environments and products in a way that considers the diverse needs of potential consumers from the inception so that adaptations are not necessary later on. Though not yet empirically based, the construct of universal design for learning (UDL) has been widely accepted in the field of education (Edyburn, 2010). Based on the principles of universal design, UDL has been recognized as a framework for instructional design established by the Center for Applied Special Technology (CAST) that promotes building multiple means of representing information to students, multiple ways for students to express what they know, and multiple methods of engaging students into the initial curricula to support the diverse learning needs of *all* students, minimizing barriers to instruction and, hence, the need for additional specialized accommodations (CAST, 2011).

Applying the guidelines of UDL in research design can benefit participants with ID involved in inclusive research (Paiewonsky, 2014; Walmsley & Johnson, 2008). For example, offering multiple means of representing information to participants increases the likelihood of participants comprehending the materials. One way of doing this would be providing participants with printed copies of consent forms in addition to reading the form orally (Hall, 2013). Other examples include using simple language as well as adding visual cues, like pictures to represent ideas being expressed (Hall, 2013; Paiewonsky, 2005; Stalker, 1998). By varying the research methodologies as previously described, researchers provide multiple opportunities for participants with ID to express their viewpoints. Finally, by providing participants with choice and decision-making roles, options for levels of participation, and opportunities to reflect on the research process, inclusive research practices apply multiple means of engagement. All of these strategies make participation in the research process more accessible for participants with ID.

**Successful Practices.** Table 4 lists practices from the literature researchers should consider when engaging in inclusive research with participants with ID. Although research is still needed to determine practices that most effectively capture the viewpoints of participants with ID (Ottman & Crosbie, 2013), these strategies have been recommended in inclusive research to date.

Table 4
*Recommended Inclusive Research Practices*

| Author(s) | Inclusive Practice | Application in Current Study |
|---|---|---|
| Aldridge, 2014;<br>Conder et al., 2011;<br>Nind, 2011 | Dissemination should involve sharing an accessible (shorter format, simpler language with illustrations as needed) "final report" with participants | Researcher created and presented a final report in simple language for co-researchers. |
| Aldridge, 2014;<br>Conder et al., 2011,<br>Nind, 2011 | The role of researcher needs to be flexible and viewed as a continuum as researchers may need to adapt in order to meet the needs of the participants with ID throughout the research process | Researcher began with the role as a leader as she introduced co-researchers to the project (focus group phase I), shifted to the role of facilitator throughout the data collection and analysis process with co-researchers (focus group phases II-IV), and then moved back into a leadership role during the last few weeks of the project (focus group phase V). Throughout the project the researcher remained flexible as co-researchers were empowered to make decisions as to the next steps in the project. |
| Conder et al., 2011 | Goals of the project should be clear | Goals of the project were written in simple language with pictorial supports. They were shared with co-researchers at the beginning of the project via the informed consent documents and in initial PowerPoint presentation. Goals were revisited in subsequent PowerPoint presentations during focus group sessions. |

| Author(s) | Inclusive Practice | Application in Current Study |
|---|---|---|
| Conder et al., 2011; Garcie-Iriarte, Kramer, & Hammel, 2009; Ward & Trigler, 2001 | Roles of everyone involved should be clarified at the beginning and rules established for group procedures and managing power | Roles of researcher, participant support persons, and co-researchers were clarified in the first focus group session. Rules and procedures for decision-making were established during the second focus group session and revisited throughout the process as needed. |
| Conder et al., 2011; Gilbert, 2004; Ward & Trigler, 2001; Williams, 1999 | Researchers need to support participants in understanding the research process initially before gaining consent | Research process and participant roles were presented to co-researchers in written handout with pictorial cues as well as reviewed via a PowerPoint presentation. Written copies of consent forms were given to co-researchers one week in advance, and then reviewed with them orally. Co-researchers were also given the opportunity to ask questions before signing consent and witnesses were present during oral explanation of consent form. |
| Hall, 2013; Jones, 2007; Knox et al., 2000; McDonald & Patka, 2012 | Consent should be viewed as a continuous process, reminding participants of the purpose of the study and their rights (to participate or stop) throughout the study | Consent was reviewed weekly before each focus group session, giving co-researchers the option to stop participating in the project if they chose. Purpose of the study was also reviewed weekly and co-researchers were given the option to provide written or oral feedback via weekly reflections. |
| Knox et al., 2000 | Building a rapport between research and participants at the beginning of the research process is critical | Researcher had already established rapport with the second and third year cohort co-researchers via her role as a former staff member in the program they were enrolled. Researcher built rapport with first year cohort through her participation in summer workshops and other program activities prior to the start of the project. |
| Sample, 1996 | Participants need to be involved in evaluating the research process | Co-researchers were given the option to provide written or oral feedback via weekly reflections at the end of each focus group session. |
| Ward & Trigler, 2001 | Clear expectations of time and expected commitment should be reviewed | Researcher provided clear expectations of time and expected commitment via the consent forms and in the PowerPoint presentations describing the project. |
| Ward & Trigler, 2001 | Begin with a small scope for project to keep participants interested and engaged in process | Researcher presented one question to co-researchers. |

**Lack of participant involvement in data analysis.** While inclusive research practices have grown in the past few decades, few studies have involved participants with ID in data analysis (Nind, 2011; Tuffrey-Wijne & Butler, 2010). This may be due to perceptions of incompetence of people with ID undertaking such tasks, or the challenges these practices present for researchers may be too daunting in terms of time, effort, and potential monetary investments required (Aldridge, 2014; Nind, 2011; Povee, et al., 2014; Stalker, 1998). Whatever the reasons, the challenge needs to be taken on. Only by supporting the inclusion of people with ID in the data analysis process can we explore the potential of their abilities. Nind (2011) suggests researchers need to adopt a more positive attitude towards data analysis and participants with ID, one that approaches the task in terms of what participants are capable of doing, rather than what they cannot do. Additionally, Nind (2011) recognized the need for researchers to be flexible in their role and maintain the assumption that no one person is the "expert" in the process; in fact, Knox and colleagues (2000) suggests researchers consider participants as the "experts" when documenting their own lived experiences. It is only by shifting paradigms that we can fully understand the potential of participants with ID.

**Photovoice.** Photovoice is a type of PAR method employed as an empowerment tool where participants, often part of vulnerable populations with limited power (e.g. youth, people who are homeless, and those with disabilities), utilize photographs to record their experiences and then engage in critical reflection with the goal of informing policymakers (Wang & Burris, 1994; Wang & Burris, 1997; Wang, Morrel-Samuels, Hutchison, Bell, & Pestronk, 2004). Photovoice has three goals which include: enabling participants to document and reflect on their situation including strengths as well as concerns; fostering critical dialogue between the participants regarding their shared experiences in a group setting; and engaging in activities to share their results and promote positive changes (Wang & Burris, 1997). Photovoice methodology is based on theoretical literature on documentary photography, empowerment education (Freire, 1970), and feminist theory (Wang & Burris, 1997).

***Documentary photography.*** Documentary photography was a term established in the early 1900s as photographers used images to impact social reform in the United States (Becker, 1995). Documentary photography recognized the need for documenting the perspectives of those who are vulnerable or marginalized and has been effectively used to document issues surrounding these often-powerless groups; however, it leaves the power in the hands of the photographer who is an “outsider” to the issues being documented (Wang & Burris, 1997). Photovoice puts the camera and, hence, the power, in the hands of participants providing them the opportunity to act as “visual anthropologists” recording their experiences from their perspective in a way that an outsider could not.

Fischman (2001) notes that visual images are not just graphical representations, but include social-cultural and economical expressions that reflect the environment of those who produce and view the images. Photovoice provides participants with the opportunity to use visual images to document their social reality (Booth & Booth, 2003;Wang & Burris, 1994)

***Empowerment education.*** Photovoice is also rooted in Freire’s (1970) empowerment education theory, which rejects the traditional role of teacher as expert who imparts knowledge onto the student who is just a receptacle. Freire’s (1970) pedagogy is based on practical knowledge that is created when people identify issues important in their lives, then reflect on them using critical dialogue that would facilitate individual change with the greater goal of influencing community policies to attain a more equitable society. In his work Freire presented visual images to people to facilitate reflection and critical dialogue utilizing problem-posing methods to create generative themes as previously discussed. Freire's approach of presenting "coded existential situations" was one of an "outsider," while photovoice enables participants to document their "coded existential situations" from their "insider" perspective and begins the social change process from their perspective (Jurkowski, 2008; Wang & Burris, 1997).

***Feminist theory.*** Lastly, photovoice is rooted in feminist theory, which is critical of one (dominant) group acting on behalf of another (minority or marginal) group (Jurkowski, 2008; Wang & Burris, 1994, 1997). Feminist research supports inclusive knowledge construction and recognizes women as the experts in their own lives who are empowered when they have the opportunity to assert themselves (Wang, 1994). Wang, Burris and Ping (1996) describe several themes in feminist theory as it relates to photovoice. First is the promotion and understanding of women's experiences through inclusive methods. Second is the highlighting of individual experiences that result in collective or shared experiences. Third is the need for representation in policymakers that "values women's experience as a catalyst for social action" (p. 1393). Photovoice, like feminist theorists, values the perspective of those who experience a phenomenon, supports marginalized participants in expressing their perspectives, and facilitates positive individual and community transformation (Povee et al, 2014; Wang & Burris, 1994).

Photovoice integrates the concepts of documentary photography, empowerment education, and feminist theory with the goal of empowering participants to learn about themselves, learn about others with same, shared experience, and inform others, including policymakers, of their valuable perspectives.

***Prior literature.*** Since its inception by Wang & Burris (1994) photovoice has been employed with a variety of participants to address an array of issues. In a recent review of literature, Hergenrather and colleagues (2009) recognized six areas of community concern that photovoice has been utilized in addressing. They were: rebuilding communities, promoting health, living with disabilities, preventing and treating HIV/AIDS, improving quality of life, and assessing the effects of war. It is rapidly gaining more popularity and widespread use as Langdon, Walker, Colquitt and Pritchard (2012) more recently utilized photovoice to determine physical education pre-service teachers' preparedness to teach.

***Common processes.*** Though level of participation and role of participants vary, common processes utilized in photovoice include: identification of a concern; recruitment of participants; introduction to photovoice and training; procurement of informed consent; identification of photo assignments; discussions of photos taken; engagement in data analysis; presentation of findings; and creation of further action plans (Booth & Booth, 2003; Hergenrather, et al., 2009; Jurkowski, Rivera, & Hammill, 2009; Wang, 1999; Wang & Burris, 1997).

***Photovoice with adults with intellectual disability.*** While inclusive research with participants with ID has increased, the use of methods like photovoice is still rare (Jurkowski, 2008). Studies that have engaged participants with ID in photovoice have recognized this approach as effective research for engaging and empowering participants (e.g. Booth & Booth, 2003; Brake, Schleien, Miller, & Walton, 2012; Graham, 2012; Jurkowski, 2008; Jurkowski et al., 2009; Paiewonsky, 2005, 2014; Povee et al., 2014; Schleien, Brake, Miller, & Walton, 2013; Walton et al., 2011; Woolrych, 2004). Table 5 summarizes studies that have engaged adults with ID in inclusive research utilizing photovoice. Booth and Booth (2003) note several features of photovoice that make it optimal for participants with ID. The uses of both visual images (photo) combined with oral discussions (voice) make available multiple means of expression, applying principles of UDL within the methodological design. Such methodological choices provide access to participants' viewpoints, helping them to more clearly communicate, which may not have otherwise been possible. These studies have supported and empowered participants to inform program or community members, who are making decisions that impact participants' quality of life, about issues that are important to participants.

Table 5
*Photovoice Studies with Adults with Intellectual Disability*

| Study | Participants | Objective |
|---|---|---|
| Booth & Booth, 2003 | 13 mothers in United Kingdom | Challenge discriminatory views and support participant confidence and development of self-identity |
| Brake, et al., 2012 | 7 members of local ARC chapter | Gain better understanding of supports and barriers to social inclusion and document the lives of participants in order to promote systems changes for more socially-inclusive community |
| Graham, 2012 | 9 adults with intellectual or developmental disabilities involved in a self-advocacy group | Combine photovoice with a dialogue process, Council, to develop self-advocacy skills |
| Jurkowski & Paul-Ward, 2007 | 4 Latinos | Understand beliefs and explore health priorities of participants in order to share with community partners |
| Jurkowski et al., 2009 | 15 Latinos | Understand beliefs to provide data to guide the development of health promotion programs that impact participants |

| Study | Participants | Objective |
|---|---|---|
| O'Brien et al., 2009 | 19 students enrolled in a PSE program for adults with ID in Dublin | Participated in focus groups, photovoice, reflective journals, and completed PATHs (a transition planning tool) |
| Paiewonsky, 2005 | 5 students involved in transition planning from high school to post-secondary services (1 student was only 17) | Support students in participation in transition planning and inform other members (family, school staff, interagency members) of transition team |
| Paiewonsky, 2011 | 9 students enrolled in 4 different PSE programs | Use photovoice and Voicethread (digital tool) to document participants' college experience as part of a national college access initiative. |
| Schleien et al., 2013 | 7 adults living in a community | Document lives to inform community members and support changed for more socially-inclusive community |
| Walton et al., 2011 | 22 members of a self-advocacy group | Gain better understanding of supports and barriers to social inclusion and document the lives of participants in order to promote systems changes for more socially-inclusive community |

*Best Practices.* Based on prior literature utilizing photovoice with adults with ID, several common, best practices can be discerned. The first is the necessity of building rapport with participants (if a prior relationship has not already been established) before beginning the research process (Paiewonsky, 2005, 2014). It is also important to meet with participants, either individually or collectively to explain what research means, the purpose and scope of the project to be undertaken, and their expected role (Brake et al, 2012; Jurkowski, 2008; Paiewonsky, 2005, 2010, 2011, 2014; Walton et al., 2011). On-going, regular meetings throughout the photovoice process provide additional support for participants (whether for technical difficulties or procedural reminders), opportunity to confirm consent, and increased likelihood of continued interest in participation (Graham, 2012; Paiewonsky, 2005; Walton et al., 2011). Accommodations need to be provided to meet the unique needs of the participants involved when explaining these processes (Paiewonsky, 2005, 2010, 2011, 2014). Additionally, the researcher needs to recognize that participants may not fully comprehend matters until they actually experience them (Jurkowski, 2008). Consent and assent issues for engaging with vulnerable populations also need to be considered (see Table 6).

Table 6

*Considerations for Informed Consent for Adult with Intellectual Disability*

| Considerations | Application in this study |
|---|---|
| Collaborate with IRB (McDonald and Patka, 2012; Walton et al., 2011) | Researcher met with IRB reviewer previously and completed checklist for research involving participants who are cognitively impaired |
| Give participants a copy of consent form before meeting with them to the explain study (McDonald and Patka, 2012; Walton et al., 2011) | Co-researchers were given a copy of the consent form prior to meeting with researcher. Researcher provided a visual overview of study and oral presentation of informed consent. |
| Use simple language and multiple examples of what study is about and what their participation will involve (Hall, 2013; McDonald & Patka, 2012) | With the exception of two IRB required paragraphs and the witness statement, the language used in the consent form is at a 5.4 readability level. Additionally, a modified consent form with pictorial cues was given to co-researchers to support comprehension. |
| Use accommodations such as reading consent form aloud; verbally check for understanding (by asking participants to state their understanding or use a question-and-answer strategy); or add pictures if necessary to support comprehension (Hall, 2013; Jurkowski, 2008) | Consent form was read aloud and the researcher verbally confirmed co-researcher understanding of document. Witnesses and researcher agreed co-researchers understood and no additional accommodations were necessary. |
| Regard consent as a continuous process by reminding participants of the purpose of the study and their rights (to participate or stop) throughout the study (Hall, 2013; Jones, 2007; Knox et al., 2000; McDonald and Patka, 2012; Walton et al., 2011) | Researcher reminded co-researchers of their rights to participate or to stop participation in the study each meeting. |
| Provide participants with examples (verbal responses, scripts, or pictures with phrases) of ways they can express their feelings if they feel stressed during the study or want to stop participating in the study (Hall, 2013) | Researchers provided examples of ways co-researchers could notify her if they were upset or no longer want to participate (via a verbal response, note, or email). |
| Provide participants with examples (verbal responses, scripts, or pictures with phrases) of ways they can express their desire to continue in the study (Hall, 2013) | Researcher asked co-researchers each time they meet if they wanted to continue in the study and provided the opportunity to give feedback via weekly reflections. |

Before sending participants out to take photos, ethics of taking photos need to be explained and any necessary training provided regarding use of photo equipment (Brake et al., 2012; Jurkowski, 2008; Paiewonsky, 2005; Walton et al., 2011; Woolrych, 2004). It is also beneficial to assign an "assistant" to support (not coerce) participants throughout the process (Brake et al., 2012; Jurkowski, 2008; Paiewonsky, 2014; Povee et al, 2014; Walton et al., 2011). Assistants, typically friends or family members, escort participants during their photo missions to ensure photo ethics are followed and provide someone to take a photo that includes the participant. Assistants have also been included in interviews or focus groups to contextualize and discuss photos. Although they may help prompt participants or occasionally clarify what participants are trying to communicate, it critical that support persons understand their specific role so that they do not unknowingly (or knowingly with good intentions) influence participants during their photo missions, interviews or focus groups (Brake et al., 2012).

Participants should be given an "assignment" or "photo mission," which is basically a reason for taking their photos. This is typically a prompt like "take pictures of people, places or things that are important to you" (Brake et al, 2012; Booth & Booth, 2003; Jurkowski, 2008; Paiewonsky, 2005, 2010, 2011, 2014). Participants in previous studies were often given a maximum number of photos and a time frame in which to take them (Brake et al, 2012; Booth & Booth, 2003; Jurkowski, 2008).

Once photos are taken, either in one or multiple iterations, individual or group sessions need to be scheduled for participants to contextualize and discuss their photos (Brake et al, 2012; Booth & Booth, 2003; Jurkowski, 2008; Paiewonsky, 2005, 2010, 2011, 2014). Participants should also be given a printed copy of their photos to keep; this is often done in the form of a scrapbook (Booth & Booth, 2003; Jurkowski, 2008). Some participants (and often their assistants) were engaged in an individual interview to discuss and contextualize their photos utilizing the SHOWED protocol (Wallerstein, & Bernstein, 1988; Wang et al., 1998; Wang, et al., 2004) or similar questioning method (Booth & Booth, 2003; Brake et al., 2012; Jurkowski, 2008). Interviews were audio-taped and transcribed for further thematic analysis and to provide descriptions of photos in future exhibitions (Brake et al, 2012; Jurkowski, 2008). Participants were also engaged in selecting photos to bring to a group discussion session to share with other participants involved in the study (Booth & Booth, 2003; Brake et al., 2012; Jurkowski, 2008). Some studies used the discussion group as a form of member-checking regarding the themes previously identified by researchers (Jurkowski, 2008), while other studies facilitated the discussion to assist participants in engaging in critical dialogue as an additional means of data collection (Brake et al., 2012).

Thematic analysis has typically been completed separately from participants with some form of member checking for verification, although a few researchers have embarked on involving participants with ID in the analysis process (e.g. Brake et al., 2012; O'Brien, et al., 2009; Paiewonsky, 2005, 2011, 2014). Brake and colleagues (2012) had participants identify three "themes" from their photos based on the discussion during their interview; participants then selected a photo to represent the theme. Researchers engaged in further analysis of individual themes separately to identify six collective themes across participants. O'Brien and colleagues

(2009) mention students taking photos for “group discussion and analysis” (p. 287); however, no specific details as to how this was accomplished were documented.

Paiewonsky (2005, 2011, 2014) has several publications documenting how she has engaged participants with ID in in participatory analysis as defined by Wang & Burris (1997). Participatory analysis involves participants in a three-step procedure of selecting, contextualizing and codifying ,or identifying emerging themes, from pictures (Wang & Burris, 1997). In 2005 Paiewonsky utilized photovoice to support the participation of high school students with ID in their transition planning. After participants shared photos of their choosing, Paiewonsky (2005) engaged them in a discussion of similar feelings, hopes, and concerns regarding their transition from high school. Participants were then prompted to write narratives based on the SHOWED protocol (Wallerstein, & Bernstein, 1988; Wang et al, 1998; Wang, et al., 2004). Paiewonsky offered alternative questions as needed to accommodate needs of participants. Participants were taught what a “theme” was, presented their photos and narratives to the group, and then identified five themes independently and one with assistance from Paiewonsky. In 2011 Paiewonsky engaged students with ID in analyzing photos they had taken to document their PSE experience. Participants reviewed each other’s photos and then organized them to identify and comment on themes. More recently, Paiewonsky (2014) published a monograph describing a PAR process to engage students with ID in photovoice to document and evaluate their college experience. Paiewonsky documented steps for involving participants in data analysis by having them sort and organize photos into categories. The process described involved using digital tools like Voicethread. Once participants identified themes, they selected pictures to represent them.

The literature also recommends participants should be involved in the planning and presenting in some sort of dissemination to reach “outsiders” like family, friends, policy-makers, or other community members (Brake et al., 2012; Jurkowski, 2008; Paiewonsky, 2005). Finally, any final reports should include a modified version using simple language or other necessary accommodations for participants to review (Jurkowski, 2008).

*Benefits for researchers and communities.* There are many benefits for researchers and the communities when photovoice is utilized with participants with ID. First, by having participants take photos to capture their viewpoints, photovoice can provide a deeper, richer understanding of participants’ perspectives (Jurkowski, 2008). Having participants take photographs allows researchers to gain insight into the worlds of participants that may not have been access via other methodologies (interviews or surveys). Additionally, the photos provide a more concrete representation of issues and minimize chances of acquiescence (Booth & Booth, 2003; Jurkowski, 2008). Visual data provides a more trustworthy data analysis (Jurkowski, 2008), which can and should involve participants (Nind, 2011). Photovoice has the potential of impacting community members’ perceptions of people with ID and inclusion. This can have long-term impacts on creating more socially inclusive communities (Booth & Booth, 2003; Brake et al, 2012; Paiewonsky, 2005; Schleien et al., 2013; Walton et al., 2011). The visual imagery from participants could change stereotypical roles as viewed by support persons or family members or other key policymakers (Lemay, 1995; Wolfensberger, 2002; Wolfensberger, 2011). Additionally, photovoice can provide valuable data to inform program development and evaluation (Jurkowski, 2008; Jurkowski & Paul-Ward, 2007; Jurkowski, et al., 2009; Paiewonsky, 2005).

*Benefits for participants.* The use of photovoice in the research process also offers benefits for the participants with ID. Photovoice engages participants as active participants and collaborators in the research process versus being the subjects of it, promoting empowerment and self-advocacy skills (Booth & Booth, 2003; Graham, 2012; Paiewonsky, 2005). Photovoice also provides opportunities to develop new skills and self-confidence (Brake et al., 2012; Jurkowski 2008; Jurkowski & Paul-Ward, 2007). Participants would not normally have the opportunity to reflect on or critically evaluate their lives (Jurkowsky, 2008). Moreover, the photos can bring about perceptual changes for adults with ID; this can be helpful in changing the social roles of adults with ID (Jurkowski, 2008). Not only that, most participants find the process enjoyable and often receive some sort of token of appreciation for their participation like their photos, a scrapbook, or even monetary compensation (Jurkowski, 2008).

*Challenges***.** The use of photovoice with participants with ID can also present some challenges. Projects can be time consuming and take longer than anticipated (Booth & Booth, 2003; Jurkowski, 2008, 2014). Participants may struggle with operation of cameras, understanding photo ethics, taking the photos, or returning the photos for development (Booth & Booth, 2003; Jurkowski, 2008). Some participants may also have difficulties understanding the project's purpose, the "photo mission," or the concept of consent (Jurkowski, 2008). Participants may also struggling engaging in critical reflection regarding their photos (Jurkowski, 2008).

Additionally, if participants have legal guardians, those caregivers may heavily influence whether or not participants get involved in the study (Jurkowski, 2008).

*Usefulness in program evaluation.* Photovoice has been utilized as an effective tool to promote health and changes in communities through program development and systems assessment for people with ID (Brake et al., 2012; Jurkowski & Paul-Ward, 2007; Jurkowski et al., 2009; Schleien et al., 2013; Walton et al., 2011). In their early use of photovoice Wang & Burris (1997) recognized it as a useful evaluation tool in inclusive research. More recently Paiewonsky (2014) wrote a monograph describing how to utilize photovoice as a non-traditional PSE program evaluation tool based on prior studies where she utilized photovoice to document transition planning (2005) and college experiences (2011) for individuals with ID. The use of alternative, inclusive methodologies to document the perspectives of participants with ID to inform program evaluation provides authentic data that benefits both researchers and participants while informing policy-makers.

## Post-Secondary Educational Programs for Adults with ID

The Individuals with Disabilities Education Act (IDEA) and the Americans with Disability Act (ADA) were grounded in an effort to provide equality of opportunity, full participation in communities, economic self-sufficiency, and independent living for individuals with disabilities through education and access (Turnbull, 2013). Adults with ID have right to access higher education and, thanks to the self-advocacy movement as well as the incorporation of universal design principles in post-secondary settings (Silver, Bourke, Strehorn, 1998), PSE options for adults with ID are increasing (Paiewonsky, 2014). This is backed by research that shows a positive correlation between the level of education and employment opportunities for people with disabilities (Thoma et al., 2011; Zafft, Hart, & Zimbrich, 2004). Access to more employment opportunities ensures a better chance of becoming productive and independent members of society and improvement in quality of life.

**Existing Literature.** There have been two major literature reviews completed in regarding the topic of adults with ID and post-secondary educational programs. The first was done by Neubert, Moon, Grigal and Redd (2001) where they reviewed 27 published works from the 1970s, 1980s and 1990s which recognized trends in post-secondary opportunities for adults with ID and types of programs available. Programs were classified as segregated, inclusive or some combination of the two. Neubert and colleagues (2001) noted that during the 1970s PSE programs for adults with ID were limited, segregated, and focused on providing remedial education, development of vocational skills, and leisure opportunities. Although low expectations continued to reinforce students with ID's lack of preparedness for PSE programs, the number of PSE options was slowly beginning to increase, as was their level of inclusiveness in the 1980s (Neubert et al., 2001). In the 1990s two trends emerged; the first was an increase in dual enrollment programs where eligible students could continue to receive services from their local schools until age 22, but received services in PSE settings. The second trend was an emphasis on individualized transition planning and support (Neubert et al., 2001).

In 2011 Thoma and colleagues expanded this first review citing 24 new studies regarding PSE options for students with ID from 2001-2010, which were categorized into specific program descriptions or evaluations (n=10), regional or national studies (n=9), and independent individually designed options (n=5). This review revealed studies providing more details about program features and their development as well as challenges and recommendations, information that is critical as PSE program options increase (Thoma et al., 2011). While some of the literature focused on identifying broad, regional trends, Thoma et al., (2011) noticed an increased focus on individual experiences; such data is also important in recognizing specific services and supports that reinforce student success in PSE programs.

***Post-secondary program research with adults with ID.*** The emphasis of my review of literature regarding PSE programs for adults with ID has been on what data has been collected regarding inclusive PSE programs and what methodologies have been utilized, specifically whether or not they were inclusive (see Table 7). The majority of the data has been collected via surveys (Hart, Mele-McCarthy, Pasternack, Zimbrich, & Parker, 2004; Papay & Bambara, 2011; Stodden, Whelley, Chang, & Harding, 2001) or program reviews (Getzel, 2008; Hafner, 2011; Neubert & Moon, 2006; Zafft et al., 2001) from faculty or staff with only very little data collected from students with ID themselves (Fuller et al., 2004; Paiewonsky, 2011).

Table 7

*Post-Secondary Educational Program Research: Methods and Participant Involvement*

| Study | Type of PSE program | Methodological Approach, Data Collection Methods, and Purpose | Contribution of Individual with ID |
|---|---|---|---|
| Casale-Giannola & Kamens (2006) | Individualized experience of one participant in an inclusive PSE course | Case study collected qualitative data via interviews with mother, faculty, a few classmates and student with ID; mother's journal; and researcher field notes. Quantitative data from pre and post peer surveys. Purpose was to explore the impact of the experience for student with ID, classmates and pre-service teacher peer supporter. | Participated in interview |
| Grigal et al., 2001 | Dual enrollment programs (n=13) | Qualitative data from teachers in dual enrollment programs in Maryland consisting of semi-structured interviews regarding program start-up, staffing designs, program components, technological needs, and challenges. Purpose was to provide overview of programs in Maryland. | None documented |

| Study | Type of PSE program | Methodological Approach, Data Collection Methods, and Purpose | Contribution of Individual with ID |
|---|---|---|---|
| Hafner, 2008 | Inclusive PSE program (n=1) | Phenomenological approach collecting qualitative data which included: interviews with research participants, reflection papers written by the peer mentors, and focus group discussions with both peer mentors and faculty. Quantitative data included surveys of classmates in inclusive courses. Purpose was to gain a better understanding of the inclusion of individuals with ID in a PSE program. | Participated in interviews |
| Hafner et al, 2011 | Inclusive PSE program (n=1) | Program evaluation reviewing findings from survey data qualitative and quantitative data from surveys of students with ID, classmates, peers living in residence halls, and peer mentors | No data analyzed (although authors indicate survey and interview data were collected from participants with ID) |
| Hamill (2003) | Individualized experience of one participant taking two PSE courses and engaging in inclusive social activities | Qualitative study utilizing observations and interviews from participant, faculty and peers. Purpose was to examine the college experience of one individual with down syndrome. | Participated in interview |
| Hart et al, 2004 | Dual enrollment programs (n=25) | Quantitative data via surveys from program staff in order to describe PSE program characteristics. | None documented |
| Neubert, Moon, & Grigal, 2004 | Dual enrollment programs in Maryland (n=13) | Both quantitative (descriptive) data and qualitative (thematic analysis from open-ended questions) was collected from teachers via surveys. Purpose was to describe level of inclusion at PSE site and in the community, as well as interagency efforts with adult services, and follow-up activities after students leave program. | None documented |
| O'Brien et al., 2009 | Inclusive PSE program in Dublin (n=1) | Qualitative data from students with ID, family members, and tutors via focus groups, questionnaires, Photovoice, and document analysis. Purpose was to investigate the experiences of student with ID in this program. | Participated in focus groups, photovoice, reflective journals, and completed PATHs (a transition planning tool) |

| Study | Type of PSE program | Methodological Approach, Data Collection Methods, and Purpose | Contribution of Individual with ID |
|---|---|---|---|
| Paiewonsky (2011) | Dual enrollment programs in Massachusetts Inclusive Concurrent Enrollment initiative (n=9) | Participatory Action Research where students with ID document their college experience using multi-media tools including photos, video clips, narratives and stories, and researcher field notes and photographs. Purpose was to document participants' PSE experience as part of a national college access initiative. | Participated in photovoice; thematic data analysis (grouping and assigning themes to photos); developing action plan; and reflecting on research process |
| Papay & Bambara (2011) | Dual enrollment programs across U.S. (n=87) | Quantitative data via PSE program web survey from program staff (coordinators) to gain insights as to general characteristics of programs on a national level and level of participation of students with ID in college courses. | None documented |
| Redd (2004) | Dual enrollment program (n=1) | Single case study collecting qualitative data via interviews with students, teachers, college staff, employers, and same-age peers; observations of students; document analysis; and student and parent focus groups. Purpose was to describe the characteristics the and document perspectives of students and parents. Program served students with ID as well as those with emotional disabilities, multiple disabilities, or other health impairments (considered to be "significant disabilities"). | Participated in interviews |
| Weir, Grigal, Hart, & Boyle (2013) | PSE programs (n=5) | Monograph describing program backgrounds, structure, and best practices based on site visit by researchers. Purpose was to promote development of policy, programs and resources to expand PSE options for students with ID. | None documented |

The majority of the research regarding PSE programs has been centered identifying services and supports provided (Getzel, 2008; Hafner et al., 2011; O' Brien et al., 2009; Paiewonsky, 2011), whether students audited classes or took them for college credit (Papay & Bambara, 2011), and professional development needed for faculty (Carroll, Blumberg, & Petroff, 2008; Hafner et al., 2011).

Services and supports identified as helping individuals with ID be successful in these programs include incorporating principles of UDL into course design; providing access and use of assistive technology (AT); using of peer mentors; teaching and supporting independence and self-management skills; professional development for faculty; social inclusion; and internships or employment skills training (Getzel, 2008; Hafner et al., 2011; O' Brien et al., 2009; Paiewonsky, 2011). It is not clear, however, how many PSE programs utilize these strategies and if these skills are both beneficial and generalizable in the lives of the participants with ID upon completion of their PSE program.

According to Papay and Bambara (2011) student participation in programs depended on which program model they were enrolled in and their level of academic ability. Additionally, many studies noted the inconsistency of student participation in classes and the purposes for the selection of courses. Some were based on student interest while other choices were made based on professor's openness to having students with ID participation (Papay & Bambara, 2011).

Although faculty professional development materialized as another key factor to program success, no clear protocols have emerged for best practices for teaching and assessment (Fuller et al., 2004). As previously noted, faculty were often selected based on openness to the program concepts. Getzel (2008) found that students benefited from faculty understanding the needs of students with ID and incorporating the principles of UDL into their lessons..

**Gaps in the Research.** One of the first issues that become apparent after reviewing the literature is the lack of evidence of short-term or long-term impact for adults with ID (Hafner, 2011). These outcomes include whether or not the programs provide students with ID the skills necessary to improve their ability to live independently, maintain employment, and improve their overall quality of life. Services and supports have been listed and categorized, but there are few measures of how these impact the students during the program or if similar services were continued afterwards. There is also little documentation of the impact of specific curricula for students with ID and no comparisons of the results of adults with ID involved in PSE programs with those who stay in a typical high school setting or those who move on to a segregated model. Finally, if the goals of the programs are improved employment, then data needs to be collected to determine whether these programs affect students' ability to obtain and maintain employment, and if the students are able to generalize the skills they utilized in the program in their vocations (Neubert & Moon, 2006). Data on effectiveness of program components and outcomes is critical for improving the quality of life for adults with ID.

Another gap lies in identifying common characteristics of the various program designs (Papay & Bambara, 2011). Studies need to define details such as how students are participating; courses taken; academic, social and employment skills being taught; relationship of employment skills to academics goals and skills; levels of social integration; effectiveness faculty strategies; faculty professional development; and length of program time.

Lastly, there is a lack of student participation in the research data to date. There are only a few studies (e.g. Hafner et al., 2011; O'Brien et al., 2009; Paiewonsky, 2011) that have utilized research methods that directly involve gathering data from the students with ID themselves. Program effectiveness cannot be determined without collecting data directly from the participants themselves. By utilizing inclusive research methods designed to collect data directly from participants involved in PSE programs, future studies have the potential to identify effective program components. This data can then be employed to inform on-going program evaluation to ensure valuable PSE experiences that lead to improved quality of life for people with ID.

## Program Evaluation

As PSE programs for adults with ID increases, so does the need to evaluate their effectiveness. Although research supports the use of student-centered and participatory evaluation methods as part of the PSE program model for students with ID (Hart et al., 2001), few studies have engaged in such practices to date. In 2009 a European study was done at Trinity College Dublin (O'Brien et al., 2009). This qualitatively designed study involved students ID who were participating in a 2-year certificate course. They utilized numerous processes to collect data including photovoice, questionnaires, and focus groups (O'Brien et al., 2009). By triangulating data of the perspective of both students with ID and their families, they were able to identify the benefits of PSE for the students with ID, which included perceived improvements in independence, self-confidence, and socialization (O'Brien, 2009).

More recently Paiewonsky (2011) conducted a qualitative PAR study involving students with ID where they used the photovoice strategy utilizing digital cameras and web 2.0 tool, Voicethread (http://voicethread.com), to document and share experiences, which led to the identification of practices that are beneficial for students with ID, their parents, and college faculty and staff (Paiewonsky, 2011). Program benefits identified by participants included use of multimedia tools, appreciation of supports that incorporated principles of UDL, improved self-determination, increased academic involvement, and enhanced self-identity (Paiewonsky, 2011).

Finally in 2011, Hafner and colleagues used both qualitative and quantitative methods of collecting data including focus groups, interviews, surveys and observations of students ID, their parents, peer mentors, and faculty members to evaluate the effectiveness of the four-year Cutting-Edge program at a private Catholic university. This study enabled researchers to identify key practices such as application of UDL guidelines in courses, peer mentors, inclusion to promote independence, and collaborative relationships with parents to support the success of students with ID in their PSE program (Hafner, 2011).

These few studies model the effective use of inclusive methods, providing rich data that are critical to inform both new and existing PSE programs for participants with ID. It is imperative that studies like this continue to inform on-going program evaluation, especially as more and more individuals with ID participate in PSE programs.

## Contribution to literature

This study expands the literature by authenticating the seldom-documented perspectives of participants with ID regarding their PSE experience and documenting the impact of their engagement in inclusive research processes. Although utilizing inclusive methodologies with participants with ID has increased, the use of photovoice is still rare (Jurkowski, 2008). Photovoice provides alternative means by which participants can express their viewpoints. Moreover, by including co-researchers in the data analysis process, I explored the potential of their abilities to contribute to the research process and document the flexibility of the researcher's role. While researchers have noted challenges involving participants with ID in participatory analysis, they have also recognized the value and necessity of such practices (Nind, 2011).

The use of multiple forms of data collection in this project continue to inform best practices in inclusive research with adults with ID and provide rich data that has the potential to inform program evaluation. Think College, an organization devoted to improving PSE programs for young adults with ID, has established standards for inclusive higher education (http://www.thinkcollege.net/topics/think-college-standards) and recommends programs collect satisfaction data from individuals with ID enrolled in the programs. The use of inclusive methodologies offers researchers the opportunity to gain much needed insights into the perceptions and experiences of individuals with ID (Paiewonsky, 2011), fosters empowerment, and supports the self-advocacy movement as participants gain new skills and acquire new knowledge, which may empower them to act positively in their own lives. This is necessary to sustain and, ultimately, improve quality of life for individuals ID who have often been marginalized members of society (Paiewonsky, 2011).

# Chapter III. Method

## Purpose

The purpose of the study was to document, describe, and analyze the perceptions of students with intellectual disability regarding the post-secondary educational program they are enrolled in through the use of inclusive qualitative methods. Photovoice, focus group sessions, semi-structured interviews, and questionnaires were utilized to capture co-researchers’ viewpoints. Additionally, co-researchers' inputs were solicited throughout the research process including data analysis. The objectives were to: (a) provide participants with intellectual disability with the opportunities to document and critically discuss their post-secondary educational program in order to evaluate its effectiveness; (b) share their results with peers, policymakers, and other potential stakeholders; and (c) document the inclusive research practices utilized to achieve these objectives and how they influenced participants. Such data is rare, but valuable to inform ongoing program evaluation to enhance participants' inclusive experiences and improve their quality of life.

### Research questions

As post-secondary educational options have increased for adults with ID over the past decade, little data has been collected from the perspective of the program participants (Hafner et al., 2011; O'Brien et al., 2009; Paiewonsky, 2011). In fact, the use of inclusive methods involving individuals with ID has been scarce or vaguely described in the literature (Burke et al, 2003; Chapman & McNulty, 2004; Jurkowski, 2008). Based on the growing number of PSE programs for individuals with ID, the need to evaluate the impact of such programs for participants, and the lack of data from their perspectives, the following questions emerged:

1. How do adults with intellectual disability perceive their college experience?
2. How does participation in an inclusive research project impact participants with intellectual disability?
3. How can photovoice data inform ongoing evaluation for this specific post-secondary educational program?

## Pilot Study

I had been working with young adults with ID enrolled in new a four-year post-secondary educational program, which was part a large (enrollment approximately 40,000) Midwestern university in an urban setting. From my review of the literature, I realized that further research was needed to document experiences of the participants with ID in PSE programs. Additionally, I knew that if I was going to do this, the data needed to be based on their perspective versus the staff or parent's. This could only be accomplished through the use of participatory qualitative methods. Therefore, I decided to utilize both photovoice and semi-structured interviews to capture participants' perspectives in the pilot study. Additionally, I engaged participants as co-researchers during data analysis. My objectives were to identify ways the program was influencing participants and document their views on effective program supports as well as barriers. Such data is necessary to inform ongoing program evaluation to enhance participants' inclusive experiences.

The pilot study involved three adults with ID who were invited to be a part of the study based on purposeful and homogeneous sampling (Patton, 2002). Participants were asked to take photos that represent what they thought about the program they were enrolled in. Semi-structured individual interviews were scheduled to provide participants with the opportunity to share and discuss their photos, specifically providing contextual data (Brake, Schleien, Miller, & Walton, 2012; Jurkowski, 2008). The interviews were audiotaped and transcribed; transcriptions were used for further data analysis. I facilitated a focus group meeting with all participants and their peer supporters who had helped them take their photos. The focus group session provided an opportunity for participants with ID to share their photos with their peers to discuss and identify common themes from their photographs (Brake et al., 2012). The focus group was also used for member checking purposes (Miles et al., 2014) as participants confirmed the accuracy of the descriptions of photos from the interview process. A photo exhibition was held so that participants could share their photos with the college community including peers, program staff, and university faculty members.

Results indicated that participation in this inclusive post-secondary educational program provided these participants with a variety of opportunities, supports, and challenges. While data supported common themes across their perspectives, the uniqueness of each individual's experience was apparent. The pilot study revealed specific opportunities and experiences that are important to the participants as well as the various supports that helped them in the program and personal challenges they had been confronted with. From this pilot study I recognized the potential for further inclusive research methods engaging participants with ID as co-researchers in order to document the impact of inclusive post-secondary educational programs from their perspective, as well as empower them by involving them in a greater role in the research process.

## Participants and Setting

This study was conducted within the same university setting as the pilot. All co-researchers were enrolled in a four-year non-degree inclusive program providing adults with ID a college experience, which includes participation in classes, residential campus living, vocational internships, and campus social life. The program requires participants to enroll in two traditional inclusive college courses (typically audited) and two courses explicitly designed for the program.

The program provides peer tutors who are typically developing for both academic and social support.

A flyer was made and posted in the dorm inviting students enrolled in this program to participate as research partners in a photovoice project (see Appendix F). Sampling was homogenous (Patton, 2002) since all participants were self-identified as having an intellectual disability and enrolled in the same program. Stratified sampling (Creswell, 2012) was planned to be used, as two participants from each cohort were going to be randomly selected from those who volunteered with the goal of having two participants from each cohort participate in the study (n = 6). However, in the initial meeting, seven individuals attended, expressing their interest in being a part of the study; therefore they became the seven co-researchers and stratified sampling was unnecessary. Three co-researchers were part of the first year cohort, three were part of the second year cohort and one was in the third year cohort. Co-researchers chose their own pseudonyms that were used throughout the study. Table 8 provides details regarding their demographics.

Table 8
*Co-Researcher Demographics*

| Participant | Age | Gender | Ethnicity | Cohort | Diagnosis and other relevant data |
|---|---|---|---|---|---|
| C-Baggs | 23 | Female | Caucasian | 1st year | Graduated with high school equivalent diploma from Ohio. Took alternate assessments for state testing. Latest evaluation team report (ETR) indicated she was eligible for special education services due to a multiple disabilities diagnosis due to deficits in the areas of cognitive, academic, adaptive and motor skills delays. Various assessment data, including IQ scores, indicate she has a mild intellectual disability [Stanford Binet-4 full scales IQ of 75; Wechsler Intelligence Scale for Children third edition (WISC-III) IQ of 59; and Woodcock-Johnson Test of Cognitive Abilities third edition (WJ III) General intellectual ability of 69]. |

| Participant | Age | Gender | Ethnicity | Cohort | Diagnosis and other relevant data |
|---|---|---|---|---|---|
| Dragon Ball Z | 22 | Female | Caucasian | 2nd year | Graduated with high school diploma from Colorado. She has a diagnosis of Down Syndrome. Her most recent assessments, including IQ scores, indicate she has a moderate intellectual disability (WISC IV full scale IQ of 46). |
| Jasmine | 23 | Female | Egyptian (came to U.S. in 5th grade) | 3rd year | Graduated with high school equivalent diploma from Ohio. Her most recent ETR indicated she qualified for special education services in school due to significantly sub-average intellectual functioning and significantly sub-average ability to acquire age appropriate academic skills. She was described as having moderate, severe and/or profound deficits in socialization, communication and adaptive behavior in receptive, expressive and written communication skills; personal, domestic and community daily living skills; interpersonal relationships, play/leisure time and coping skills. Various assessments indicate she has a mild to moderate intellectual disability (WISV III full scale IQ scores of 48). |
| Mouse | 26 | Female | Caucasian | 1st year | Received high school diploma from Ohio (non-academic track). Her most recent ETR indicated she qualified for special education services due to mood disorder not otherwise specified, ADHD, and borderline intellectual functioning with difficulties in intellectual abilities, social function, and mood regulation. Her most recent assessments, including IQ scores, indicate she has a mild intellectual disability (WAIS III full scale IQ of 72). |
| Mysterious & Mischievous | 19 | Male | Caucasian | 1st year | Received his high school diploma from Ohio. His most recent ETR indicated his overall cognitive abilities are “in the borderline range” of mild intellectual disability. His verbal skills are in the below average range, his nonverbal skills in the range of mild intellectual disability, and his visual spatial skills were also “in the borderline range.” He demonstrated below average general intellectual functioning, which exists concurrently with deficits in academic skills, communication, and adaptive behaviors that manifested during the developmental period and adversely affect his educational performance. |
| Ricky | 23 | Male | Nigerian | 2nd year | Received a high school diploma from Nigeria. He is considered to have a mild intellectual disability based on his most recent assessments including the Wechsler adult intelligence scale third edition (WAIS III) UK edition administered by a private psychologist indicating his full scale IQ of 71. |

| Participant | Age | Gender | Ethnicity | Cohort | Diagnosis and other relevant data |
|---|---|---|---|---|---|
| Simone | 25 | Male | Caucasian | 2nd year | Graduated high school from independent study program in California. His most recent evaluations indicate he has had a history of learning disability and a diagnosis of Asperger's disorder (or possible non-verbal learning disability). A WAIS-IV administered in 2013 indicated a full scale IQ of 82. |

Additionally, four female undergraduate students who are typically developing at the same university were purposefully selected and invited to participate as peer supporters based on their involvement in the program and their prior experience with the co-researchers in the pilot study. Their role was twofold: (a) to provide support as needed for peers with ID during photo taking missions and data analysis; and (b) take field notes during designated focus group sessions. Peer supporters ensured any necessary permission or acceptable use forms were signed by anyone in the photos taken (Brake et al., 2012). They were available to take photos in situations where co-researchers wanted to be in their own photo. Peer supporters were trained to minimize any influence on co-researchers regarding the pictures they chose to take and had previous experience in the pilot study. During the photo sharing and discussion focus group sessions (weeks 3-6), peer supporters took field notes to provide documentation of the data analysis process in addition to the video recordings of the sessions. Peer supporters also provided structured support for co-researchers during the data analysis phase (week 9) by helping to read photo descriptions, clarify directions, or scribe for co-researchers as necessary.

**Informed consent.** Researchers need to consider how they obtain and document informed consent when working with participants considered being vulnerable, like those with ID (Clouse et al., 2015; McDonald & Patka, 2012). Documenting such processes support ethical practices and inform future researchers (Clouse et al., 2015). Accommodations or modifications provided to support comprehension of ongoing consent should be clearly specified (McDonald & Patka, 2012).

Although this study was deemed “not human subject determination” by the local institutional review board (IRB) due to its non-generalizability, informed consent was obtained from all participants. Even though co-researchers are adults capable of providing consent independently, I completed the IRB’s checklist for participants who are cognitively impaired and designed a modified consent form using simple language around a fifth grade readability (see Appendix G).

It is important to support participants’ understanding of what the term “research” means in order to ethically gain informed consent, recognizing that some participants may not fully conceptualize what the study will involve until they actually experience various aspects (Burke et al, 2003, Gilbert, 2004). Consent forms were given to co-researchers one week in advance to review and then read orally to them before signing (see Table 6 for other consent considerations). During the first focus group session, I reviewed the purpose of the study and explained what research is in simple terms. In a PowerPoint presentation I defined research as “a planned way of studying a topic” and explained that researchers collect information to “learn more about a topic.” I described research as a three-step process where researchers: ask a question; collect information to answer the question; share what they find. I provided co-researchers with a handout with pictorial depictions explain the purpose and the potential steps of this research process (see Appendix H). I explained their role as co-researchers in this inclusive project, which meant that they would be able to make decisions to determine our next steps as we met each week. A second, standard consent form for the peer supporter participants who are typically developing was also used (see Appendix I). Peer supporters were provided with a printed copy of their consent form as well.

## Data Collection

As a former staff member of the PSE program for the past two years, I had already established a relationship with co-researchers in the second and third year cohorts. However, I needed to build connections with the first year cohort participants. I attended several program activities and meetings over the summer before and at the beginning of the semester (prior to the initiation of the study) in order to accomplish this. Stalker (1998) and Paiewonsky (2005) note the importance of taking time to build rapport with participants before beginning data collection and continuing throughout research process.

In order to ensure the chosen methodologies did not limit co-researcher participation in the research process and to triangulate findings, I collected data from multiple sources as described in Table 9.

**Focus group sessions.** Focus group sessions in this study served multiple purposes and were defined by five phases: (a) Phase I: Introduction and training; (b) Phase II: Photovoice process; (c) Phase III: Co-researcher engagement in data analysis; (d) Phase IV: Dissemination; and (e) Phase V: Wrap up (see Table 10). The focus group sessions consisted of one-hour weekly meetings with participants and their peer supporters for 14 weeks.

Table 9

*Data Collection*

| Research Questions | Data Collection Method | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Photovoice Focus Group Sessions | | | | | Question-naires from dissemination | Semi-Structured Interviews | Final Co-Researcher Question-naires |
| | Photos and transcript-tions | Results from Co-Researcher Data Analysis | Field notes | Analytic Memos | Weekly Reflection | | | |
| How do adults with intellectual disability perceive their college experience? | x | x | x | x | | x | x | |
| How does participation in an inclusive research project impact participants with intellectual disability? | x | x | x | x | x | x | x | x |
| How can photovoice data inform ongoing evaluation for this specific post-secondary educational program? | x | | x | x | | x | x | |

Table 10

*Weekly Focus Group Sessions*

| Phase | Session | Date/time Tuesdays 7-8pm | Purpose/Activity | Data Source and Collection Method |
|---|---|---|---|---|
| I | 1 | 9/16 | -Introduce project and answer questions<br>-Continue establishing rapport<br>-Distribute copies of consent | -Researcher memo regarding session |
| I | 2 | 9/16 | -Established focus group meeting rules and decision-making processes.<br>-Gain informed consent<br>-Reviewed project purpose, photo ethics, and sent out to take first round of photos | -Researcher memo regarding session<br>-Field notes |

| Phase | Session | Date/time Tuesdays 7-8pm | Purpose/Activity | Data Source and Collection Method |
|---|---|---|---|---|
| II | 3 | 9/23 | -Discuss photos using SHOWED protocol<br>-Co-researchers determine next steps | -Researcher memo regarding session<br>-Field notes<br>-Audiotape and transcripts<br>-Co-researcher photos<br>-Generative themes from dialogue |
| II | 4-8 | 9/30-10/28* | -Discuss photos using SHOWED protocol<br>- Co-researchers determined next steps, which was four iterations of taking photos and engaging in critical dialogue.<br>*Meeting on 10/14 was cancelled since co-researchers could not attend due to a schedule conflict | -Researcher memo regarding session<br>-Field notes<br>-Audiotape and transcripts<br>- Co-researchers photos<br>-Generative themes from dialogue |
| III | 9 | 11/4 | -Engage in structured data analysis with co-researchers | -Researcher memo regarding session<br>-Results from data analysis (co-researchers' themes) |
| IV | 10 | 11/11 | -Plan dissemination | -Researcher memo regarding session |
| IV | 11 | 11/18 | -Dissemination | -Attendee questionnaire responses<br>-Researcher memo regarding session |
| V | 12 | 11/25 | -Final individual interviews with co-researchers | -Audio tape and interview transcriptions |
| V | 13 | 12/2**<br>Cancelled | -Final reflection & discussion of next steps<br>-Complete final questionnaires.<br>** Co-researchers were not able to make this session, so questionnaires were sent out electronically | -Researcher memo regarding session<br>-Co-researchers questionnaire responses |

| Phase | Session | Date/time Tuesdays 7-8pm | Purpose/Activity | Data Source and Collection Method |
|---|---|---|---|---|
| V | 14 | 3/10 | -Presentation of found poems.<br>-Staff presentation (separate meeting without co-researchers due to schedule conflicts) | -Verbal confirmation for member checking<br>-Researcher memo regarding session<br>-Staff questionnaire responses |

***Phase I: Introduction and training.*** Phase I occurred during the first two focus group sessions. The first week I met with co-researchers and their support peers to explain the study (including an explanation of photovoice) and the anticipated role of the co-researchers, continue building rapport, and review and distribute copies of informed consent forms to participants. Week two activities included: (a) reviewing project; (b) obtaining informed consent; (c) establishing focus group meeting rules and decision-making processes; (d) discussing photo ethics (e) assigning the first photo mission. The modified consent form for co-researchers was read orally and explained with peer supporters as witnesses. Co-researchers chose to use their own cell phones or other mobile devices to take photos, so training on equipment was not necessary. A photo release and acceptable use form was reviewed and co-researchers instructed to have the form signed if they take pictures of people. Co-researchers and their peer supporters reviewed a script they were given to read to people when asking permission to take their picture. Co-researchers selected their peer support person and were asked to go out and take pictures to document their college experience.

I held an additional training meeting separately with the peer supporter persons to reiterate the importance not influencing photographers in their photo choices. Peer supporters were told to remind photographers of the questions they were answering with their photos and ensure they obtain permission when appropriate. Peer supporters were also provided with training so that they could take field observation notes during focus group sessions two through eight when co-researchers were sharing and discussing photos (see Table 2).

***Phase II: Photovoice process.*** Phase II occurred over weeks the next six weeks. Co-researchers and the peer supports independently determined when they could get together to take photos. Photos were taken in multiple settings on or off the college campus based on each co-researcher's academic and social schedule. Co-researchers took photos using their cell phones each week for five iterations with the instruction to take photos that describe what they think about their college experience. Photos were saved digitally to a private account utilizing a web 2.0 tool called Snapfish (www.snapfish.com). An individual digital folder was created for each co-researcher to post his or her photos.

*Weekly Structured Routine.* In order to be able to accomplish our goals in the limited one-hour time frame each week, the focus group sessions during phase II followed a consistent format that was collaboratively developed by the co-researchers and myself. I facilitated the routine utilizing a PowerPoint presentation. This comprised of: (a) a brief review of project and procurement of on-going consent via participant sign in sheet (see Appendix J); (b) an overview of the previous week's photos including a summary of the critical dialogue for member checking purposes; (c) engagement in Freire's (1970) problem-posing methods (p. 109) to generate more themes and expand co-researchers' viewpoints; (d) presentation of new photos and engagement in critical dialogue; (e) determination of next week's plans; and (f) completion of weekly reflection checklist (see Appendix B).

*Selecting and contextualizing***.** Following Wang & Burris' (1997) first two of the three stages of analysis, photos were *selected* by co-researchers and *contextualized*. This also aligns with Freire's process of identifying generative themes (1970). Co-researchers selected one photo each week to share with the focus group. Printed copies of photos were deemed unnecessary since co-researchers were saving their photos electronically to our private account in Snapfish, which could then be presented using the technology in the conference room. Co-researchers determined the order in which they would present and then they "contextualized" their photos by engaging in critical dialogue regarding the photos following an adapted SHOWED method (Wallerstein, & Bernstein, 1988; Wang et al, 1998; Wang et al., 2004). Co-researchers were given a printed copy of Paiewonsky's (2005) adapted SHOWED and I posed the alternative questions as deemed necessary during the discussion (see Appendix A). These focus group sessions were videotaped and transcribed as needed for further data analysis and member checking.

*Field notes.* The undergraduate participants who are typically developing provided support for co-researchers as they took their photos. While they did not participate in the discussion, these peer support persons attended all focus group sessions and took objective observational field notes (Yin, 2014) as co-researchers were sharing and discussing photos (see Table 2). Their observations included recording details of the setting and circumstances as events occur in addition to noting specific photos shared and various participant comments, reflections, and responses. The use of observational field notes in addition to transcriptions of audio-taped focus group sessions involving data analysis with co-researchers assisted in documenting and interpreting the inclusive data analysis practices (Creswell, 2012; Kramer, Kramer, Garcia-Iriarte, & Hammel 2011; Paiewonsky, 2005).

*Weekly research reflection checklist.* At the end of each focus group session co-researchers completed a research reflection checklist (see Appendix B). While co-researchers had the opportunity to give their input verbally during the focus group sessions, the reflection provided a more formal evaluation tool to document their perceptions regarding their participation in the research process and make suggested changes Jurkowski (2008). The questionnaire could be completed anonymously or with their name.

***Phase III: Co-researcher engagement in data analysis.*** Continuing to follow Wang & Burris' (1997) three stages of analysis, co-researchers were engaged in the third stage, codifying the photos, to identify issues, themes, or potential theories. One of my objectives in this collaborative group approach to inclusive research was to engage co-researchers in the data analysis process; few studies to date have done so (Nind, 2011; Tuffrey-Wijne & Butler, 2010). First, as previously described, co-researchers selected and contextualized their photos engaging in critical dialogue utilizing the SHOWED protocol (Wallerstein & Bernstein, 1988; Wang et al., 1998, Wang et al., 2004) and problem-posing methods to identify generative themes (Freire, 1970), which were documented via transcriptions and field notes. Next, I engaged co-researchers in a structured multi-step process of data analysis to code their photos and identify themes (see Figure 2). The process included individual co-researchers undertaking two cycles of coding as suggested by Miles and colleagues (2014): (a) descriptive coding; and then (b) thematic or pattern coding of their individual photos and descriptions Then, as a collective group, co-researchers took part in cross-case analysis (Yin, 2014).

Figure 3. Co-Researcher Data Analysis Steps

**STEP 1.** Look at each of your pictures and write a **descriptive code** on a post-it and place on picture

**Descriptive code**: a **word** or **group of words** that summarizes or explains the basic topic for the picture

**STEP 2:** **Sort** your pictures into **themes** or **categories** and write each of the themes on a card

**Theme or Category:** the common idea or category from all of the person's codes and pictures

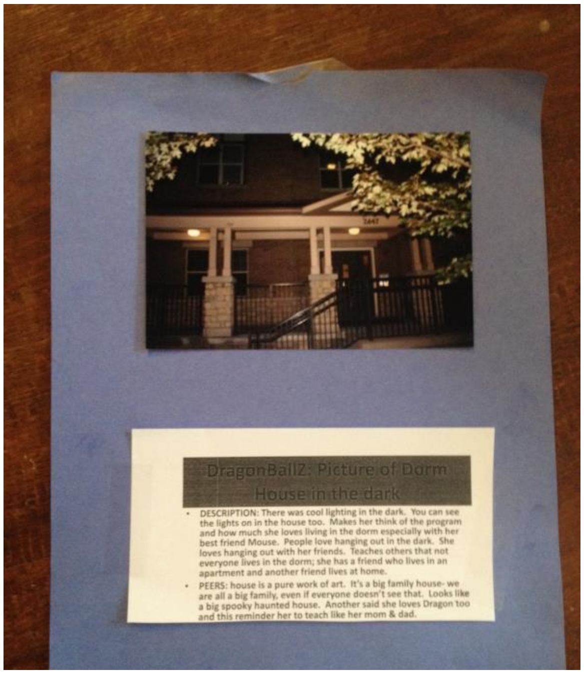
**STEP 3:** Post everyone's theme cards on wall and sort them into categories or themes as a group

Some pre-training was necessary in order for this to happen. Prior to engaging co-researchers in the data analysis process, I prepared a Power Point presentation explaining what data analysis is, where it fit in our research project, as well as what descriptive codes and themes were. I engaged co-researchers in an activity where I provided descriptive codes (a dog, a cat, a snake and a bird) and ask them to identify a theme (animals). After completing this activity I felt confident from their responses that co-researchers understood expectations and were capable of engaging in the data analysis process. This was confirmed by the results of our data analysis session.

In order to support co-researchers in the data analysis process, I printed copies of each of the their photos they had selected to share with the group. Each photo was taped to a piece of colored paper, which included a summary of the discussion from the focus group session (see Figure 3). Co-researchers were instructed to provide a descriptive code for each of their photos and then to identify a theme for their photos. Support peers were present to help read photo descriptions, clarify directions if participants had questions, or scribe for participants. Support peers were reminded that they should not provide any input towards identifying descriptive codes and themes, but they should redirect co-researchers back to the directions or to the example provided during the training presentation. Once all of the co-researchers had completed steps one and two (some co-researchers took longer than others), they were asked to post their photos with theme cards in a column on a wall. Table 11 presents the individual co-researcher's descriptive codes and themes for their photos, while figure 4 displays individual co-researcher's data analysis as it was visually displayed on the wall.

I read each of the co-researchers' codes and themes out loud to the group. Next, I asked co-researchers for suggestions to identify group themes, or themes they had in common. Simone got up and started making suggestions about moving the photos around that he thought were

Figure 4. Example of Co-researcher Photo with Discussion Summary



DragonBallZ: Picture of Dorm House in the dark

- DESCRIPTION: There was cool lighting in the dark. You can see the lights on in the house too. Makes her think of the program and how much she loves living in the dorm especially with her best friend Mouse. People love hanging out in the dark. She loves hanging out with her friends. Teaches others that not everyone lives in the dorm; she has a friend who lives in an apartment and another friend lives at home.
- PEERS: house is a pure work of art. It's a big family house- we are all a big family, even if everyone doesn't see that. Looks like a big spooky haunted house. Another said she loves Dragon too and this reminder her to teach like her mom & dad.

Table 11

*Results from Co-Researcher Individual Data Analysis*

| Co-Researcher | Individual Theme | Descriptive codes and picture description | | | |
|---|---|---|---|---|---|
| | | 1st photo sharing session | 2nd photo sharing session | 3rd photo sharing session | 4th photo sharing session |
| C-Baggs | College Life | No photo: Attended but pictures were accidentally deleted. | Awesome: Picture of C-Baggs hanging around and having fun | Cheerful: Picture of Bearcat mascot at a university sporting event | Best Hangout: Picture of the "hang out room" |
| Dragon Ball Z | Having Fun | Funny Sweet: Picture of support peer laughing | Bearcats Rule: Picture of Dragon Ball Z in a Bearcat pose at the football game | Love, Awesome: Picture of Dragon Ball Z singing in dorm room. | Mellow, Cool: Picture of dorm house in the dark. |
| Jasmine | Living at college dorm with four roommates independently | No photo: Not able to attend due to schedule conflict | University or College: Picture of UC sweatshirt | House: Picture of dorm where we live | College Campus: Picture of sign with name of university. |

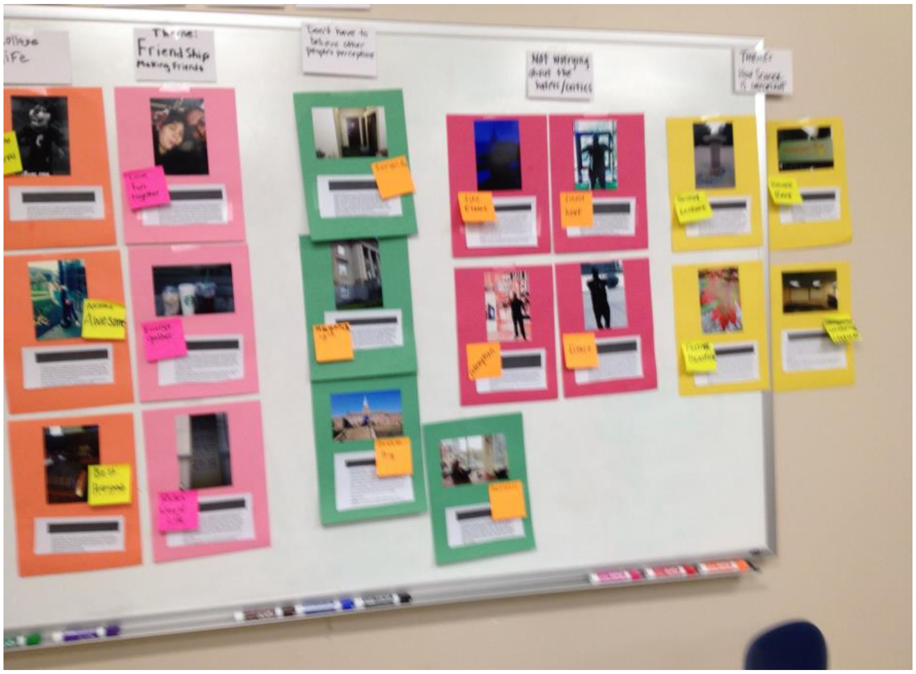
| Co-Researcher | Individual Theme | Descriptive codes and picture description | | | |
|---|---|---|---|---|---|
| | | 1st photo sharing session | 2nd photo sharing session | 3rd photo sharing session | 4th photo sharing session |
| Mouse | Friendship: Making friends | No photo: not able to attend due do family emergency | Energy Gather: Picture of 3 different cups from Starbucks | Love Fun Together: Picture of Mouse and her boyfriend at a university sporting event | Rules, Way of Life: Picture of inspirational poster. |
| Mysterious & Mischievous | How school is important | Interactive Learning: Picture of classroom for educational technology course. | Hunger Rave: Image of sign of dining hall | Festive, Beautiful: Close up picture of leaf. | Serious Lecture: Picture of a podium. |
| Ricky | Not worrying about the haters/critics | Fire Flame: Picture of Ricky to say “I'm happy being here” | Finest Hour: Picture of Ricky standing in front of windows where he got his first paycheck. | Fierce: Picture of Ricky holding a basketball. This is Ricky saying, "I’m back in the building; I’m reclaiming my crown.” | Redemption: Picture of Ricky with red tint standing in front of bookstore wearing all black and holding his mouth to say college is not all about books. |
| Simone | Don't have to believe other people's perceptions | Dream Big: Picture of Simone in a “Gulliver’s Travel Scenario” in front of a building on campus | Haunted, Aged: Picture of an aged building on campus; has a spooky look. | Business: Picture of C-Baggs in their Entrepreneur class with windows and view of city/campus in the background | Dorm: Picture of entrance way to Simone’s dorm room; taken within room looking towards door. |

*Note*. Descriptive codes are from co-researchers, while researcher provided picture descriptions.

similar, so I suggested everyone get up and help. As a co-researcher made recommendations, I asked for group approval of the suggested change and then we moved the picture as indicated.

Because each of the co-researcher's photos was on different colored paper, co-researchers could easily visualize how their individual themes had contributed to the group themes. I pointed this out to them and reviewed the new information they had discovered during their data analysis: four subdomains or group themes. Finally, I asked if they could identify one overall theme for the group. I wrote down their ideas as they shared them and posted them on the wall. They were: how to live our college years; independent life; best of college; and having fun in life. Ricky suggested they combine the ideas to make one statement, which was: "Our finest hour is our independence and having fun in our college life." All co-researchers agreed on this overall theme. When we were finished one person commented about how well they all worked together during the process. There was minimal disagreement with very few instructions,

Figure 5. Individual Co-researcher Data Analysis



although I did note an irritated look from M&M when he initially saw his pictures being moved. Table 12 lists the group themes, or subdomains from the cross-case analysis and figure 5 provides a visual display of the cross-analysis.

Table 12
*Results from Co-Researchers Group Data Analysis*

| Overall theme: Our finest hour is our independence and having fun in our college life | | | | | |
|---|---|---|---|---|---|
| Group theme: Living at college dorm with 4 roommates independently | Group theme: Having fun | Group theme: College life | Group theme: Friendship: Making friends | Group theme: Don't have to believe other peoples' perceptions/not believing the haters/critics | Group theme: How school is important |
| Dragon Ball Z: Mellow Cool (Dorm house at night) | C-Baggs: Cheerful (school mascot at game) | C-Baggs: Awesome (self hanging out/modeling) | C-Baggs: Best hang out (area to hang out, socialize) | Ricky: Fire Flame (self posing in front of building) | Mysterious & Mischievous: Serious Lecture (podium with words about campus building) |
| Jasmine: University or college (college sweatshirt) | Dragon Ball Z: Bearcats Rule (self at college game) | Simone: Haunted, aged (Van Warner Hall) | Mouse: Energy Gather (3 different Starbucks cups) | Ricky: Finest Hour (self posing where got first paycheck) | Mysterious & Mischievous: Festive, Beautiful (leaf) |
| Jasmine: House (dorm hall) | Dragon Ball Z: Love, Awesome (self listening to music in dorm) | | Mysterious & Mischievous: Hunger Rave (center court dining hall) | Ricky: Redemption (self posing by bookstore) | Mysterious & Mischievous: Interactive Learning (technology classroom |
| Jasmine: College campus (college sign) | Dragon Ball Z: funny, sweet (peer support laughing) | | | | Simone: Dream Big (self posing in front of building) |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
| Overall theme: Our finest hour is our independence and having fun in our college life |  |  |  |  |  |
| Simone: dorm life (entrance to his dorm) | Mouse: Love fun together (self and boyfriend at game)<br>Ricky: Fierce (self pose holding basketball) |  |  |  | Simone: Business (peer in Entrepreneurship class) |

*Note:* Descriptive codes are from co-researchers, while pictures descriptions in parenthesis are from researcher

Figure 6. Cross-Case Co-Researcher Data Analysis

***Phase IV: Dissemination.*** This case study took an "empowerment evaluation" approach utilizing photovoice as a communication tool to inform others of the co-researchers' perspectives. A photo exhibition, or dissemination, is typically held as part of the photovoice process, so that participants can share their photos with the community members, program staff, and other stakeholders (Jurkowski, 2008). Co-researchers were offered the opportunity to display their photos in an exhibition where they would have the opportunity to share their perspectives with their guests. All seven co-researchers decided they wanted to plan and participate in dissemination; in fact, they displayed pronounced enthusiasm regarding the event. They collectively planned dissemination during focus group session 10. Co-researchers chose whom we invited and designed the invitation, which I sent to them electronically as well as printed flyers to distribute as they chose (see Appendix F). Co-researchers wanted to invite the president of the university, so I suggested that one of them send him an email to personally invite him. Dragon Ball Z did this with the help of her peer support. Unfortunately, the president responded that he was unable to attend. Co-researchers wanted the event to have a carnival theme, requesting snacks like popcorn and animal crackers; they titled the event, “TAP Photo Gallery: Premier Showing.” TAP is the acronym for the program co-researchers were enrolled in; it stands for Transition and Access Program. Co-researchers decided that they would make their own presentations and request help from their peer support persons, as they needed it. Dragon Ball Z, Mouse, Ricky and Simone each made a PowerPoint presentation that included their photos. M&M also made a PowerPoint presentation, but chose to utilize the Smart board that was available at the dissemination. C-Baggs utilized an app called Flipagram to display her photos on her iPad for the dissemination. Jasmine chose to have her photos printed, and, with the help of her support peer, displayed them on a trifold poster. I requested co-researchers email their completed presentations so that I knew they were prepared for the dissemination.

Dissemination was held during our normal focus group time frame, although I requested that co-researchers arrive at least one half hour prior to the start so they could help me set up and prepare for their presentations. During our planning session we determined that the dress code would be “business casual” (no sweatpants or jeans) and discussed the importance of having appropriate personal appearances like showering and brushing hair and teeth. I began the dissemination with a PowerPoint presentation sharing the purpose of the study, an overview of photovoice and our research process, and results from the co-researchers’ data analysis. I ended my presentation by introducing each of the co-researchers, who were in their prospective presentation areas, and invited guests to begin walking around and viewing their presentations.

Twenty people signed the attendance sheet at the initial dissemination including four program employees who were the support peers for this project, four friends of co-researchers or interested bystanders, one doctoral student, one faculty member, two parents, and two other program participants with ID who were not part of this project. These attendees were invited to respond to a brief seven-question questionnaire to document their interpretations and perceptions of the co-researchers’ presentations and the value of the photovoice data (see Appendix D).

***Phase V: Wrap up.*** The last phase of our focus group sessions consisted of activities to complete data collection for the research process and provide the opportunity for final member checks and social validity. My goal was to finish the focus group sessions by the end of the semester, which left us with about a two-week time frame. The Thanksgiving holiday and upcoming final exams posed changes to co-researchers’ schedules and potential challenges to their availability.

*Semi-structured interviews.* The next step in the research process was for each of the co-researchers to interview with me if they chose. Six of the seven co-researchers scheduled a time for an individual interview with me the following week. Although C-Baggs shared her desire to be interviewed, we were not able to find a time that suited both of our schedules; therefore, I did not get to interview her. The purposes of these semi-structured interviews (see Appendix K) were to provide an additional opportunity in a different format for co-researchers to express their individual viewpoints about college and being part of the research process (Booth & Booth, 2003; Conder et al., 2011) as well as additional data for triangulation (Miles et al., 2013). The individual interviews took about 15 minutes and were conducted in a setting that was familiar, convenient, and comfortable for co-researchers (Azmi et al, 1997; Hall, 2013; Knox et al., 2000; McDonald & Patka, 2012).

Best practices and guidelines were followed to ensure co-researchers' perspectives emerged from the interviews, minimizing any recency effects or acquiescence issues that can be common when interviewing individuals with ID (Ottmann & Crosbie, 2013). Appendix L provides an overview of how these practices were implemented in this study. Interviews were audiotaped and transcribed; transcriptions were used for further data analysis and triangulation.

*Co-researcher final questionnaires.* My plan for the last focus group session of the semester was to provide one final meeting for participants to reflect on the process, discuss potential future actions, and complete final questionnaires (see Appendix C). Unfortunately co-researchers were not able to make this session due to final exam schedule changes, so questionnaires were sent out electronically via email. I requested that support peers read and record the participants' responses. Five of the seven participants were able to complete the final questionnaires; Mouse and Simone were unable to meet with their support peers and did not complete their final questionnaire.

*Found Poems.* During the next semester, I conducted final member checking by creating found poems (Reilly, 2013) based on focus group and interview transcripts (see Appendix M). The poems were typed and pasted to a painted canvas along with a photo of each co-researchers' choice using a decoupage technique. These final art pieces also served as a token of appreciation from me for their participation; they were presented to the participants during one of their program meetings. Presenting the found poem paintings was a very heartfelt and emotional moment for me since I knew my co-researchers well and felt very proud of them for their contributions to this project.

*Staff Presentation.* Unfortunately many of the program's staff were unable to attend the initial participant dissemination for various personal reasons. At their request, and with permission of the participants, I attended one of their staff meetings during the next semester and shared the co-researchers' presentations. Paiewonsky (2005) faced a similar dilemma in her dissertation research utilizing photovoice with high school students with ID to support their involvement in the transition-planning portion of their individualized education plan. Members of the interagency transition support team were unable to attend the students' photo exhibitions, so she arranged a separate presentation of the students' work at the next support team meeting. My preference was for the co-researchers to give their presentations themselves; however, their new schedules, which now included vocational internships, made it impossible for them to attend. Therefore, I created a PowerPoint presentation similar to the one from the initial dissemination to share the purpose of the study, an overview of photovoice and our research process, and results from data analysis. I ended my presentation by reviewing each of the participant's presentations they had shared at the dissemination. Staff members were then invited to respond to a brief five-question questionnaire (similar to the one from the initial dissemination) to document their interpretations and perceptions of the co-researchers' presentations and the value of the photovoice data to contribute to program evaluation (see Appendix F).

## Data Analysis

An inductive, systematic, thematic approach to data analysis was utilized to recognize emerging themes based on general insights from the data and common threads among participants throughout the study (Bradley, Curry, & Devers, 2007; Richards & Morse, 2013). I utilized a two-cycle coding approach for analysis. In the first cycle I identified and operationally defined descriptive codes as sub-domains and then, during the second cycle of pattern coding, I identified domains or themes (Miles et al., 2013). Additionally, I followed Yin's (2014) suggestion to focus on individual participants before engaging in cross-case analyses. Throughout the data collection process I recorded and reviewed memos to enhance my analyses (Corbin & Strauss, 2008). Finally, data triangulation was achieved through the multiple data sources collected for each of my three questions (Miles et al., 2013).

# Chapter IV. Results

The objectives of this study were to: provide participants with ID the opportunity to document and critically discuss their college experience in order to evaluate their program's effectiveness from their perspective; share the results with peers, policymakers, and other potential stakeholders as identified by the participants; and document the inclusive research practices utilized to achieve these other goals. Multiple sources of data were collected to answer three distinct questions.

## Question One: How Do Adults With ID Perceive Their College Experience?

There is a lack of data from the perspective of participants in the literature regarding PSE programs for adults with ID (Hafner et al., 2011; O'Brien et al., 2009; Paiewonsky, 2011). Therefore, my first research question was: How do adults with ID perceive their college experience? I collected data from focus group sessions including the photovoice process, semi-structured interviews, and final questionnaires from co-researchers. Data triangulation was achieved through questionnaires from dissemination and the staff presentation. Two domains emerged from the data; they were personal and relational impact. Four subdomains were identified within the personal domain: (a) recognizing college as their preferred option; (b) defining themselves; (c) adapting to challenges; and (d) exceeding others' expectations. There were four subdomains within the relational domain: (a) developing friendships; (b) emerging bonds; (c) belonging to a college community; and (d) having meaningful social experiences. These subdomains have operationally defined in Table 13.

**C-Baggs.** The three pictures C-Baggs selected included one of herself, one of the school's mascot at a university sporting event and one of the "hangout room" where students go to study or socialize. She identified her overall theme as "college life." She coded the picture of herself as "awesome." This highlighted her self-confidence, also apparent in her dialogue from the focus group sessions. She expressed college as her preferred option since it was an alternative to living at home with her parents where she would "probably [otherwise] be sleeping all day." She seemed to view herself as a role model showing other students how they could go to college and learn more. Her pride in being a college student and exceeding others' expectations of her was apparent when she commented about how, "most people will say you can't go to college and most of us are like, look at us now we are in college." She also proudly remarked, "I wanted to show kids what I'm made of."

Not only did C-Baggs display confidence in her self, but many of her comments throughout the focus group sessions demonstrate her respect and admiration for her peers in the program as she made multiple comments about their strengths and potential abilities. She continued to define herself by sharing her desire to model for pictures, noting her attributes as a friend, and her pride in receiving an accolade in high school for being "most spirited." This attribute was obvious in her many comments about being spirited throughout the focus group sessions. These comments related to the picture of the school mascot she coded as "cheerful." She pointed out how the many social events in college kept her from being "cooped up" in the house and enabled her to connect with her peers, many of whom she would have never met otherwise since they are from different parts of the country. She recognized the social supports provided by the program helped to motivate her to talk with other college students. While she had strong, kinship-like relationships with her peers in the same program, she also commented on how she valued friendships that had developed outside of the program.

She coded her third picture of the hangout room as “best hangout.” The room in the photo was a place where students could go to study that has “peace and quiet.” This was just one of the strategies for managing stress she alluded to. She referred to her screen saver on her mobile device that she likes to read that reminds her to, “keep calm and just dance” and noted how having a Starbucks® to get coffee was important so that she does not “sleep in and miss class."

**Dragon Ball Z.** The four pictures Dragon Ball Z selected were a picture of her support peer laughing, a picture if herself posing as the school mascot at a game, a picture of herself singing in her dorm room, and a picture of the dorm house at night. Her theme from her analysis was “having fun.” One of the domains Dragon Ball Z’s photos centered was relationships and the social aspect of college life. For example, she coded the picture of her peer support as “funny, sweet.” When discussing the photo it was clear that Dragon Ball Z had a strong adoration for her peer support person, pseudonym Tangled. Some of her remarks included, “She’s always nice to me and I like to be around her… she is really fun and she's very funny…I love her smile." Dragon Ball Z’s fondness of Tangled was best expressed when she stated, “She's amazing…we all love her." Throughout the weekly discussions Dragon Ball Z made several references to friendships she has made through her college experience. Comments include, "I have a special person who really cares, my BFF. It's Mouse" and “I have tons of fun with friends and not family." Some of these relationships, like that with Tangled, have evolved into deeper bonds. Dragon Ball Z made the statement, "I love everyone and you all make me happy" when referring to her peers in the focus group session.

Dragon Ball Z coded the picture at the college sporting event as “Bearcats rule” demonstrating her sense of belonging to the college community and her meaningful social experiences. Dragon Ball Z’s school spirit was apparent in remarks like, “You have…red and black…the school colors from here" and “I love being a Bearcat!” Going to sporting events seemed to be a social activity she enjoyed, which is supported by her comment, “[This is a picture of] the game on Saturday where we had tons of fun.”

Dragon Ball Z coded the picture of herself singing in her dorm room as “Love, awesome.” This photo seemed to be one way she was defining herself, she described it as, “I'm singing. I love to sing” and “I feel good; that's what I do in my free time." She also defined herself with her photo of the dorm house at night, which she coded as “Mellow, Cool.” When describing this picture, Dragon Ball Z stated, “really cool lighting…the back lights are inside … through the door.” This picture signified not only the dorm house where she has been living independently and developing relationships with her peers, but it represented her love of photography. She pointed out how the lighting looked in the house at night. Her comments about many of her peers’ photos also involved specific details she had learned to look for in the photography course she had taken at college. For example she noticed the shadows in one photo commenting, "I see a little bit of a shadow on there…the shadow is one of my favorite parts."

The social and relational aspect of Dragon Ball Z's college experience was stressed in her interview when I asked her what she thought about being in college. She stated, "I love everybody and it's fun to be here." She said her roommate and all of her friends were helpful to her because "they make me feel better." She also mentioned that she liked the "[program] staff" most about college.

**Jasmine.** Jasmine's three pictures included a sweatshirt with the college logo on it, a sign with the college's name, and her dorm room. The theme she identified during analysis was, "Living at college dorm with four roommates independently." Jasmine's code for the college sweatshirt was "University or College" and she described it as something you wear to sporting events "for spirit," representing a sense of belonging within the college community. She indicated she took the picture because she likes to go to events. Having meaning social experiences like this and making friends seemed important to Jasmine, as she made the comment, "I like going to college and meeting new people." She also associated college with success as she explained the picture made her, "think about being successful… being successful when you're in college."

Jasmine took another photo of a sign with the college logo, which she coded "college campus." Her discussion of the picture revolved around the academic aspect of college and her appreciation for academic supports. Jasmine mentioned going to classes and how "the professors helps you with homework and study, if you don't understand it." This photo also signified the close relationships she is building as Jasmine mentioned she took the photo when walking with a friend and commented that, "I'm glad I met all of you guys and you guys are like my sisters…slash brothers."

Jasmine's third picture was of her dorm room, coded "house." Living independently resonated throughout Jasmine's dialogue. She emphasized how living in the dorm "could teach independence, chores, doing your laundry." She really defined herself through her pride in developing skills for independent living. Living in the dorm also seemed to be a conduit for fostering the new friendships and kinships. She describes the dorm as "living there with your best friends."

In her interview Jasmine reiterated the importance of independent living is to her and how college, specifically living in the dorm is providing this opportunity. She also recognized the program's supports like academics mentors as helpful "with homework [and] they calm you down when you are stressed" and the social aspect of "meeting new people, new [program] friends" as what she likes most.

**Mouse.** Mouse's three pictures included cups from Starbucks®, a picture with her boyfriend at a college sporting event, and an inspirational poster in her dorm room. She identified her overall theme as "Friendship: Making friends." Her friendship theme is consistent with her comment in her dissemination presentation that she made her first friend while at college. Mouse coded the picture with her with her boyfriend as "love fun together." It was representative of one of the new relationships she had developed and how she enjoys access to the social experiences and belonging to the college community. She noted, "Whenever there's football games, you can hang out with friends." She also made several comments during the focus group sessions about having fun and how without sporting events “it would get lonely because you wouldn't have anyone to share school spirit with.” Mouse also seemed to be defining her personality in this photo as she pointed out that she was dressed up like a cat and that the photo could teach others “we can all be silly and fun, like me.”

Mouse coded the photo of the three different cups from Starbucks® as “energy gather.” She had specifically arranged the different size cups for the picture and said she was excited because she, "finally found a Starbucks®” since she did not have one in her hometown. Mouse was clearly defining herself and her love for coffee. She described coffee as important for anyone who wants to “wake up really good in the morning and feel really energized.”

Mouse coded her third photo of an inspirational photo as “Rules, Way of Life.” This seemed to be not only a source of emotional support for her as she described it as helping her “get through the day,” but another reminder of the new friendships she has developed. She commented on the part of the poster that states “make new friends” and remarked, “I’ve already made new friends.” She also seemed to be relating college with achievement when she stated, “[This picture makes me think about] college, because it shows how much you have to learn to get to what you want to get to.”

In her interview Mouse talked about how college has inspired her and given her the opportunity to take new classes. She noted how the program’s mentors, staff, and resident advisor (RA) are helpful. She reiterated the social significance college has had for her, sharing that having friends and a boyfriend is what she likes most about college.

**Mysterious & Mischievous.** Mysterious & Mischievous' (M&M) four photos were of a classroom, a dining hall, a leaf and a podium statue. His theme was “how school is important.” All of the photos M&M selected were very clearly about defining his personality and what he values. He emphasized the importance of education and being successful in college. He coded the picture of the classroom as “interactive learning.” It was a picture of the technology in his educational technology classroom. M&M discussed how much he loved technology, specifically Smartboards and computers stating, “I'm in love with all this stuff.” This photo represented how much he values education as he commented that the photo could teach others “the classroom is important.” M&M also seemed to be reiterating behavioral expectations in college for peers (and presumably himself). Once he noted, “listen to the teacher [and] pay attention in class.” Another time he stated, “You're going to have to learn about how to get along with every single person…being open minded…accepting everybody.” During one of the focus group sessions M&M shared, "if you couldn't express yourself...potentially you could potentially do the wrong thing. You might regret what you did that is wrong... if you couldn't express yourself through maybe talking. I would use hands and feet and head... I had to learn that that stuff isn't…acceptable anymore."

He coded the picture of the dining hall on campus “hunger rave.” He was again defining himself and his love for food. He commented on how the dining hall is a buffet where “you can eat until you get full.” He noted that this reminded him of the all-you-can-eat buffets on a cruise he had taken with his parents. M&M also commented on the social opportunities the dining hall provided, he stated, “I like eating and I like meeting people in [the dining hall].”

M&M took a close up picture of a leaf and coded it “festive, beautiful.” This represented his “love for nature.” He noted that it was fall, so we were in the season when “the leaves start turning and it's colder weather.” He remarked, “it's kind of festive with all the leaves.” M&M also shared that he selected the photo specifically because “you can see the inner markings of the leaves;” he had learned how to take photos like this in a photography course he took in high school. M&M related this photo back to education as well stating, “I present a clear picture of myself in the classroom. I also present a clear picture by visually showing a picture and critiquing it.”

M&M coded his last picture was of a podium statue as “serious podium.” The podium was an outdoor statue that had some information about one of the campus buildings on it. The podium reminded him of a courtroom and he shared how it reflected his personality. He stated, “I have a distinct personality and I speak loud…I like enthusiasm...it's important for people to understand that I'm a pretty loud person myself." It also reminded him of college because “it resembles the school and the nature of school and the expectation of getting all the assignments turned in.”

In his interview M&M reiterated the importance of a college education to him. He said, “ we further our education and we get to learn more and study what we’re interested in.” He also identified the extra supports provided by the program as most helpful and he expressed pride in his achievement since he has “an A in every single one of my classes.” He also stated, “I just want to show my parents that I'm putting effort into whatever I need to do.” His family was very

Table 13

Focus Group Data: How do adults with ID perceive their post-secondary educational program?

| Domain | Subdomain (Theme) | Operational Definition | Quotes | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | C-Baggs | Dragon Ball Z | Jasmine | Mouse | Mysterious & Mischievous | Ricky | Simone |
| Personal Impact | Recognizing college as their preferred option | Participant expresses college as a preferred option or a pathway for getting a job, being successful, or some other desired outcome | "[If I didn't have the opportunity to go to college classes] I'd probably be sleeping all day"…"we would still be with our parents [if we didn't have access to college or living in the dorm"… | "I would say, 'mom, I want to go to college' and my mom said yes and so I go here" | "[College is important] to get like more experience [for] jobs"…"[this picture] makes me [think about] being successful" … "[showing people]…being successful when you're in college" | "[when I look at this picture it makes me think about college because] it shows how much you have to learn to get to what you want to get to" | "[I chose this picture] because I really like my classroom and I feel like the classroom is important." | "To me college isn't more about eating, to me it's about you are hungry for success"… "[College is ] a place of success, love and conquering fears"… "…if you didn't go to college...parents would see that they're such a huge disgrace" | "when you're done with college there could be a job waiting for you at the end"…"[If you didn't have the opportunity to go to college] you'd be sitting in your parents' basement…" |
| Personal Impact | Defining Themselves | Participant expresses their values, interests, preferences, or confidence | "I like to model...I like to take pictures of myself... "I like to smile and I am helpful when my friends are down"… "I was voted most spirited over 470 students" | "show off my singing skills"… "I love to sing."…"I'm really a fun person to be around"… "I love taking a picture in the dark of the dorm house" …" I like to drink coffee also" | …"I hate being cooped up"… "[This picture makes me think about] living independently" | "[I chose this picture because] I love coffee"… "[this image can teach others that] we can all be silly and fun, like me. I'm dressed up as a cat" | "[I want people to learn] that I'm in love with computers. …"I'm a genius of PowerPoint" … "[I want people to learn] I'm a person of nature …"I love...eating so I picked this [picture] on purpose" | ""I'm very strong when it comes to competition"… "I basically dress in my own way. …I'm Black so why wouldn't I wear black?" | "you are projecting yourself as tall and confident is because that's what people want to feel like"…"I want [people] to learn…that I'm not a really kind of messy person" |
| Personal Impact | Adapting to Challenges | Participant discusses ways they have learned to cope with challenges of college, living away from family, or mention specific people or strategies that have been helpful | "when I feel down I'll put this on…it says keep calm and just dance"… "[Program] students come there for … relaxation and…studying. [To] make sure you get some peace and quiet"…"[having a Starbucks at college is important] so students don't sleep in class" | "You need to learn for a subject for each class…and you need to learn more things for each step of each topic and subject that the teacher is saying"… "She's our RA again and helps…with our problem and cares about everybody"… "my roommate [and] all of my friends [are helpful]…they make me feel better" | "[going to classes is important] to get your grades up and getting homework done for professors"……"[this picture makes me think about how] the professors helps you with homework and study, if you don't understand it"… "academic mentors…help with homework…they help you calm down when you [are] stressed"… | "This [inspirational poster] helps me get through the day"… "being with the mentors and having help from staff or RAs…having pre and post [tutoring sessions is helping]." | "I think [the picture] can educate others…to listen to the teacher ...pay attention in class"… "getting extra support within my classes are what's driving me to be the best of my abilities"… "pre and post [tutoring sessions] are good" | "[what's helping me is] all my friends [and] all the staff are amazing people. They just they give you the motivation to get up in the morning and see their smiling faces"… "[without inspirational posters] we would be…down in the dumps." | "Better to have balance between school and social life then just having one or the other"… "you need to have fun and learning…if you only have one or the other then you either stress yourself out or you won't go anywhere"… "living in a dorm is important because it's a great way…to get acclimated to college" |

| Domain | Subdomain | Operational Definition | Quotes | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | C-Baggs | Dragon Ball Z | Jasmine | Mouse | Mysterious & Mischievous | Ricky | Simone |
| Personal Impact | Exceeding Others Expectations | Participants advocate for themselves or refer to their ability to achieve more than others expected of them | "Most people will say oh you can’t go to college. And most of us are like, look at us now we are in college”… "I wanted to show kids what I'm made of” | | | | | "I remember that everyone was saying you were never going to get to college, but I was like…you can continue talking because I'm just there”… "[this is] a message to my critics…this is me saying I'm basically happy being here” | "C-Baggs is in [this picture to show] that people like us can actually have a business like this some day where we’re actually in an office”… “We’re not tied down to what everybody else thinks of us…it shows that we are just like everyone else we just do it at a different speed” |
| Relational Impact | Developing friendships | A participant commenting on having friends or a relationship with peers | "having awesome friends outside of [the program] who care about me"… | I have a special person who really cares, my BFF; it's Mouse"… "I have tons of fun with friends and not family”… "[this picture makes me think about] your best friend, like me" | "Hangout with your best friends"…"so you can be social with your friends”… “I took that picture when I was walking with one of my friends"… “you get to be living [in dorm] with your best friends." | "time to get to know each other and make some friends"… "[people can learn] always have good friendships” | “College is good because you can meet people by way of the dining hall…that's where I've made a lot of friends so far” | “all my friends are helping.” | “I do have a social life”… “Living in college is a great way to meet people” |
| Relational Impact | Emerging Bonds | Participant expresses connectedness, closeness, or emotional bond that implies a relationship is that is more like that with family members | “I love Dragon Ball Z she's taught me a lot of ways to be with friends. More than my parents”… "Mouse is like a second sister to me" | “we all love her[Tangled]"..."she's always there for me in my heart”… "I love everyone and you all make me happy" (referring at peers in room)… “this dorm is fun to be with them (pointing to peers), with you all around me"… | "Mouse is like a second sister to me” … “I'm glad I met all of you guys and you guys are like my sisters…slash brothers (referring to peers in room)" | | | "The way the house is…it's kind of like a big family. We are all a big family… …it's just like saying we're one big happy family apart from our blood families" | |
| Relational Impact | Belonging to a college community | Participant expressing a sense of by aligning emotions for the college or expressing school pride | “I'm spirited”..."It shows Bearcats are cool and they are"…"…inflatable Bearcat from volleyball game...I thought it was neat. I'm spirited. I like that picture a lot" | "You have…red and black… the school colors from here"…"I love being a Bearcat!"... “I'm doing the bearcat cat. I've got spirit yes I do; I've got more spirit like bearcats do!" | "sport events we do…for spirit week…like for wearing for Friday…spirit week"…"it…helps you when you're in the game… like what player win the game" | "[it makes me think about] school spirit" | “…I think that people should go down to the game and cheer the Cats on in the end zone" | “It's more of a loyal thing"…"it's more of like you can say have your own group or squad"… | “it's the same team we lost to in soccer" |

| Domain | Subdomain | Operational Definition | Quotes | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | C-Baggs | Dragon Ball Z | Jasmine | Mouse | Mysterious & Mischievous | Ricky | Simone |
| | Having positive social experiences | Participant expresses a sense of being accepted, something meaningful to do, or engaging in positive social interaction | "So I'm not cooped up in the house”…"people like to hang out sometimes”… "Hanging around pole having fun"… "[It makes me think about] going to a lot more things [activities]”…"[Going to events] gets us out more and be with other college students" | “[this is a picture of] game on Saturday where we had tons of fun!" | "He's actually having fun in college. Actually I would say he's having a blast in college”… "going to sporting events” …"the reason why I pick that picture is because there's some events I like to go to sometimes"… "I like going to college and meeting new people"… | "[this is a picture of] me and my boyfriend at the game"… "just have fun"… “whenever there's football games you can hang out with friends"… | “I had a lot of fun at the game”… "[Going to games is important because you'd] miss out on a lot of things" | "[college] is the first place to make me happy in like A LOT of years. This is the first place that accepted me for who I am from the first day"… | “When you go to college, even though is all about books and degrees and going through it. You also need to take a break and have a little fun once in awhile" … “they just treat [me] like a person, not [based on my] ability” |

important to him and he mentioned having to adjust to not seeing them as often, but saw this as “important” for him to “be able to be independent and be on [his] own.”

**Ricky.** Ricky’s four photos were of himself in various, specifically staged poses. He identified his theme as “not worrying about the haters [or] critics.” Much of Ricky’s dialogue and photos focused on his sense of pride and accomplishment in going to college. He coded his first photo as “fire flame.” He described this as him saying “I’m happy being here.” He specifically covered his mouth in the photo to send a message to “his critics” that “you can continue talking because… I'm keeping quiet and laughing at my scoffers.” He is referring to people who told him he could not get into college, he views his acceptance into college as a personal success and he is “hungry for more.” Ricky described college as “a place of success, love and conquering fears.” Being accepted as a college student seems to have inspired him and bolstered his self-determination. This was evident when Ricky remarked how he had “achieved [going to college] and nothing's going to stop me.” He coded his second photo as “finest hour.” He took this picture of himself at the office on campus where he earned his first paycheck last year. Ricky is a second year student and every spring students have a paid vocational internship. He stated that he took the photo to encourage others to go to college.

Ricky coded his third photo, “fierce.” He is standing in a gym holding a basketball. He described this as his way of saying, “I’m coming back to the team” for his second year in the program. Ricky related to being part of the college community as being part of a “team.” He recognized this program as “the first place to make me happy in like a lot of years. This is the first place that… accepted me for who I am from the first day." Not only was Ricky grateful for the acceptance and respect he has received, he reciprocated this back towards his peers. He complemented peers’ photos throughout the focus groups sessions, giving remarks like “impressive,” “pure work of art,” “exquisite art,” and “wonderful piece of creative art.”

Ricky coded his final photo of himself as “redemption.” He is standing in front of the college bookstore wearing all black and covering his mouth. He shares that he is expressing several things in this picture. First, he is wearing black to show that he can “dress [his] own way.” He states, “I am Black so why not wear black.” Second, he commented that he wanted to express that he “doesn’t like reading.” Self-expression and self-advocacy is important to Ricky; he reiterates this by stating, “I’m going to make my point be heard” and “tell them that I run this place and not you.”

In his interview Ricky emphasized the fact that he was not just part of this specific program, but a member of the “college as a whole.” He expressed his sense of belonging to the college community in the weekly focus groups as he commented on being “loyal” to the “squad.” He recognized the closeness of his relationships with peers in the dorm, recognizing “we're one big happy family apart from our blood families."

When asked what was most helpful, Ricky also recognized his friends and the program staff. He stated, “The staff are amazing people. They just give you the motivation to get up in the morning and see their smiling faces.”

Ricky recognized a few things that he felt were not helpful to him in his college experience. While most of the other participants said “nothing” was not helpful in their interviews, he mentioned his frustration with having restrictions or boundaries as to where he could go on campus. He was referring to the program specific guidelines regarding going off-campus or out at night. He noted that he realized the restrictions were there to ensure students’ safety, but he also recognized that “when we’re done with college and the real world no one is going to say don’t do this or don’t do that.” Additionally, even though he was proud to be a part of the larger college community through this inclusive program, he shared that has experienced racial discrimination on campus. He explained how recently he was at the cinema and some female students he did not know made a comment not to sit near him because he was a “Black dude.” He said he was “insulted,” but chose to just “walk away.”

**Simone.** Simone’s four photos included one of himself posing in front of a campus building, one of a campus building, a peer in his entrepreneurship class, and the entrance to his dorm room. The overall theme he identified for himself was “Don’t have to believe other people’s perceptions.” This was an important topic for him. He made several comments like, “we’re not tied down to what everybody else thinks of us” and "we should strive for something bigger than what everyone else is telling us…we should strive for what we can see.” This theme was echoed as he coded the picture of himself as “dream big.” He had purposefully posed in this photo in, as he referred to it, a "*Gulliver's Travel* scenario." He explained as "when people see me they see me as short. In this photo I actually feel taller 'cause when you look at it I feel tall." He also shared that he posed like this to show others that he's "having fun." Keeping balance between academic and social life was important to Simone. He mentioned several comments like "even though is all about books and degrees…you also need to take a break and have a little fun once in awhile" and "you need to have fun and learning…if you only have one or the other then you either stress yourself out or you won't go anywhere."

Simone coded the picture his peer, C-Baggs, as "Business." He seemed to be emphasizing the idea of breaking stereotypes as he had her pose sitting at a desk in their entrepreneurship class. He shared that he wanted to show "that people like us can actually have a business like this some day where we're actually in an office." He noted that there were other buildings and businesses in the background, "so it's a picture of a person [and] what their goal could be later on in life." He also stated, "I picked this one over other ones because it actually shows that people like us, 'cause we're different or unique, that were not tied down to what everybody else thinks of us." He continued by saying, "It shows that we are just like everyone else we just do it at a different speed than everyone else."

Simone, like many of the other participants in this project, also chose some pictures for their artistic characteristics. He took a picture of one of the campus buildings and coded it as "haunted, aged." He noted how the building has a "spooky kind of vibe" and how, after it rains, "it [looks] gray…like it's aged." He then related the scariness of the building, to the experience of being at college. He stated, "college isn't as scary as you think…the first couple of weeks is scary…but once…you've been there for about a couple of months it's actually not that scary of an experience."

Simone coded the picture of his dorm as "dorm." He was very purposeful in how he took this picture too, wanting it to be different and unique. He mentioned that he wanted to take a picture of the "entrance to the room because not a lot of people are going to show that side of the room because they think it's plain and usual." He also remarked that the dorm is "important because it's a great way to meet people and then also get acclimated to college." He discussed how adjusting to college was difficult and that "the dorms [are] a good place for me to be able to interact with people and hang out in various activities and all that." Finally, Simone shared that he wanted others to learn more about him from this photo, that “he’s not a really kind of messy person. [He’s] pretty clean, but not the clean as neat-freak kind of clean."

In his interview Simone described college as a “shifting experience.” He said he came to college with one career in mind, becoming a voice actor; however, now he has found that he makes coffee well and would like to learn more about that as a career option. He stated that he feels accepted or valued as a person versus a person with certain abilities in college. Relating back to his theme of “don’t have to believe other people’s perceptions,” he recalled in the past “there have been times that I’ve been told that my ability is the only thing that they see, so that’s what people would go on.” Overcoming being “labeled” seemed very important to Simone.

Simone, like Ricky, shared some challenges he has faced in college. He stated that being in the dorm with a lot of other people has been stressful and distracting for him to complete work. Simone also mentioned that he does not like the long walk to classes.

**Cross-Case Results.** Table 13 displays quotes from each of the participants that support the domains and subdomains identified. Eight subdomains were identified in the first cycle of coding and then two overarching domains were recognized in the second cycle of coding. There were four subdomains for both personal development and relational development. While data supports commonalities across the participants’ perspectives, the uniqueness of each individual’s experience was also apparent. Several attendees at the dissemination commented on this. One remarked, “These students have unique talents and skills including photography, storytelling and humor.” Other comments included how, “each had such a different perspective” and “how diverse each of the students are.” One of the staff members noted, “students value different things, but there is some overlap.”

***Recognizing college as their preferred option.*** Each of the participants referred to college as a preferred option for them. C-Baggs, M&M, and Simone made comments that if they did not have the opportunity to go to college, the alternative would be living with their parents and just “sleeping”, “playing games," or "sitting around [their] basement." Dragon Ball Z shared that she told her mom she wanted to go to college, then "[she said] yes and so I go here." Ricky associated college with success and pride; he noted, "if you didn't go to college…[your] parents would see [you] as a huge disgrace." Both Jasmine and Simone made reference to college as a way to get a job, while Mouse referred to learning in college as a means to "get to what you want to get to."

Participants' satisfaction with their choice to go to college was evident in their focus group dialogue and confirmed by attendees at the dissemination and staff presentation. Jasmine remarked one of her peers looked "excited to be in college." Ricky stated, "It makes me proud to be part of this whole legacy," referring to being in college and being part of the college community. One of the staff member's commented in their questionnaire, "students love their college experience."

***Defining themselves.*** Each of the participants chose photos and shared dialogue that expressed their confidence, interests, values, or preferences that highlighted their unique strengths and abilities. C-Baggs emphasized her personal strengths of being "helpful" and "spirited," as did M&M by noting he is "a genius at PowerPoint." Dragon Ball Z boasted that she was "a fun person to be around." Ricky was very proud to give this program "an international outreach." Dragon Ball Z voiced her love for singing; Mouse expressed her love for coffee, and M&M his many interests like technology, food, nature, and sports.

It was apparent that many of the participants viewed their photos not just as a venue to document their college experience, but an artistic outlet and opportunity to express their creativity. Dragon Ball Z noted colors, shadows and lighting in not only her photos, but also her peers. M&M discussed his love for photography and pointed out specific details from his photos as he presented them. Mouse arranged the three cups from Starbucks® so that each logo was turned a specific way and Simone took his photos with decisive vantage points in mind. C-Baggs, Dragon Ball Z, Mouse, and Simone all purposefully modeled for their photos, and Ricky held a unique pose in each of his four photos, creatively choosing the background and coloring. Dragon Ball Z, M&M, and Ricky all commented on the specific artistic aspects of their peers' photos; Ricky referred to many of his peers photos as "a work of art."

Participants' personal values were also illuminated. Valuing independence echoed throughout the dialogue. Jasmine talked about dorm living as "teaching independence" and C-Baggs referred to "living by myself" and stated, "[college is important because] it is the way you are…independent." Additionally, Ricky emphasized effort and succeeding as significant stating, "even if you don't like something, you put effort into it." He also mentioned, "if you have to go very far to achieve something, you've got to just do it" even if it means, "struggling for what you want." Simone reverberated these values as he talked about "working harder... to get a job" and "leaving…a mark along the way." Simone promoted perseverance as he talked about college not being as scary as it first seems. He remarked, "Once you've been there a couple of months, it's actually not that scary." While Simone supported hard work, he also encouraged "balance." He mentioned the importance of having "balance between school and social life" several times. Diversity seemed to be valued as well. M&M mentioned, "being open minded…accepting everybody" and shared "how [in America] we have people that of all different races, genders, and...cultures." He stated he was proud "to be making friends from all over." Ricky expressed how he valued the diversity he brought to the program, stating how being "the first Nigerian international" in the program is "making a big statement." Finally, Simone expressed a desire to be accepted, even though he categorized himself and his peers as "unique" or "different." Ricky also articulated during his interview the importance of acceptance for him by sharing that college was "the first place that… accepted me for who I am from the first day."

Staff observations further supported this subdomain in their questionnaires. One commented, "I gained insights as to what their true passions and interests are." Another staff person noticed "students value different things, but there is some overlap. Still another remarked how the dissemination "helps to demonstrate the unique abilities of students." An attendee at the dissemination noted how they "learned about [students'] identities."

***Adapting to challenges.*** Each of the participants mentioned specific ways they are coping with either academic or emotional challenges they have faced in college. C-Baggs talks about studying and drinking coffee to stay awake; she and Mouse both mention having a "quiet" place to go and "relaxation." Simone also explained how students “use Starbucks like to help them warm up, relax…they can go get coffee and do homework in a mellow setting instead of where it's completely hectic." Jasmine refers to “getting homework done for professors" and how they can “help you… if you don't understand." She also mentions how technology “helps you with college classes." Dragon Ball Z notes the importance of learning in each class and M&M reiterates the need to “listen to the teacher ...pay attention in class.” Simone talks about maintaining “balance” between academic and social life in college. He states, "You need to have fun and learning…if you only have one or the other then you either stress yourself out or you won’t go anywhere.” Mouse shared an inspirational poster that she said, “helps me get through the day.” Both Ricky and Simone agreed that inspirational posters or sayings help so students do not feel “down.” C-Baggs shared a saying on her mobile device that she reads when she feels down. It states, “keep calm and just dance.” All of the participants except Simone mention program support persons who have been helpful to them. These included academic and social mentors, resident assistant (RA), and pre and post tutoring sessions. C-Baggs, Dragon Ball Z, and Ricky all mention how their friends have also been helpful to them. One staff member noted that they “learned [about students’] experiences adjusting to college lifestyle and figuring out how they fit in” after viewing their presentations.

***Exceeding others’ expectations.*** C-Baggs, Ricky and Simone expressed a sense of pride in exceeding expectations others had set for them, specifically by going to college and setting their own goals. C-Baggs shared that “most people will say…you can’t go to college…[but] now we are in college.” She stated that she took the photo of herself to “show kids what I’m made of.” Ricky also recalled people telling him “you were never going to get to college” and he stated one of his photos was “ a message to the critics” that he was not going to “fuel their perception” of him. He remarked that he was “laughing at [his] scoffers.” Simone took a photo of C-Baggs to demonstrate that “people like us can actually have a business like this some day” and he stated, “we should strive for the goals we set out for us, not what everybody expects us to go out for.”

***Developing friendships.*** Each of the participants made specific references to friendships or social relationships as part of their college experience. While Simone never referred to anyone as his friend, he mentioned living in the dorm as “a great way to meet people” and also stated, “I do have social life.” C-Baggs pointed out that she had “awesome friends outside of [the program].” Dragon Ball Z referred to Mouse as her “BFF" (best friend forever) and share that she has "I tons of fun with friends.” Jasmine mentions hanging out with her “best friends” and “being social with friends.” Mouse stated that people could learn to “always have good friendships” from one of her photos. M&M noted how he has met many friends in the dining hall and Ricky stated how all of his friends “are helping” in college. Multiple staff members mentioned the relationships being made in the program. Both staff members and dissemination attendees commented on how Mouse had “made her first friend here.” Another staff member observed how “[the students] are enjoying college life and building friendships.” Attendees at the dissemination also affirmed the friendships being built. One stated how they learned, “that building friendships and relating to one another was very important [to students].”

***Emerging bonds.*** Living together in the dorm and participation in the program has created a level of deeper connectedness or bonding with one another, similar to relationships with family members. In fact, Ricky compared the peers he lives with in the dorm as “a big family.” He said, “It's just like saying we're one big happy family apart from our blood families." C-Baggs talked about how Dragon Ball Z has taught her “ways to be with friends, more than my parents.” Both C-Baggs and Jasmine refer to Mouse as being “like a sister to me.” Jasmine referred to all of her peer participants as “like my sisters [and] brothers” and Dragon Ball Z remarked how she loved Jasmine and hugged her. Participants also shared the bonds they have developed with attendees at the dissemination. One attendee noted how a participant shared that “her roommates were like sisters.”

***Belonging to the college community.*** All of the participants referred to being part of this specific college’s community by rooting for them at sporting events or expressing school pride in general. C-Baggs talked about being “spirited” as she shared her photo of the school mascot, a bearcat. Dragon Ball Z was standing in a “bearcat” pose in one of her pictures and pointed out the school colors in one of Ricky’s photos as he was sharing. Jasmine had picture of a sweatshirt with the college’s name and talked about wearing it for "spirit" and to show "what player [you want to] win the game." Mouse also talked about how one of her peers' photos reminded her of school spirit and Simone noticed that the team in one of the photos was the same one "we" lost to in soccer last week, referring to the college's soccer team with the pronoun "we." Ricky described having school spirit as being "a loyal thing" and having your "own squad." Attendees at the dissemination also sensed participants' sense of belonging. Comments that support this include: "students really are part of a community;" "[students] becoming an integral participant in the university;" "saw a lot of bearcat pride;" "school spirit among the students;" and "becoming a bearcat."

***Having positive social experiences.*** In addition to the relationships being formed and the sense of belonging to the college community being developed, participants all made comments relating to having positive social experiences. C-Baggs, Dragon Ball Z, Jasmine, Mouse, M&M, and Simone all refer to having "fun" by going to an event or just hanging out. Ricky and Simone both reflect on having their differences accepted in college. One attendee at the dissemination commented how students were having "valuable experiences," while others noted, "[students] seem very happy about where they live and their roommates" and "all of the pictures show [students] having a good time at college."

## Question Two: How Does Participation In Inclusive Research Project Impact Participants With Intellectual Disability?

There is little evidence as to the impact of taking a collaborative group approach to research utilizing inclusive methods engaging participants as co-researchers (Bigby et al., 2014). Therefore, one of my objectives was to document how participation in this process impacted co-researchers. To answer question two I analyzed multiple sources of data, which included transcripts from focus group sessions; co-researchers' weekly research reflection checklist responses, interview transcripts, and final questionnaire responses; and, for data triangulation purposes, questionnaire responses from attendees at dissemination and staff presentation. One domain, personal impact, was identified with three subdomains: (a) fulfilling experience; (b) expressive outlet; and (c) self-advocacy (see Table 14).

Overall participation appears to have had a positive impact on all of the co-researchers. Feedback from the weekly research reflection checklist questionnaires (see Appendix B) supported this. Co-researchers rated three statements with the options to respond 3(yes), 2(sort of), or 1(no). The statements read: (1) I like being in the photo research project; (2) I am able to make choices in the project; and (3) I understand what we are doing in the project. Co-researchers could provide examples to explain their responses and share other ideas. Each week there was a mean of three for all three statements with the exception of one response on 10/7/14. One of the co-researchers anonymously responded "1" or "no, I do not like being in the photo research project." Since I did not know who recorded this I followed up with an email reminding co-researchers that they have the option of quitting if they do not like being in the project. I also reminded all co-researchers the next time we met that they could quit by telling or emailing me, telling or emailing their peer support person, or by just not coming anymore. I concluded that someone must have been bored or just did not enjoy that week's discussion because all of the responses continued to be "3" or "yes, I like being in the photo research project."

**C-Baggs.** C-Baggs shared that "being with friends and peers" was the best part of the project. She also noted that she like taking photos and commented, "I love everything from this [project]. Her self-confidence was clear in the data. In one of her comments in the weekly reflections she stated, "I am independent." She also remarked, "I love making choices with group" and made several suggestions for the group as far as the type of pictures she thought they should take. She suggested, "do sports [pictures] and "do activities [pictures]."

**Dragon Ball Z.** Dragon Ball Z described being part of the project as "fun" and also commented, "I love this project." She expressed enjoyment in taking pictures and noted, "Photography is important to me in my life." She expressed several times how presenting her PowerPoint at the dissemination was her favorite part of the project. She did not make any suggestions for changes on her weekly reflection responses.

Table 14

Q2: How does participation in an inclusive research project impact participants with ID

| | | | Data Source | | | | |
|---|---|---|---|---|---|---|---|
| Domain | Subdomain | Operational Definition | Participant Final Questionnaires | Participant Interviews | Participant Weekly Reflections | Responses from Dissemination Questionnaire | Responses from Staff Presentation Questionnaire |
| Personal impact | Fulfilling experience | A comment is made regarding participants' satisfaction with project or being engaged in an activity they enjoy. | C-Baggs: "being with friends and peers [was the best part of the project]… "I love everything from this [project]."<br>Dragon Ball Z: "I love taking pictures"… "photography is important to me in my life"<br>Jasmine: "working with our support [person was the best part of the project]… "I had fun with the project"<br>Mouse: "I loved everything"… "[What I like most] was getting to go out and take pictures and tell about them" | Dragon Ball Z: "I love taking pictures…photography is important to me in my life"<br>Jasmine: "I like taking pictures."<br>M&M: "If you like taking pictures and critiquing them…the photo project is… the best"<br>Ricky: "[The project] was amazing"… "It took me out of my usual zone…got me out of the house."<br>Simone: [The most helpful part of the project was that] I got to take pictures"… | C-Baggs: "I love taking pics"<br>Dragon Ball Z: "I love this project"… "fun"<br>Mouse: "It's fun"… "[I] love to take pictures…<br>M&M: "It builds my interest in photography."<br>Simone: "I like to take pictures." | "Students really enjoyed taking pictures and describing them" | "Students really enjoyed taking pictures and describing them"… "I learned students had a really good time knowing that people would learn about their college experience"… |
| Personal impact | Expressive Outlet | A comment is made regarding participants having the opportunity to effectively communicate their perspectives | Jasmine: "doing the poster [was most helpful in the project].<br>M&M: "I got to present my talents"<br>Ricky: [the best part of the project] was when we showed the highlights [at the dissemination]." | Dragon Ball Z: "presenting my PowerPoint [was what I liked most about being in the project]."<br>Ricky: "[Being a part of the project] was a chance for me and my fellow team players to say this is my life"<br>Simone: "What I liked most about being part of the project is [that] people got to see my point of view." | | "I learned that the students like to share and discuss their interests with others"…"This is great to get [students] point across" … "It is cool to hear from the voice of the students, what they value and how college life has impacted them" | "The students are very expressive through photography"… "[I learned] how much students appreciate us listening to how they feel"…"The students have a lot to express through photos and it seemed like a great way for them to share their feelings"… "[students] are creative [and] love to express themselves when given the opportunity" |
| Personal impact | Self-advocacy | A participant is expressing their strengths or preferences; or a comment is made regarding participants demonstrating strengths, abilities, or confidence in themselves. | Jasmine: "[I would tell others] they can do different kind of project. The can do… a PowerPoint or poster [and] the staff can help you with it when you have a supporter."<br>M&M: "[best part of the project] was helping out in the project as far as what the picture was about and then coming up with themes…to give information out so others can learn" | M&M: "[What I liked most was] my talent and effort…[being able to] apply [my photography] skill"<br><br>Ricky:"[The project] brought out [that even if] we might have our own differences, our own issues, we are just showing them in the pictures that we are…not learning disabled; we are highly functioning individuals that just need to be accepted for who we are"<br>Simone: "I got to choose what pictures I could use. What would fit where"… | C-Baggs, "I am independent" …"I love making choices with group."… "do sports pics"… "do activities pics"<br>Mouse: "do more pictures. Pick two"…"Show pics to Launch [students]"<br>M&M: "Keep critiquing photos"… "Continue what you are doing"<br>Ricky: "Add more pictures" | "I think their photo show represented their abilities well"… "All of the students were proud of their contributions"…"They displayed their attitude of believing in themselves"… "Each student demonstrated a sense of pride in what they had accomplished at [college] so far" | "All of the students were proud of their contributions"…"They displayed their attitude of believing in themselves" …"Each student demonstrated a sense of pride in what they had accomplished at [college] so far"… "They are sharing what their perspectives are without any persuasion of anyone else"… "I was really blown away by our students' perspectives of their experience here on campus"… "They bring great insight and experiences to share"… "Our students are very talented"… "I learned that our students surprise us everyday" |

**Jasmine.** Jasmine stated that she "liked taking photos" and thought creating her poster for her dissemination presentation was most helpful. She also identified the best part of the project as working with her support person. Even though Jasmine did not indicate on her weekly reflection response, she shared in her final interview that she felt frustration at times explaining her photos. She struggled thinking of the words she wanted to use to describe them and verbally respond to the SHOWED protocol.

**Mouse.** Mouse described the project as "fun" and shared that she loved to take pictures. She noted, "I loved everything," but specifically identified "getting to go out and take pictures and tell about them" as what she liked most. Mouse voiced a couple of ideas for changes in our weekly focus group. First, she suggested each participant pick two pictures to share each week and then she wanted to make sure that they were able to share their pictures with a specific group of students from another program at the dissemination. She also commented that what she liked least about the project was "having it end so quickly."

**Mysterious & Mischievous.** M&M expressed pride in his photography skills by remarking several times how enjoyed the opportunity to share his "talent and effort." He noted how being a part of the project built on his "interest in photography." He voiced that he wanted to "keep critiquing photos" in one of his weekly reflection responses and in his interview he expressed gratitude for being part of the project, stating, "I'm glad to be a part of this project. Thank you."

**Ricky.** Ricky viewed participation in the project as something different to do. He remarked how, "It took me out of my usual zone…got me out of the house." He also referred to it as "amazing." His feedback on one of his weekly reflection responses was that he wanted to be able to "add more pictures." He described the best part of the project "was when we showed the highlights [at the dissemination]." He described this as "a chance for me and my fellow team players to say, 'this is my life'." He explained that the project was an opportunity for the participants advocate for themselves. He profoundly stated, "We are just showing them in the pictures that we are… not learning disabled. We are highly functioning individuals that just need to be accepted for who we are."

**Simone.** Simone noted that the most helpful part of the project was that he got to take pictures. Designing his presentation for the dissemination seemed important to him. He noted, “I got to choose what pictures I could use. What would fit where”…[people] got to see two different views of my college experience…the pictures I took and the story [I] put with it.” He expressed that what he liked most about the project was “[that] people got to see my point of view.” He did not make any suggestions for changes on his weekly reflection responses from the focus group, but did share in his interview that he and one of the other participants want to start a photo club of their own.

**Cross-Case Results.** Table 14 displays quotes, their sources and how they support the domain and subdomains identified. Three subdomains were identified in the first cycle of coding and then the one overarching domain was recognized in the second cycle of coding. Data supports overlap among the participants’ perspectives, but recognizes the uniqueness of each individual’s experience and perspective.

***Fulfilling experience.*** The data suggested the project provided a satisfying and enjoyable experience for all of the participants. C-Baggs, Dragon Ball Z, Jasmine, Mouse, and Simone all explicitly stated how they liked taking pictures. M&M remarked how being in the project built on his “interest in photography.” C-Baggs, Dragon Ball Z, and Mouse all shared that they loved the project. Dragon Ball Z and Jasmine also both referred to the project as “fun.” M&M expressed gratitude for being in the project, while Ricky referred to it as “amazing.”

***Expressive outlet.*** Participation in the project also provided an expressive outlet for participants to communicate their viewpoints. While the participants had expressed enjoyment in taking pictures and sharing with each other in the weekly focus groups, the dissemination presentations seemed to have the most significance. Dragon Ball Z, Jasmine, M&M, Ricky and Simone all commented on how liked presenting about themselves at the dissemination. This was apparent to the attendees at the dissemination as one remarked, “I learned that the students like to share and discuss their interests with others. Another recognized the participants’ presentations as an effective communication tool noting, “This is great to get [students’] point across.” After viewing the participants’ dissemination presentations staff members also recognized photography as an effective communication tool for participants. Some of the comments that supported this include: “The students are very expressive through photography”; “The students have a lot to express through photos and it seemed like a great way for them to share their feelings”; “Each student was able to present their viewpoint of their experiences”; and “Our students need various forms to be able to display their thoughts and feeling. Words don't always express it all.”

***Self-advocacy.*** Multiple sources of data indicated that participation in this project as co-researchers provided the opportunity for participants to advocate for themselves by giving them the chance to demonstrate their capabilities, expressing their opinions and acting on their own behalf. Co-researchers had the opportunity to verbally express their viewpoints and make choices during focus group sessions, as they were involved in the decision-making processes for the project. For example, during the second focus group session co-researchers determined how decisions would be made throughout the project (majority rules). Beginning with the third focus group session when co-researchers began sharing their photos, they decided who would present and for how long. They also made decisions about continuing to take pictures and planned the entire dissemination. Additionally, co-researchers had the opportunity to express their opinions, share ideas and suggest changes to the project in writing via their weekly reflections. C-Baggs, Mouse, M&M, and Ricky all utilized the weekly reflection format to give their input in the research process. C-Baggs, Mouse and Ricky made comments regarding the number and type of pictures the group should share. M&M just suggested continuing as we were. C-Baggs expressed in her self-confidence in one weekly reflection commenting, “I am independent.” She also noted how she liked “making choices with the group.”

The dissemination offered a venue for co-researchers to demonstrate their abilities and confirm their self-confidence. One attendee noted how the “photo show represented their abilities well.” Other comments that support this notion include: “our students are very talented;” “all of the students were proud of their contributions;” “they displayed their attitude of believing in themselves;” and “each student demonstrated a sense of pride in what they had accomplished at [college] so far.” Some staff members expressed how co-researchers’ presentations had exceeded their expectations. One noted, “I was really blown away by our students' perspectives of their experience here on campus," while another shared, "I learned that our students surprise us everyday."

**Question three: How can photovoice data inform ongoing evaluation for this specific post-secondary educational program?**

The impact of PSE programs for adults with ID cannot accurately be determined without collecting satisfaction data directly from the participants themselves who are consenting adults that have not been declared incompetent. Using participatory research methods that employ photovoice is a logical choice to collect data since photovoice provides multiple opportunities for participants to express themselves. Furthermore, participatory methods support the notion of "nothing about us, without us." Unfortunately, few studies have engaged in such practices to date, so research is needed to identify valid means of capturing the perspectives of participants with ID (Ottman & Crosbie, 2013). Therefore, the intent of my third question was to explore how photovoice data could inform ongoing program evaluation with expectation of validating its further use.

Data were from the focus group sessions and the questionnaires from the dissemination and staff presentation. Photovoice data could be grouped into two domains; these were individual participant data or program data. Three subdomains emerged in the individual participant data domain. Data indicated photovoice is: (a) an effective communication tool; (b) person-centered; and (c) supporting competence. The two subdomains for the program data indicated how photovoice is: (a) informative; and (b) documenting co-researchers' membership in the college community. Table 15 provides operational definitions and specific data that support these domains and subdomains. Additionally, attendees at the dissemination were asked to rate how valuable they felt the data presented would be regarding program evaluation on a 5-point Likert scale (from 0-not valuable to 5-very valuable). The mean response was 4.78 and all of the staff who viewed the co-researchers' presentations remarked that the data from the photovoice process seemed valuable for program evaluation.

**Effective communication tool.** The photovoice process provided multiple ways for co-researchers to communicate their viewpoints. The photos they took and selected provided a concrete visual image as starting point for engaging in critical dialogue, guided by the SHOWED protocol, during weekly focus group sessions. As indicated in the results from question one, the focus group sessions provided the opportunity for co-researchers to share insights as to the personal and relational impact college is having on them. Co-researchers were not only able to convey their viewpoints to their peers in the program during the focus group sessions, but they had the opportunity to expand their audience at the dissemination. Many attendees at the dissemination confirmed the effectiveness of the photovoice process as an effective means of communication. The co-researchers' presentations were described as "powerful visual evidence [that] allows some to contribute data they wouldn't be able to in other ways." Another attendee reiterated the effectiveness by stating, "The photos provide evidence of the students' likes, priorities, and engagement with the college." After viewing the co-researchers' presentations, staff members concurred that photovoice was an effective communication tool. One remarked, "Each student was able to present their viewpoint of their experiences," while another noted, "Our students need various forms to be able to display their thoughts and feeling. Words don't always express it all."

**Person-centered data.** Photovoice data could also be considered person-centered. As described in results from question one, co-researchers were able to define themselves, communicating their specific strengths, interests or preferences during the focus group sessions. A few examples include co-researcher comments like: "I like to model"; "I love to sing"; "I love coffee"; "I'm in love with computers"; and "I'm not a really kind of messy person." This was confirmed by attendees at the dissemination who commented how "photos and information provide insight of what is important to each students" and that "these students have unique talents and skills." Still another dissemination attendee noted, "I learned about their identities." One staff member shared that, "I gained insight as to what their true passions and interests are." Other staff members commented how, "[This] helps to demonstrate the unique abilities of our students" and "It helps to uncover hidden strengths [and] talents."

Table 15
Q3: How can photovoice data inform ongoing program evaluation?

| | | | Data Source | | |
|---|---|---|---|---|---|
| Domain | Subdomain | Operational Definition | Focus group sessions | Responses from Dissemination Questionnaire | Responses from Staff Presentation Questionnaire |
| Individual participant data | Effective communication tool | Photovoice data from co-researchers' demonstrates a clear example of a co-researchers' viewpoint or a comment is made regarding how photovoice process provided an effective way for co-researchers' to communicate their perspective | Data is provided in Table 13. | "Photos and information provide insight of what is important to each students"… "Useful tool"… "Powerful vehicle to facilitate competence, confidence, and a sense of belonging"… "it gives powerful visual evidence [that] allows some to contribute data they wouldn't be able to in other ways"… this is great to get their point across"…"I think their photo show represented their abilities well"… "The photos provide evidence of the students' likes, priorities and engagement with the college." | "Each student was able to present their viewpoint of their experiences"… "Our students need various forms to be able to display their thoughts and feeling. Words don't always express it all"… "[I learned] how they viewed their own college experience"… "The students are very expressive through photography"… "Students can express their voice by presenting in various ways"… "[This provides] more insight into what life looks like from their perspective [and] ways they chose to be creative with representing their experiences"… "Each student was able to present their viewpoint of their experiences"… "The students have a lot to express through photos and it seemed like a great way for them to share their feelings" |
| Individual participant data | Person-centered data | A comment is made that indicates a co-researchers' strengths, interests, or preferences were identified or emphasized | C-Baggs: "I like to model"<br>Dragon Ball Z: "I love to sing"<br>Jasmine: "living independently"<br>Mouse: "I love coffee"<br>M&M: "I'm in love with computers"<br>Ricky: "I basically dress in my own way"<br>Simone: "I'm not a really kind of messy person." | "Photos and information provide insight of what is important to each students"… "These students have unique talents and skills"… "I learned about their identities" | "Very unique and artistic"... "How they viewed their own college experience- very unique and artistic"… "I gained insight as to what their true passions and interests are"… "Students value different things, but there is some overlap"… "[This] helps to demonstrate the unique abilities of our students"… It shows what's meaningful to them"… "It helps to uncover hidden strengths/talents" |
| Individual participant data | Supporting participants' competence | Comments indicate that participation in the photovoice process support co-researchers' expressing competence or confidence in their abilities | C-Baggs "I wanted to show kids what I'm made of."<br>Ricky: ""[this picture is] a place of success for me"<br>Simone: "…[this picture] shows that we are just like everyone else; we just do [things] at a different speed" | "Powerful vehicle to facilitate competence, confidence, and a sense of belonging"… "They did wonderful work and truly influenced me"…"[They] have persevered more than I expected"… "Impressed with how each student presented their photo collection"… "All of the students were proud of their contributions"… "They displayed their attitude of believing in themselves"… "Each student demonstrated a sense of pride in what they had accomplished at [college] so far" | "Our students know who they are and how to tell or show others what is important to them"… "I learned that the students really have strong opinions and ideas about their college experience"… "They bring great insight and experiences to share"… "they are creative [and] love to express themselves when given the opportunity"… |

| Domain | Subdomain | Operational Definition | Data Source<br>Focus group sessions | Responses from Dissemination Questionnaire | Responses from Staff Presentation Questionnaire |
|---|---|---|---|---|---|
| Program Data | Informative | Comments identify aspects of program that are effective supports or having a positive impact on co-researchers | C-Baggs: …"[social skills group] gets us more motivated, like talking to them, with other students"<br>Dragon Ball Z: "She's our RA again and helps…with our problem and cares about everybody"<br>Jasmine: "[this picture of the dorm] could teach independence, chores, doing your laundry"<br>Mouse: "This [inspirational poster] helps me get through the day" | "[Participants] seem very happy about where they live and their roommates"… "Independent dorm living…proud of their space"… "One student said she had her first friend. Another said her roommates were like sisters"… "I learned that building friendship and relating with one another was very important to them"… | "This can be valuable for administration to know from students themselves what goals are being met and what areas need to be improved upon"… "this would be useful to know what students find the most beneficial from the program"… "key points can be rolled into curriculum"… "It could help provide a foundation for not only program evaluation, but also for the development of new programs" |
| Program Data | Documenting co-researchers' membership in the college community | Comments document how co-researchers have integrated into or express their sense of belonging with the college community | C-Baggs: "[This picture] shows Bearcats are cool and they are"<br>Dragon Ball Z: "I love being a Bearcat!"<br>M&M: "…I think that people should go down to the game and cheer the Cats on in the end zone" | "A connection with the university"… "becoming an integral participant in the university"… "all the pictures show them having a good time in college"… "these students were really part of a community" | "I learned [about students'] experiences adjusting to the college lifestyle and figuring out how they fit in"… "Relationships and a sense of community seem to be big themes, which means we need to continue to support them as they develop these things" |

**Supporting competence.** Photovoice data also supported co-researchers' competence, or their ability to assert their capabilities. During the focus group sessions, as indicated in the results from question one, the photovoice process provided co-researchers' with the opportunity to express their competence or self-confidence as they referred to their ability to achieve more than others expected of them. C-Baggs remarked how she, "wanted to show kids what she's made of." Ricky noted how, "[college] is a place of success" and Simone argued, "we are just like everyone else; we just do [things] at a different speed." One attendee at the dissemination also viewed the photovoice data as "a powerful vehicle to facilitate competence, confidence, and a sense of belonging." Another attendee noted, "[I'm] impressed with how students presented their photo collection." Staff comments verified co-researchers' competence. One observed, "Our students know who they are and how to tell or show others what is important to them," while another stated, "They bring great insight and experiences to share."

**Informative.** Photovoice provided program data that was informative, identifying aspects of the program that are effective supports or having a positive impact on participants. Results for question one from focus group sessions' data revealed various aspects of the program co-researchers' found that were supporting their success. C-Baggs noted, "[social skills group] gets us more motivated, like talking…with other students." Dragon Ball Z identified the RA "helps…with our problems and cares about everybody." Jasmine remarked how the picture of the dorm "could teach independence, chores, doing your laundry, while Simone thought "living in a dorm is important because it's a great way…to get acclimated to college." Finally, Mouse shared how "this [inspirational poster] helps me get through the day." Attendees at the dissemination made comments regarding the residential and social aspects of the program. One noted how participants seem "very happy about where they live and their roommates." Another noted how co-researchers were, "proud of their space." Attendees observed the developing friendships and emerging bonds as one remarked how, "one student said she had her first friend [and] another said her roommates were like sisters." Another attendee noted, "I learned that building friendship and relating with one another was very important to [participants]." Staff members also supported the informative nature of the photovoice data after viewing co-researchers' presentations. One staff member perceived the data as "valuable for administration to know from students themselves what goals are being met and what areas need to be improved upon." Another staff member thought, "this would be useful to know what students find the most beneficial from the program." One recognized how "key points can be rolled into curriculum," while still another believed, "[data] could help provide a foundation for not only program evaluation, but also for the development of new programs."

**Documenting co-researchers' membership in the college community.** Photovoice data documented how co-researchers have integrated into the college community. Results from question one include participant comments expressing a sense of belonging and connection with the college or a sense of school pride. A few example include comments like: "[This picture] shows Bearcats are cool and they are"; "I love being a Bearcat;" and "…I think that people should go down to the game and cheer the 'Cats on in the end zone." Attendees at the dissemination confirmed this with comments like: "a connection with the university";

“becoming an integral participant in the university”; and “these students were really part of a community.” Staff members also reinforced this notion with statements like: “I learned [about students’] experiences adjusting to the college lifestyle and figuring out how they fit in” and “Relationships and a sense of community seem to be big themes, which means we need to continue to support them as they develop these things.”

# V. Discussion

## Summary of Study

As a former staff member of a PSE program for adults with ID, I became aware of the potential of the participants and valued their perspectives. Seeking to contribute to the currently scarce literature on inclusive research with adults with ID, I chose to employ inclusive methods and undertake a collaborative group approach in this study. The purpose was to document, describe, and analyze the perceptions of adults with ID of the post-secondary educational program in which they were enrolled. A variety of data collection methods, which included focus group sessions, photovoice, semi-structured interviews, and questionnaires, provided multiple opportunities for co-researchers to communicate their viewpoints. Furthermore, co-researchers were engaged as decision-makers throughout the collaborative, inclusive process and included data analysis. I sought to document the impact of their participation in this project to contribute to the literature on inclusive research. I collected data that supports the ability of these adults with ID to contribute to the evaluation of their post-secondary educational program in order to promote the development of their self-advocacy and self-determination skills as well as validate the value of their perspectives.

## Discussion of Findings from Question One: How do Adults with ID Perceive their College Experience?

The opportunity to go to college has been a distant dream for many adults with ID. The data presented demonstrates that college, specifically this post-secondary educational program, is an achievable, preferred path that has provided these co-researchers opportunities to grow personally as well as socially. Freire (1970, p.113) contends that engagement in critical dialogue provides the opportunity for individuals to transform their praxis, with the potential of overcoming limit-situations as they shift their awareness from a situation that was perceived to be impossible to one that is achievable.  As they participated in critical dialogue, these co-researchers revealed that they were empowered, capable young adults, not bound by their diagnosis or limits others have set for them.  Data supports common themes across their perspectives regarding the impact of college, while highlighting the uniqueness of each individual's experience.

**Comparison to similar studies.** Although the results from this study and the pilot were not intended to be generalizable, there were share similarities with previous studies utilizing photovoice to document the perspectives of adults with ID enrolled in PSE programs (e.g. O'Brien, 2009; Paiewonsky, 2011).  In 2009 results from O'Brien's study revealed that participants with ID experienced acceptance, competence, and were "socially networked" (p.37), gaining new friendships in their inclusive program.  O'Brien (2009) attributed the development of these friendships to the social mentors provided by the program; a support also provided by the program in this study.  Paiewonsky (2011) noted participants having a "new identity" (p. 37), experiencing new academic classes as well as engaging in social activities.  Participants in Paiewonsky's (2011) study described how they were adjusting to new expectations that college life presented as did the participants in this study.  One of the challenges faced by Paiewonsky's (2011) participants was learning to utilize public transportation since all of the participants commuted daily to their college campuses.  While using public transportation is a potentially important skill for many adults with ID,  it was not a major concern for participants in the current study since all of the participants live on campus and are able to walk to where they need to be.  The residential component of the program in this study seems to provide more opportunities for participants to attend social activities and integrate more fully in the college community, whereas participants in the Paiewonsky (2011) study revealed their desire to attend more weekend and evening events.

Findings from this study were also analogous to the pilot study.  Participants in both studies identified new opportunities the college experience provided them, challenges they faced, and supports that were valuable.  Common opportunities mentioned in both studies were: belonging to the college community; living in the dorm; eating at the dining halls; attending university sporting events; making friends; engaging in social activities; developing skills of interest like photography; and learning independent living skills like doing laundry. Shared challenges included those related to academics as well as overcoming stereotypes. Finally, program supports noted in both studies were: the effectiveness of academic mentors; the positive qualities of staff members; and having designated places to study.

Unlike the findings from O'Brien (2009) and Paiewonsky (2011), results from this study indicated co-researchers have developed deeper emotional bonds and connectedness with their peers. Additionally, results from both the pilot and this study highlight the development of independent living skills. These new findings can seemingly be attributed to the residential component of this specific program, as the former studies involved program participants who commuted to college.

**Uniqueness of the individuals.** The question posed to participants during their photo missions in this study was, "What do you think about your college experience?" Each co-researcher took the opportunity to "shine in the spotlight," sharing specific attributes about themselves, proudly boasting their personal strengths and preferences. As one attendee at the dissemination described, "They are the center of their universe…so developmentally appropriate." College is obviously providing them the opportunity to define themselves as they interact independent of their immediate families.

Each of the co-researchers expressed that college was their preferred choice; however, they each shared a unique perspective of their experience. At the end of the study, I created found poems (Reilly, 2013) from the participants' dialogue which represent the distinctive personalities and experiences of each of the seven co-researchers, their words signifying their relationship with their world. I entitled them: Confident Friend (C-Baggs), Spirited Photographer (Dragon Ball Z), Ambitious Learner (Jasmine), Delightful Soul (Mouse), Passionate Person (M&M), Determined Advocate (Ricky), and Balanced Achiever (Simone). Throughout the data collection process I noted reoccurring subjects among the dialogue of individual co-researchers, some of which aligned with the "themes" they identified for themselves during the data analysis session. C-Baggs, for example, often mentioned getting out and socializing and recorded her theme as "college life." Jasmine regularly noted the importance of independent living and related skills; her theme was "living at college with four roommates independently." Dragon Ball Z remarked on the photographic qualities of almost every picture shared, while Ricky admired each of his peers' creativity. Dragon Ball Z also frequently mentioned having fun with friends and being spirited, which aligns with her theme of "having fun." Ricky connected most of his remarks to not giving up and having success; his theme for his photos was "not worrying about the haters or critics." Mouse tended to focus her comments around friendships, which was also her theme during data analysis. M&M focused on his distinct personality and various passions. Simone seemed preoccupied with balance of academic and social life as well as having his differences accepted by his peers. His theme was "don't have to believe other people's perception."

The results highlight distinguishing personalities and individual perspectives of these co-researchers who were capable of expressing their opinions and ideas and had a lot to contribute; they are individuals clearly able to communicate and advocate for themselves. Documenting their insights was possible through multiple opportunities to express themselves using accessible methods. Being flexible as a researcher and focusing on the co-researchers abilities rather than any preconceived notions associated with their disability label, resulted in rich data documenting their individual perspectives. These co-researchers share the label of "intellectual disability," but they each expressed their uniqueness as young adults experiencing college for the first time.

**Taking on challenges.** Data suggested that co-researchers in this study are enjoying being in college and their experiences have been positive, but not without challenges. Co-researchers shared ways they have learned to cope with the new challenges college poses. A few co-researchers referenced inspirational sayings that encouraged them emotionally, while others focused on strategies and supports they are utilizing to meet the academic challenges college presents. Their resilience is not surprising given their expressed motivation. There was an ongoing sense of pride and confidence among the co-researchers regarding being college students and living independent of their parents; they seemed to relate college to success. Several referenced the fact that being in college was something they had been told they could not accomplish. Others saw it as a stepping-stone to a better future, a means of achieving more. For some that meant the potential of living more independently or gaining better employment opportunities. One of the co-researchers reiterated this stating, "How would you be able to manage…later in life if you didn't know how to live independently?"

**Relationships.** In addition to personal development, expanding relationships were integrated among the data. Not only has their inclusive college experience provided opportunities to build new friendships with peers with disabilities as well as those who are typically developing, many of these relationships have grown into stronger, family-like kinships. These strong bonds were reiterated throughout the focus group sessions with hugs and comments like, "I love you" and "we are all a big family." One co-researcher remarked how a peer "has taught me a lot of ways to be with friends…more than my parents." These relationships, often taken for granted by peers who are typically developing, appeared to be treasured among the co-researchers. Without the chance to participate in college, these relationships probably would not have been formed, since the opportunity to meet would not have existed. Most of these co-researchers would have otherwise been, as they put it, "sitting around in [their] parents' basement" or "sleeping all day."

**Integration with the college community.** Co-researchers have thoroughly connected with the college community. Their sense of belonging and loyalty to the college and its sports teams was repeated throughout the data. In fact both Ricky and Simone describe college as the first time they experienced "being accepted" right away. This may have been due to the positive, inclusive, social interactions participants were enjoying, most of which are planned within the program and made possible through the residential component. Living on campus provides easy access to college activities. Their integration was represented by the many photos, which included the college mascot, events they attended on campus, or signs and logos representing the school.

**Themes not voiced.** Results indicate the personal and relational impact college has had for these individuals. What is more implicit in the data than what co-researchers explicitly shared, is what they did not share. Themes that were not heard include: I do not want to go to college; I am not sure of who I am; I am not able to adapt to challenges; I do not know how to develop relationships; or I do not know how to engage socially. College was the preferred path for these individuals, yet few programs like this exist; many other young adults with ID may be denied such an opportunity. Co-researchers in this study knew their strengths and preferences and had little difficulty expressing them, yet inclusive research including adults with ID continues to be sparse. Co-researchers demonstrated their abilities to adapt and overcome academic challenges they faced, develop meaningful friendships, and thrive in the inclusive social environment this PSE program offers, yet individuals with ID continue be place segregated settings without exposure to more inclusive social opportunities and challenging academic curricula (Ajuwon et al., 2012; Campbell, Gilmore & Cuskelly (2003).

**Transformation.** This study was grounded in Freire's (1970) empowerment education theory. Freire (1970) contended that through critical dialogue, individuals could become aware of "limit-situations" (p.99) and begin the empowering process of transforming their consciousness and, therefore, their praxis or how they interact with their world. Results indicate that the co-researchers in this study have been limited by the stigma of their disability and the low expectations associated with it. The limitations, however, have been externally, not internally, driven. Many of these co-researchers shared that they had previously been told they could not go to college. They also perceived others' resistance to accept their differences and expressed a sense of being de-valued; however, the results indicated *they* perceived themselves as being capable and recognized the need for *others* to adjust *their* perceptions. Engaging in critical dialogue during the photovoice process has revealed the need for a transformation on the part of societal perceptions, rather than the co-researchers. They expressed their belief in their abilities, and recognized that others have not shared their perceptions. While the disability rights movement for individuals with ID has made significant progress over the past century, results from this study indicate the need for continued growth as research documents the untapped potential of individuals with ID. The challenge to transform does not seem to be with the individuals with ID, but with those who are capable of either stifling or supporting their success.

### Discussion of Findings from Question Two: How does participation in an inclusive research project impact participants with ID?

Inclusive research that engages adults with ID as co-researchers has been limited (Burke et al, 2003; Jurkowski, 2008). Similar to prior research (Atkinson, 2004, Burke, et al., 2003; Povee, et al., 2014), embarking in this collaborative process seemed to be empowering for co-researchers and provided a venue for self-advocacy (Walmsley, 2004). Co-researchers indicated that their on-going participation in the project was a positive and satisfying experience that provided them with the opportunity to communicate their perspectives, make decisions, and demonstrate their abilities.

**Co-researchers' devotion.** Photovoice enabled them to engage in an activity they all liked, taking pictures. It was clear during the photovoice process that the co-researchers loved taking photos and were excited to share their experiences with each other each week in the focus group sessions and then to a broader audience at dissemination. Each of the co-researchers commented about how they loved or enjoyed taking pictures; in fact, Dragon Ball Z came to the first photo session ready to go with her own personal camera in hand. It is critical to point out that participants volunteered to take part in the study. If I had chosen another method to select co-researchers, they potentially may not have shared this same passion for photo taking part of the project and may not have been as committed to the project. The study required a large commitment of time and responsibility: one hour every week for fourteen weeks plus additional time to go out and take photos and prepare their dissemination presentation. Jasmine missed the first week due to a scheduling conflict. She took the initiative to change her schedule so that she could participate in the project. Mouse missed one week due to a family emergency and we had to cancel one meeting so that co-researchers could attend another program event. These were the only absences. In fact, for some, the project should have been longer. During his interview Ricky shared that they did not get "a chance to share all of our creativity." With further prompting he stated that he did not feel limited by what we did, but he wanted the project to continue. Simone announced that he and M&M were going to start a "photo club." He explained that it would be "not just for students of the house, but also anybody that wants to take photos. Ours is going to be more of a photo enjoyment than a really a project for people that want to take pictures."

**Co-researchers as decision-makers.** Having previously established a trusting relationship with my co-researchers authenticated their role as decision-makers in this project. Co-researchers not only chose to be a part of this project, but they had the chance to engage in volitional action, making decisions regarding how we moved forward throughout the project. They made decisions weekly about what pictures they took, how many they shared, or what order they would share. Co-researchers also had the opportunity to problem-solve when making decisions. For example, several wanted to share more than one photo each week. This led to a discussion about how that would work within our one-hour time frame. I facilitated the conversation, presenting the potential that if each person would present two photos, there would be the risk of running out of time so that some co-researchers would not get to present that week. The co-researchers decided to have each present one photo and then, if there were time, they would present additional photos. When planning dissemination each had the option to participate. They decided who would be invited and how they would present their photos as well as which ones they would present. Co-researchers also determined the format for dissemination presentations. They chose to have everyone presenting at the same time and allow guests to walk around and view them versus having more formal one-at-a-time presentations in front of the guests.

**Co-researchers as educators.** Participation in the project also provided the chance for co-researchers to express their viewpoints and engage in critical dialogue as a means of educating and influencing others. The photos provided the concrete symbol or “coded existential situation” (Freire, 1970, p.105) that represented each co-researcher’s existential reality, or the piece they wanted to reveal that week. The photos provided the starting point for our critical dialogue. Using the adapted SHOWED protocol and problem-posing methods to examine generative themes were effective ways to engage co-researchers in a way that provided rich data that informed others of their perceptions. As previously noted, Freire (1970) discussed ways engagement in these processes have supported the transformation of individuals’ consciousness from one that is unaware of ways to overcome their limit-situation to one that is aware of their own potential influence (p.113). Freire (1970) also argued that this redefines the roles of the traditional “teacher-of-the-student” (or researcher) and “students-of-the-teacher” (or objects of the researcher in traditional research) to “teacher-students” and “student-teachers” (or researcher and co-researchers in inclusive research) who are both growing from the process and whose roles continuously fluctuate (p.80). The co-researchers in this case recognized their limit-situation (the stigma of disability), but through their participation in these inclusive research processes, they were able to educate this researcher and potentially transform the consciousness of others, as to their potential abilities.

***Recognizing different perspectives***. Through the photos and dialogue co-researchers were able to connect and relate with one another as well as recognize different perspectives; Freire (1970) would contend that the co-researchers were noting the various "parts" of their "whole" shared experience, helping them to comprehend a more accurate view of their reality (Freire, 1970, p.104-5). As they shared their photos, a comment from one of the co-researchers would stimulate a related comment or one that presented a completely different viewpoint. For example, when Mouse presented her photo of the three different Starbucks® cups, several participants related by mentioning how much they enjoyed coffee and noted how it supported their academic success by helping them stay awake. Ricky, however, said he viewed the three different cups as representing different levels of success. Ricky shared that, for him, the smaller cups represented former successes he had achieved, but the biggest cup represented being in college. Ricky also referred to success when discussing other photos. When M&M shared his photo of the dining hall, the discussion initially centered on eating and M&M remarked that he liked to eat until he was full; noting the dining hall satisfied his hunger. Ricky shared that to him, "college isn't more about eating, to me it's about you are hungry for success." Ricky's metaphoric comparison represented his, and perhaps his peers,' aspirations, which have seemingly come to fruition through his college experience.

During another discussion, co-researchers' dialogue once again moved from the concrete representation of a photo to a metaphorical perspective. This occurred when Simone was sharing his photo of an old building on campus, which he coded as "haunted, aged." He began discussing how the building had a "spooky kind of vibe" and peer comments were initially centered on how artistic the photo was. However, later in the dialogue Simone revealed how the building represented the fear he experienced when he first came to college. Then he revealed that after awhile, "college isn't as scary as you think." He stated that the photo could encourage others to "go out and grab what you want" rather than "sitting there." He appeared to be relating back to his on-going theme of "don't have to believe other people's perceptions;" he was inspiring others to take chances and believe in themselves. Throughout the on-going dialogue during the project, each of the co-researchers described college as their preferred choice, one they thought would improve their lives. Most, however, had been told this was not an option for them. Participation in the project gave co-researchers the opportunity to voice their desires and show others, “look at us now, we are in college.”

**Co-researchers breaking stigmas.** The co-researchers seemed to relate to one another as members of a collective group based on their disability “label.” Throughout the project, I noted remarks from various participants referring to one another as "people like us" or being "different or unique," implying their identification as members of a marginalized group that has not always perceived themselves as “accepted” by others. Several comments were made about the significance of “being accepted” and being treated like a person, “not [based on] ability” in college versus prior experiences. Participation in this project provided an opportunity for co-researchers to demonstrate their strengths and likeness to their peers who are typically developing. This actuated their role in transforming negative or limited societal perceptions of individuals with ID. During my interview with Ricky, I asked him what was helpful about being in the photo project and he responded:

> “Well it kind of brought out like oh, yes we might have our own differences, our own issues. We are just showing them in the pictures that we are not, we are not what they say. We are not learning disabled. We are highly functioning individuals that just need to be accepted for who we are. That is just basically what this project was saying.”

**Role of Technology.** Technology played a significant role throughout this project supporting communication and managing data. The co-researchers’ technological skills and access to current technologies played a significant role in data collection and dissemination. At the first meeting I requested that participants share their email addresses and phone numbers with me. Since I was no longer a staff member with the program, I would not be on the college campus on a daily basis. Sending and receiving emails and text messages was an integral part of their participation in their PSE program, so no training was necessary for co-researchers to utilize these technologies to communicate with me. Also, since each of the co-researchers had a smartphone, no training was needed for actually taking the pictures, as has been the case in prior photovoice studies. The conference room we reserved for our weekly focus groups was equipped with Smart boards and monitors so that co-researchers’ photos were projected around the room when they were presenting. The projector and screens also provided visual reference of the PowerPoint presentations I presented each week for our member checking. We utilized a web 2.0 tool called Snapfish (www.snapfish.com) to store and access the photos co-researchers took, which provided one convenient place to access all of the co-researchers' photos. C-Baggs independently found an app, Flipagram, to display her photos on her personal iPad. An iPod was utilized to record focus group sessions, which I then downloaded to a secure laptop and transcribed. When co-researchers were unable to meet for the final focus group, I was able to email the final questionnaire for each of them to complete. Finally, field notes, memos, transcriptions, and data analysis were all created and stored as Word or Excel documents.

**Challenges of the project.** Participation in the project did present some challenges for a few of the co-researchers. While most co-researchers enjoyed presenting their photos and responding to the SHOWED protocol, Jasmine mentioned how she had "a difficult time explaining stuff." She struggled verbally explaining her photos. She may have benefited from additional support. Perhaps working with her support peer prior to focus group sessions to prepare her responses to the SHOWED protocol would have been helpful for her. Simone was frustrated by the location of the dissemination. It was in a new meeting room, not the same location as the focus group sessions due to the anticipated number of guests. It was difficult to find and no one had been there before so directions were confusing. Even one of the attendees at the dissemination noted how, if we were to do this again, the event should be in "a more prominent location." Unfortunately, it was the only space large enough that was available on that date and time.

## Discussion of Findings from Question Three: How can Photovoice Data Inform On-going Evaluation for this Specific Post-Secondary Educational Program?

Think College, an organization aspiring to enhance PSE programs for young adults with ID, recommends collecting satisfaction data from program participants (http://www.thinkcollege.net/topics/think-college-standards) as a component of program evaluation. As one attendee at the dissemination put it, "How in the world can you evaluate a program without the perspective of the participants? Their voices naturally matter; they are the ones that matter the most." Freire (1970) reinforces this viewpoint, stating "One cannot expect positive results from an educational or political action program which fails to respect the particular view of the world held by the people" (p.95). Consistent with prior research (Jurkowski, 2008; Jurkowski & Paul-Ward, 2007; Jurkowski, et al., 2009; Paiewonsky, 2005), photovoice has the potential to provide valuable data documenting co-researcher perspectives to inform on-going program evaluation of this inclusive PSE program for adults with ID. Objectives of this PSE program include participants: (a) being empowered to be in control of their lives; (b) capable of advocating for themselves; (c) able to live a lifestyle of choosing with minimal supports; (d) possessing skills for successful employment; (e) becoming lifelong learners; and (f) having improved quality of life.

**Person-Centered.** Empowerment evaluation promotes input from program participants in the evaluation process and, ideally, in the planning and implementation phases (Wandersman et al., 2005). Results from this study indicate the photovoice process was an effective way to highlight co-researchers' individual interests, strengths, personal preferences and challenges. Such data could be utilized to design on-going person-centered program supports and interventions to continue to support personal growth towards program outcomes. Just as this PSE program strives to educate participants to improve their skills and quality of life, the program participants can educate policy-makers as to the best way this can be done. Freire (1970) would refer to the program participants as student-teachers in the expansion of their own education and the program policy makers as teacher-students, learning what is best for the program through the perspective of the participants (p.84).

**Supporting Competence**. Photovoice has been utilized as an empowerment tool to inform policy makers for changes concerning issues of social justice; in this study co-researchers were able to inform stakeholders of their experiences and validate, not only the positive impact college is having on their lives, but their ability to communicate for themselves regarding their experiences. Participation in the photovoice process as a means of documenting co-researchers experiences was in itself an empowering experience, which promoted participants' self-advocacy skills and validated their capabilities and insights. Dissemination provided a venue for co-researchers to demonstrate their competence to stakeholders within and outside of the program. Viewing multiple presentations at dissemination enabled attendees to identify both the uniqueness of individual's experiences as well as commonalities among the group. The dissemination presentations empowered co-researchers, giving them the opportunity to advocate for themselves.

**Flexibility and Accessibility**. Photovoice as a participatory methodological tool is a flexible and accessible way to accurately document the perspectives of individuals with ID. The process itself can easily be adapted to meet the needs of co-researchers, minimizing potential barriers to their input. The photos, taken by the co-researchers, were concrete, visual representations that articulated what was important to them and a starting point to engage in critical dialogue. This study utilized Paiewonsky's (2005) adapted SHOWED protocol, which could be further altered if needed. Other, simpler, protocols (e.g. Graziano, 2004; Hergenrather et al., 2009; Hussey, 2006; Mamary et al., 2007; Rhodes & Hergenrather, 2007) could have been utilized as well. The photo mission in this study was broad: document your college experience. More specific questions regarding certain aspects of the PSE program could easily be posed to co-researchers if more explicit feedback were desired.

### Credibility

Miles and colleagues (2014) suggest building triangulation into data collection. This was accomplished through multiple sources of data and collection methods (Maxwell, 2013; Miles et al., 2013; Shenton, 2004) and documented in table 9. Data from focus group sessions, interview transcripts, weekly reflection checklists, and questionnaires were utilized to provide multiple modes for co-researchers to communicate their ideas and gain deeper understanding of their perspectives. Questionnaires from disseminations provided multiple data sources to confirm themes emerging from co-researcher data, which were also corroborated by another faculty member involved in the study who examined data to confirm analyses.

**Member checking.** Barnes (1992) notes that conducting member checking throughout the data collection and analysis processes ensures "accountability" of the inclusiveness of the research process. Member checks (Miles et al., 2013, Shenton, 2004) in this study included: (a) a review of prior week's focus group results and current week's agenda at beginning of weekly focus group sessions; (b) utilization of a research reflection checklist (see Appendix A) each week to facilitate participants with ID reflecting on their role in the research process throughout the stages of the study (Garcia-Iriarte, et al., 2009); (c) participant involvement in evaluating the research process using final questionnaire as suggested by Sample (1996); (d) presentation of found poems (Reilly, 2013) created from focus group and final interview transcripts; and (e) a final report summarizing the study and the findings in language and format that is easily understood (Gilbert, 2004, Stalker, 1998).

**Reflexivity.** I recognize that I have to consider my impact and the influence of my actions and interactions with co-researchers when considering data generated in this study. Cunliffe (2004) related to this citing Gouldner (1970) who stated, “There is no knowledge of the world that is not a knowledge of our own experience of it and in relationship to it” (p. 28). I cannot ignore the fact that, as a former staff member, co-researchers may have viewed me as a figure of authority. I employed practices to minimize my role as an authority figure and empower co-researchers in order to document their perspectives. As the literature suggests (Aldridge, 2014; Conder et al., 2011, Nind, 2011), I maintained a flexible role throughout the process, adapting to meet the needs of the participants with ID throughout the research process. In my analytic memos I continuously considered accessibility issues regarding methodological choices and the level of participation, role, and control of co-researchers in the research process. My assumptions in this study were that, because co-researchers volunteered and were reminded weekly of their option to quit the study, that they acted out of their own volition. I tried to promote a collaborative, responsive and ethical approach to this research. The first photo mission began with an open-ended question, “What do you think about your college experience” and then co-researchers guided photo-taking process. I purposefully did not engage in discussion during focus group sessions, although at times I would repeat what co-researchers stated, or clarify statements. I follow SHOWED protocol, but asked alternative questions as I deemed necessary or if a co-researcher prompted me, indicating that they did not understand. I engaged in continuous member checking, soliciting participant feedback both verbally and in their written reflection as suggested by Garcia-Iriarte et al.(2009).

## Limitations

While the data from this study is valuable to this specific PSE program, it is not generalizable to other programs. It would be careless to make assumptions regarding the impact other PSE programs for participants with ID based on this data. Additionally, data was only collect during one college semester. More, extensive studies may reveal additional themes. For example, participants in this PSE program engage in a paid internship every spring semester during the four-year program; continuing the focus group sessions during this time could provide insights as the impact of the vocational aspects of the program. Finally, co-researchers self-determination or self-advocacy skills were not assessed prior to the study, nor were their perceptions of research; such data could provide additional insights regarding the outcomes of this study.

## Implications and Next Steps

The voices of individuals with ID matter and need to be heard. They have individual preferences and abilities that need to be respected as well as valuable insights to contribute to the literature. As PSE programs for adults with ID expand, the impact of these programs cannot accurately be determined without collecting data directly from the participants themselves. Researchers, support persons, or other professionals involved with adults with ID, need to continue to examine the assumption that they know "what's best" for individuals with ID and can speak on their behalf. Walmsley (2004) began her article on inclusive research with a quote from bell hooks that sums this best:

> "no need to hear your voice when I can talk about you better than you can speak about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I rewrite myself anew. I am still author, authority. I am still the colonizer, the speaking subject, and you are now the centre of my talk" (Hooks 1990, p. 151).

Inclusive methods hold remarkable promises in supporting adults with ID take on a more significant role in the research process and contributing valuable data to program evaluation. Tools like photovoice promote co-researchers' strengths and abilities and offer the opportunity for self-advocacy and potential for influencing policy and decision makers.

This study contributes to the literature in several ways. Data exposed specific opportunities and experiences that are important *to the co-researchers* as well as the various supports that have helped them be successful in their post-secondary educational program and personal struggles they have been confronted with. Data also revealed that these adults with ID are capable of communicating their preferences, reflecting on their experiences, engaging in critical dialogue and data analysis, as well as advocating for themselves. These co-researchers demonstrated the skills and abilities that researchers previously considered adults with ID incapable of.

More inclusive research studies are needed to continue to identify practices that most effectively capture the viewpoints of participants with ID (Ottman & Crosbie, 2013) and involve participants with ID in data analysis (Nind, 2011; Tuffrey-Wijne & Butler, 2010). Additionally, future research is needed to identify effective practices and interventions that support the success of participants with ID enrolled in PSE programs (Grigal, Hart, & Lewis, 2012) as well as document long-term outcomes for these adults compared to peers who have not participated in a PSE program (Hafner, 2011). Such data is critical for program development and enhancement to ensure a better college experience, resulting in improved quality of life for people with ID.

## Conclusion

Less than 50 years ago, children with ID were denied access to public education. As we have moved forward with legislation supporting inclusion and education in the least restrictive environment in the P-12 settings, we also need to advance this movement in the post-secondary setting (Grigal et al., 2012). Post-secondary educational programs for adults with ID are valuable and necessary. We can no longer deny adults with ID access to inclusive education, employment, and community living. We also cannot continue to deny adult participants with ID engagement in the research processes that aim to improve their quality of life.

Individuals with ID continue to meet and exceed the expectations placed before them, when they are afforded the chance to do so. Negative perceptions will not be overcome without the opportunity to prove otherwise. Society has consistently held low expectations for individuals with ID (Grigal & Hart, 2013; Wehmeyer, Agran et al., 2000). Such practices reinforce a culture of overprotection and perceptions of inability for people with ID, limiting their ability to act autonomously (Wehmeyer, Bersani, & Gagne, 2000). Professionals need to recognize that, although individuals with ID may always be dependent on others to some varying degree, they still need to be supported and engaged in activities that strengthen their abilities to act as causal agents in their lives (Browder & Shapiro, 1985; Wilson et al., 2008). In order to be respected as self-advocates in an increasingly inclusive world, adults with ID need to be able to manage their own lives and the behaviors that constitute life (Browder & Shapiro, 1985; Taber-Doughty, Miller, Shurr, & Wiles, 2013; Wehman, Shutz, Bates, Renzaglia, & Karan, 1978). Inclusive research studies like this one provide and document empowering opportunities for adults with intellectual disability, demonstrating their strengths and abilities. These inclusive practices support the notion of "Nothing about us, without us."

# References

Ajuwon, P. M., Lechtenberger, D., Griffin-Shirley, N., Sokolosky, S., Zhou, L., & Mullins, F. E. (2012). General education pre-Service teachers perceptions of including students with disabilities in their classrooms. *International Journal of Special Education*, *27*(3), 100-107.

Aldridge, J. (2007). Picture this: The use of participatory photographic research methods with people with learning disabilities. *Disability & Society*, *22*(1), 1-17.

Aldridge, J. (2014). Working with vulnerable groups in social research: Dilemmas by default and design. *Qualitative Research*, *14*(1), 112-130.

Atkinson, D. (2004). Research and empowerment: Involving people with learning difficulties in oral and life history research. *Disability & Society*, *19*(7), 691-702.

Barnes, C. (1992). Qualitative research: Valuable or irrelevant? *Disability, Handicap and Society, 7,*115-124.

Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*, *13*(4), 544-559.

Becker, H. S. (1995). Visual sociology, documentary photography, and photojournalism: It's (almost) all a matter of context. *Visual Studies*, *10*(1-2), 5-14.

Benz, M. R., Lindstrom, L., & Yovanoff, P. (2000). Improving graduation and employment outcomes of students with disabilities: Predictive factors and student perspectives. *Exceptional Children*, *66*(4), 509-529.

Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing Inclusive Research with People with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, *27*(1), 3-12.

Booth, T., & Booth, W. (2003). In the frame: Photovoice and mothers with learning difficulties. *Disability & Society*, *18*(4), 431-442.

Bradley, E. H., Curry, L. A., & Devers, K. J. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health services research*, *42*(4), 1758-1772.

Brake, L.R., Schleien, S. J., Miller, K.D., & Walton, G.W. (2012). Photovoice: A tour through the camera lens of self-advocates. *Social Advocacy and Systems Change Journal, 3*(1), 44-53.

Burke A., McMillan J., Cummins L., Thompson, A., Forsyth, W., McLellan, J., ... & Wright, D. (2003) Setting up participatory research: A discussion of the initial stages. *British Journal of Learning Disabilities, 31*, 65–69.

Campbell, J., Gilmore, L., & Cuskelly, M. (2003). Changing student teachers' attitudes towards disability and inclusion. *Journal of Intellectual and Developmental Disability*, *28*(4), 369-379.

Carroll, S. Z., Blumberg, E. R., & Petroff, J.G. (2008). The promise of liberal learning: Creating a challenging post-secondary curriculum for youth with intellectual disabilities. *Focus on Exceptional Children, 4*(9), 1-12.

Casale-Giannola, D., & Kamens, M. W. (2006). Inclusion at a university: Experiences of a young woman with Down syndrome. *Mental Retardation, 44*(5)*,* 344-352.

CAST (2011). *Universal design for learning guidelines version 2.0.* Wakefield, MA: Author.

Chappell, A. L., Goodley, D., & Lawthom, R. (2001). Making connections: The relevance of the social model of disability for people with learning difficulties. *British Journal of Learning Disabilities*, *29*(2), 45-50.

Chapman, R., & McNulty, N. (2004). Building bridges? The role of research support in self-advocacy. *British Journal of Learning Disabilities*, *32*(2), 77-85.

Clouse, D., Bauer, A., & Oettinger, L. (2015). *Valuing "Self" In Self-Monitoring Research: A Qualitative Review of Literature*. Manuscript submitted for publication.

Conder, J., Milner, P., & Mirfin-Veitch, B. (2011). Reflections on a participatory project: The rewards and challenges for the lead researchers. *Journal of Intellectual and Developmental Disability*, *36*(1), 39-48.

Corbin, J., & Strauss, A. (Eds.). (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage.

Cornwall, A., & Jewkes, R. (1995). What is participatory research?. *Social science & medicine*, *41*(12), 1667-1676.

Creswell, J. (2012). *Educational Research: Planning, conducting, and evaluating quantitative and qualitative research*. (4th ed.). Boston, MA: Pearson.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Thousand Oaks, CA: Sage.

Cunliffe, A. L. (2004). On becoming a critically reflexive practitioner. *Journal of Management Education*, *28*(4), 407-426.

Dybwad, G., & Bersani, H. A. (1996). *New voices: Self-advocacy by people with disabilities*. Cambridge, MA: Brookline Books.

Edyburn, D. L. (2010). Would you recognize universal design for learning if you saw it? Ten propositions for new directions for the second decade of UDL. *Learning Disability Quarterly*, *33*(1), 33-41.

Fetterman, D.M. (1994). Empowerment Evaluation. *Evaluation Practice, 15*(1), 1-15.

Fetterman, D., & Wandersman, A. (2007). Empowerment evaluation yesterday, today, and tomorrow. *American Journal of Evaluation*, *28*(2), 179-198.

Fischman, G. E. (2001). Reflections about images, visual culture, and educational research. *Educational Researcher*, 28-33.

Freire, P. (1970). Pedagogy of the oppressed (2008 30th anniversary edition ed.,).(MB Ramos, Trans.). New York. *NY:* The Continuum International Publishing Group.

Fuller, M., Healey, M., Bradley, A., & Hall, T. (2004). Barriers to learning: a systematic study of the experience of disabled students in one university. *Studies in higher education*, *29*(3), 303-318.

Garcia- Iriarte, E., Kramer, J. C., Kramer, J. M., & Hammel, J. (2009). 'Who Did What?': A Participatory Action Research Project to Increase Group Capacity for Advocacy. *Journal of Applied Research in Intellectual Disabilities*, *22*(1), 10-22.

Getzel, E. (2008). Addressing the Persistence and Retention of Students with Disabilities in Higher Education: Incorporating Key Strategies and Supports on Campus. *Exceptionality*, *16*(4), 207–219. doi:10.1080/09362830802412216

Gilbert, T. (2004). Involving people with learning disabilities in research: Issues and possibilities. *Health & social care in the community*, *12*(4), 298-308.

Gilmore, D., Schuster, J., Zafft, C., & Hart, D. (2001). Postsecondary education services and employment outcomes within the vocational rehabilitation system. *Disability Studies Quarterly*, *21*(1).

Goodley, D. (2005). Empowerment, self-advocacy and resilience. *Journal of Intellectual Disabilities*, *9*(4), 333-343.

Graham, J.R. (2012). *The development of self-advocacy in people diagnosed with developmental disabilities: Enhancing communication through photovoice and council.* (Doctoral dissertation). Retrieved from ProQuest Information and Learning Company.

Graziano K. (2004). Oppression and resiliency in a post-Apartheid South Africa: Unheard voices of Black gay men and lesbians. *Cultural Diversity & Ethnic Minority Psychology*, *10*(3), 302-316.

Grigal, M., Hart, D., and Lewis, C. (2012). A prelude to progress: The evolution of postsecondary education for students with intellectual disabilities. *Think College Insight Brief, (12)*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

Hafner, D. (2008). *Inclusion in postsecondary education: phenomenological study on identifying and addressing barriers to inclusion of individuals with significant disabilities at a four-year liberal arts college* (Doctoral dissertation). Retrieved from ProQuest Information and Learning Company.

Hafner, D., Moffatt, C., & Kisa, N. (2011). Cutting-Edge: Integrating Students With Intellectual and Developmental Disabilities Into a 4-Year Liberal Arts College. *Career Development for Exceptional Individuals*, *34*(1), 18–30. doi:10.1177/0885728811401018

Hall, S. (2013). Including people with intellectual disabilities in qualitative research. *Journal of Ethnographic & Qualitative Research, 7,* 128-142.

Hamill, L. B. (2003). Going to college: The experiences of a young woman with Down syndrome. *Mental Retardation, 41*(5)*,* 340-353. doi:10.1352/0047-6765(2003)41<340:GTCTEO>2.0.CO;2

Hart, D., Mele-McCarthy, J., Pasternack, R. H., Zimbrich, K., & Parker, D. R. (2004). Community College: A Pathway to Success for Youth with Learning, Cognitive, and Intellectual Disabilities in Secondary Settings. *Education & Training in Developmental Disabilities*, *39*(1), 54–66.

Hergenrather, K. C., Rhodes, S. D., Cowan, C. A., Bardhoshi, G., & Pula, S. (2009). Photovoice as community-based participatory research: A qualitative review. *American journal of health behavior*, *33*(6), 686-698.

Hooks B. (1990). *Yearning: Race, Gender and Politics*. Boston, MA: South End Press.

Hong, B. S. S., Ivy, W. F., Gonzalez, H. R., & Ehrensberger, W. (2007). Preparing Students for Postsecondary Education. *TEACHING Exceptional Children*, *40*(1), 32–38.

Hussey, W. (2006). Slivers of the journey: The use of photovoice and story telling to examine female to male transsexuals' experience of health care access. *Journal of Homosexuality, 51*(l), 129-158.

Jones, M. (2007). An ethnographic exploration of narrative methodologies to promote the voice of students with disabilities. *Journal of Ethnographic & Qualitative Research, 2*, 32-40.

Jurkowski, J.M. (2008). Photovoice as participatory action research tool for engaging people with intellectual disabilities in research and program development. *Intellectual and Developmental Disabilities*, 46(1), 1–11.

Jurkowski, J. M., & Paul-Ward, A. (2007). Photovoice with vulnerable populations: Addressing disparities in health promotion among people with intellectual disabilities. *Health Promotion Practice*, *8*(4), 358-365.

Jurkowski, J. M., Rivera, Y., & Hammel, J. (2009). Health perceptions of Latinos with intellectual disabilities: the results of a qualitative pilot study. *Health Promotion Practice*.

Knox, M., Mok, M., & Parmenter, T. R. (2000). Working with the experts: Collaborative research with people with an intellectual disability. *Disability and Society, 15*, 49–61.

Koenig, O. (2012). Any added value? Co-constructing life stories of and with people with intellectual disabilities. *British Journal of Learning Disabilities*, *40*(3), 213-221.

Kramer, J. M., Kramer, J. C., García-Iriarte, E., & Hammel, J. (2011). Following through to the end: The use of inclusive strategies to analyze and interpret data in participatory action research with individuals with intellectual disabilities. *Journal of applied research in intellectual disabilities*, *24*(3), 263-273.

Langdon, J. L., Walker, A., Colquitt, G., & Pritchard, T. (2014). Using Photovoice to Determine Preservice Teachers' Preparedness to Teach. *Journal of Physical Education, Recreation & Dance*, *85*(1), 22-27.

Lachappelle, Y., Wehmeyer, M.L., Haelewyck, M.C., Courbois, Y., Keith, K.D., & Schalock, R. (2005). The relationship between quality of life and self-determination: An international study. *Journal of Intellectual Disability Research, 49*, 740-744. doi: 10.1111/j.1365-2788.2005.00743.x

Lemay R. (1995). Normalization and Social Role Valorization. In A. E. Dell Orto and R. P. Marinelli (eds), *Encyclopedia of Disability and Rehabilitation* (pp. 515-521). New York: Simon & Schuster Macmillan.

Lock, R.H. & Layton, C.A. (2001). Succeeding in postsecondary education through self-advocacy. *Teaching Exceptional Children, 34*(2), 66–71.

Mamary, E., McCright, J., Roe, K. (2007). Our lives: an examination of sexual health issues using photovoice by non-gay identified African American men who have sex with men. *Culture, Health, & Sexuality, 9*(4), 359-370.

Maxwell, J. A. (2013). *Qualitative research design: An interactive approach*. (3rd ed.). Thousand Oaks, CA: Sage.

McDonald, K. E., Keys, C., & Henry, D. (2008). The gatekeepers of science: Attitudes toward the research participation of adults with intellectual disabilities. *American Journal on Mental Retardation, 113*, 466–478.

McDonald, K. & Patka, M. (2012). "There is no black or white": Scientific community views on ethics in intellectual and developmental disability research. *Journal of Policy and Practice in Intellectual Disabilities, 9*(3), 206-214.

Miles, M. B., Huberman, A. M., & Saldaña, J. (2013). *Qualitative data analysis: A methods sourcebook*. Thousand Oaks, CA: Sage.

Mole, H. (2012). A US model for inclusion of disabled students in higher education settings: The social model of disability and universal design. *Widening Participation and Lifelong Learning, 14*(3), 62-86.

Neubert, D. A., & Moon, M. S. (2006). Postsecondary Settings and Transition Services for Students with Intellectual Disabilities: Models and Research. *Focus on Exceptional Children*, *39*(4), 1–8.

Neubert, D. A., Moon, M. S., & Grigal, M. (2004). Activities of students with significant disabilities receiving services in postsecondary settings. *Education and Training in Developmental Disabilities*, *39*(1), 16-25.

Neubert, D. A., Moon, M. S., Grigal, M., & Redd, V. (2001). Postsecondary Educational Practices for Individuals with Mental Retardation and other Significant Disabilities: A Review of Literature. *Journal of Vocational Rehabilitation*, 16, 155-168.

Nind, M. (2011). Participatory data analysis: a step too far?. *Qualitative Research*, *11*(4), 349-363.

Nind, M. & Seale, J. (2009). Concepts of access for people with learning difficulties: Towards a shared understanding, *Disability & Society* 24(3): 273-87.

Nirje, B. (1994). The normalization principle and its human management implications**.** *The International Social Role Valorization Journal*, *1*(2), 19-23.

Nonnemacher, S. L., & Bambara, L. M. (2011). “I’m supposed to be in charge”: Self-advocates’ perspectives on their self-determination support needs. *Intellectual and Developmental Disabilities*, *49*(5), 327–340. doi:10.1352/1934-9556-49.5.327

Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. (2007). Self-determination, social abilities and the quality of life of people with intellectual disability. *Journal of Intellectual Disability Research*, *51*(11), 850–865. doi:10.1111/j.1365-2788.2006.00939.x

O’Brien, P., Shevlin, M., O’Keefe, M., Fitzgerald, S., Curtis, S., & Kenny, M. (2009). Opening up a whole new world for students with intellectual disabilities within a third level setting. *British Journal of Learning Disabilities*, *37*(4), 285–292. doi:10.1111/j.1468-3156.2009.00584.x

Ottman, G., & Crosbie, J. (2013). Mixed method approaches in open-ended, qualitative, exploratory research involving people with intellectual disabilities: A comparative methods study. *Journal of Intellectual Disabilities*, *17*(3), 182-197. doi: 10.1744629513494927

Paiewonsky, M. C. (2005). *See what I Mean: Photovoice to Plan for the Future* (Doctoral dissertation). Retrieved from ProQuest Information and Learning Company.

Paiewonsky, M. (2011). Hitting the Reset Button on Education: Student Reports on Going to College. *Career Development for Exceptional Individuals*, *34*(1), 31–44. doi:10.1177/0885728811399277

Paiewonsky, M. (2014). See what I mean: Participatory Action Research with college students with intellectual disabilities. Boston, MA: Institute for Community Inclusion, University of Massachusetts Boston.

Paiewonsky, M., Sroka, A. Ahearn, M., Santucci, A., Quiah, G. Bauer, C., Fearebay, J., Wright, S., Chu, C. & Lee, W. (2010). Think, Hear, See, Believe College: Students Using Participatory Action Research to Document the College Experience. Think College Insight Brief, Issue No. 5. Boston, MA: Institute for Community Inclusion, University of Massachusetts Boston.

Papay, C. K., & Bambara, L. M. (2011). Postsecondary education for transition-age students with intellectual and other developmental disabilities: A national survey. *Education and Training in Autism and Developmental Disabilities*, *46*(1), 78–93.

Patton, M. (2002). *Qualitative research & evaluation methods.* Thousand Oaks, CA: Sage Publications.

Povee, K., Bishop, B. J., & Roberts, L. D. (2014). The use of photovoice with people with intellectual disabilities: Reflections, challenges and opportunities. *Disability & Society*, (ahead-of-print), 1-15.

Reason, P., & Bradbury, H. (Eds.). (2001). *Handbook of action research: Participative inquiry and practice*. Thousand Oaks, CA: Sage Publications.

Redd, V. (2004). *A public school-sponsored program for students ages 18 to 21 with significant disabilities located on a community college campus: A case study* (Doctoral dissertation). Retrieved from ProQuest Information and Learning Company.

*Reilly, R.C. (2013). Found Poems, Member Checking and Crises of Representation. The Qualitative Report, 18(30), 1-18.*

Rhodes S. & Hergenrather K. (2007). Recently arrived immigrant Latino men identify community approaches to promote HIV prevention. *American Journal of Public Health, 97*(6), 984-985.

Richards, L., & Morse, J. M. (2013). *Readme first for a user's guide to qualitative methods*. (3rd ed.). Thousand Oaks, CA: Sage Publications.

Rioux, M.H. (1997). Disability: The place of judgment in a world of fact. *Journal of Intellectual Disability Research, 41*(2), 102-111.

Sample, P. L. (1996). Beginnings: Participatory action research and adults with developmental disabilities. *Disability & Society*, *11*(3), 317-332.

Schleien, S. J., Brake, L., Miller, K. D., & Walton, G. (2013). Using Photovoice to listen to adults with intellectual disabilities on being part of the community. *Annals of Leisure Research*, *16*(3), 212-229.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, *22*(2), 63-75.

Silver, P., Bourke, A., & Strehorn, K. C. (1998). Universal instructional design in higher education: An approach for inclusion. *Equity and Excellence in Higher Education*, 31(2), 47–51.

Simons, H., & McCormack, B. (2007). Integrating arts-based inquiry in evaluation methodology opportunities and challenges. *Qualitative Inquiry*, *13*(2), 292-311.

Smagorinsky, P. (1995). The social construction of data: Methodological problems of investigating learning in the zone of proximal development. *Review of Educational Research*, *65*(3), 191-212.

Stalker, K. (1998). Some ethical and methodological issues in research with people with learning difficulties. *Disability & Society*, *13*(1), 5-19.

Stodden, R. A., Whelley, T., Chang, C., & Harding, T. (2001). Current status of educational support provision to students with disabilities in postsecondary education. *Journal of Vocational Rehabilitation*, *16*(3/4), 189.

Stone, E., & Priestley, M. (1996). Parasites, pawns and partners: disability research and the role of non-disabled researchers. *British Journal of Sociology*, 699-716.

Tatnall, A. (2014). A shared mission: Adult agencies and colleges working together to support lifelong learning. *Think College Insight Brief, 24*. Boston, MA: University of Massachusetts Boston,

Institute for Community Inclusion

Thoma, C. A., Lakin, K. C., Carlson, D., Domzal, C., Austin, K., & Boyd, K. (2011). Participation in Postsecondary Education for Students with Intellectual Disabilities: A Review of the Literature 2001-2010. *Journal of Postsecondary Education & Disability*, *24*(3), 175–191.

Tuffrey- Wijne, I., & Butler, G. (2010). Co- researching with people with learning disabilities: an experience of involvement in qualitative data analysis. *Health Expectations*, *13*(2), 174-184. doi: 10.1111/j.1369-7625.2009.00576

Turnbull, A. (July, 2013). *Enviable lives*: *A lifespan perspective on family and community partnerships*. [Presentation Video and Power Point slides]. Retrieved from https://www.osep-meeting.org/Keyvideos2013.aspx

Wallerstein, N., & Bernstein, E. (1988). Empowerment education: Freire's ideas adapted to health education. *Health Education & Behavior*, *15*(4), 379-394.

Walmsley J. (2001) Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society, 16*, 187–205. doi: 10.1080/09687590120035807

Walmsley, J. (2004). Inclusive learning disability research: The (nondisabled) researcher's role. *British Journal of Learning Disabilities*, *32*(2), 65-71.

Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures*. London: Jessica Kingsley Publishers.

Walton, G., Schleien, S. J., Blake, L. R., Trovato, C., & Oakes, T. (2012). Photovoice: A collaborative methodology giving voice to underserved populations seeking community inclusion. *Therapeutic Recreation Journal*, *46*(3).

Wandersman, A., Snell-Johns, J., Lentz, B. E., Fetterman, D. M., Keener, D. C., Livet, M., ... & Flaspohler, P. (2005). The principles of empowerment evaluation. *Empowerment evaluation principles in practice*, 27-41.

Wang, C., & Burris, M. A. (1994). Empowerment through photo novella: Portraits of participation. *Health Education & Behavior*, *21*(2), 171-186.

Wang, C. & Burris, M.A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior, 24(3)*, 369-387.

Wang, C., Burris, M. A., & Ping, X. Y. (1996). Chinese village women as visual anthropologists: A participatory approach to reaching policymakers. *Social Science & Medicine*, *42*(10), 1391-1400.

Wang, C. C., Morrel-Samuels, S., Hutchison, P. M., Bell, L., & Pestronk, R. M. (2004). Flint photovoice: Community building among youths, adults, and policymakers. *American journal of public health*, *94*(6), 911.

Wang, C., Yi, W., Zhan, W., & Carovano, K. (1998). Photovoice as a participatory health promotion strategy. *Health Promotion International*, *13*(1), 75-86.

Ward, K., & Trigler, J. S. (2001). Reflections on participatory action research with people who have developmental disabilities. *Journal Information*, *39*(1).

Wehmeyer, M. L., Agran, M., & Hughes, C. (2000). A national survey of teachers' promotion of self-determination and student-directed learning. *Journal of Special Education, 34(2)*, 58–68.

Wehmeyer, M., Bersani, Jr., H., & Gagne, R. (2000). Riding the third wave. *Focus on Autism & Other Developmental Disabilities*, *15*(2), 106.

. Weir, C., Grigal, M., Hart, D. and Boyle, M. (2013). *Profiles and Promising Practices in Higher Education for Students with Intellectual Disability.* Think College. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

Williams V. (1999) Researching together. *British Journal of Learning Disabilities 27*, 48–51.

Wolfensberger, W. (2002). Social role valorization and, or versus, "empowerment". *Mental Retardation*, *40*(3), 252-258.

Wolfensberger, W. (2011). Social role valorization: A proposed new term for the principle of normalization. *Intellectual and developmental disabilities*, *49*(6), 435-440.

Woolrych, R. (2004). Empowering images: Using Photovoice with tenants with special needs. *Housing, Care and Support*, *7*(1), 31-36.

Yin, R. K. (2014). *Case study research: Design and methods*. Los Angeles, CA: Sage publications.

Zafft, C., Hart, D., & Zimbrich, K. (2004). College Career Connection: A Study of Youth with Intellectual Disabilities and the Impact of Postsecondary Education. *Education & Training in Developmental Disabilities*, *39*(1), 45–53.

Zarb, G. (1992). On the road to Damascus: First steps towards changing the relations of disability research production. *Disability, Handicap and Society, 7*, 125-138.

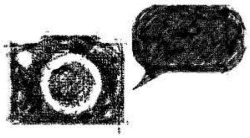
# Appendix A

## *Weekly Research Reflection Checklist*

Research Reflection Checklist

Name (if you WANT): ________________________________________

1. I like being in the photo research project.



| | | |
|---|---|---|
| 3 | 2 | 1 |
| Yes ☺ | Sort of 😐 | No ☹ |

WHY? ____________________________________________________________________________

2. I am able to make choices in the project.

| | | |
|---|---|---|
| 3 | 2 | 1 |
| Yes ☺ | Sort of 😐 | No ☹ |

WHY? ____________________________________________________________________________

3. I understand what we are doing in the project

| | | |
|---|---|---|
| 3 | 2 | 1 |
| Yes ☺ | Sort of 😐 | No ☹ |

I need help with ______________________________________________________________________

4. I think we should: ______________________________________________________________

# Appendix B

*Adapted SHOWED (Paiewonsky, 2005 adapted from Wallerstein & Bernstein, 1988 and Wang & Burris, 1997)*

| Adapted SHOWED Protocol | | | | | | |
|---|---|---|---|---|---|---|
| S | What do you **S**ee? | What is this picture of? | When you look at this picture, what does it make you think about? | | | |
| H | What is really **H**appening here? | What is going on in this picture? | Why did you take this picture? | Explain what made you take this picture? | What were you thinking about when you took this picture (that made you take it?) | Who is in the picture and where was it taken? |
| O | How does this relate to **O**ur lives? | When you look at this picture how does it make you think about the program/college? | What does this picture mean to you? | What are you trying to tell people about or show people with this picture? | How could this image Educate others? | |
| W | **W**hy does this situation (problem or strength) exist? | What made you want to take this picture? | Why is this picture important for you to take and for others to look at? | | | |
| E | How could this image **E**ducate others (peers, community members, staff members)? | What could this picture teach other people? | What do you want people to learn about you from looking at this picture? | | | |
| D | What can we **D**o about it? | What is one thing that this picture makes you think about doing? | What does this picture make you want to do? | What do you think people who look at this picture could do to help? | What are some suggestions you could make to others who look at this picture? | |

## Appendix C

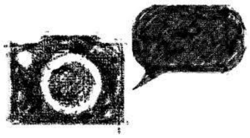
### *Co-Researcher Final Questionnaire*

Thank you for participating in the photo research project! Please answer some questions about our work over the past semester. Circle the number to rate each part of the Photo Research Project.

1. Learning about the project and about doing research.

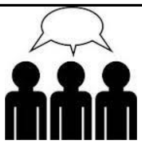
| | | |
|---|---|---|
| 3 | 2 | 1 |
| Helpful ☺ | Sort of Helpful 😐 | Not Helpful ☹ |

2. Going out on your photo missions and taking pictures to describe your college experience.



| | | |
|---|---|---|
| 3 | 2 | 1 |
| Helpful ☺ | Sort of Helpful 😐 | Not Helpful ☹ |

3. Discussing your photos to identify themes.



| | | |
|---|---|---|
| 3 | 2 | 1 |
| Helpful ☺ | Sort of Helpful 😐 | Not Helpful ☹ |

4. Making decisions about what to do next in the photo research project.

| | | |
|---|---|---|
| 3 | 2 | 1 |

Helpful ☺ Sort of Helpful 😐 Not Helpful ☹

---

5. Planning the photo show.

3 2 1
Helpful ☺ Sort of Helpful 😐 Not Helpful ☹

---

6. Sharing your pictures at the photo show.

3 2 1

Helpful ☺ Sort of Helpful 😐 Not Helpful ☹

---

7. Interviewing with Diane about the program and the project.

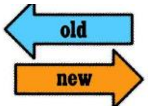
3 2 1

Helpful ☺ Sort of Helpful 😐 Not Helpful ☹

---

8. What was the **best** part of being in the photo research project? ☺

9.  What was the **worst** part of being in the photo research project?  ☹ or something you would **change**?



11. Is there anything else you want to share about the photo research project?

# Appendix D
## *Questionnaire for Attendees at Dissemination*

**Welcome to the T.A.P. PHOTO GALLERY: PREMIER SHOWING**

Students from UC's new **T**ransition and **A**ccess **P**rogram (TAP is a four year non-degree program for students with intellectual disability) have been engaged as co-researchers in a photovoice project documenting their college experience. Thank you for coming today to see their work. After attending their presentations, please answer the following questions regarding what you think about today's photo showcase. Thank you!

1. What is your interest in the University of Cincinnati's Transition and Access Program (TAP)?
    a. Employee
    b. Friend of participant
    c. Interested bystander
    d. Other (please indicate)______________________________

2. If you are currently employed by the University of Cincinnati please describe your role.
    a. I am not an employee of the University of Cincinnati
    b. Faculty member
    c. Undergraduate student
    d. Graduate student
    e. Administrator
    f. Support staff
    g. TAP staff
    h. Other (please indicate) ______________________________

3. Did you learn anything from the photo showcase that was new to you?

4. Did you notice any themes (common idea or categories) among the TAP students' photos? If so, explain.

5. How has your perspective regarding TAP or the TAP students changed after viewing the photos in the showcase?

6. Indicate how valuable you think the photos and information presented by the TAP students will be in informing on-going TAP program evaluation? (circle your response and provide a brief explanation)

| | | | | | |
|---|---|---|---|---|---|
| NOT<br>valuable at all | | | SOMEWHAT<br>valuable | | VERY<br>valuable |
| 0 | 1 | 2 | 3 | 4 | 5 |

    Explain:

7. Do you have any other reactions or suggestions regarding today's photo showcase you would like to share?

# Appendix E

*Staff Questionnaire*

Thank you for your attention during my presentation today. As I mentioned, one of my research questions was:

**How can photovoice data inform ongoing evaluation for this specific program?**

Data regarding ongoing program evaluation is critical and aligns with Think College Standards for inclusive higher education. Specifically, standard which states:

STANDARD 8: ONGOING EVALUATION

To facilitate quality postsecondary education services for students with intellectual disabilities, the comprehensive post-secondary program should:

Quality Indicator 8.1: Conduct evaluation of services and outcomes on a regular basis, including:

8.1A: Collection of data from key stakeholders, such as students with and without disabilities, parents, faculty, disability services, and other college staff.

---

Based on today's presentation, please answer the following questions:

1. Which of the following best describe your role(s) with TAP

    a. Administrative
    b. Academic peer mentor
    c. Social mentor
    d. Other (please indicate) ________________________________

2. What did you learn from the students' photo presentations today?

3. What did you learn from the data analysis presented today?

4. How might the data presented inform ongoing program evaluation?

5. Do you think utilizing the photovoice process could be valuable in informing on-going program evaluation? Circle the response that best describes your perspective and explain why.
    a. Data from the photovoice process ***does not seem valuable*** for program evaluation. Explain.

    b. Data from the photovoice process ***seems somewhat valuable*** for program evaluation. Explain.

    c. Data from the photovoice process ***does seem valuable*** for program evaluation. Explain.

# Appendix F

## *Interview Questions*

**Directions to participants**: Thank you for coming today. As always, I want to confirm that you still want to participate in the photo group research project and in this interview. I would like to ask you a few questions about your college experience and then what you thought about being a part of the photo group research project. With your permission, I will tape record our conversation so that I can review it later. If I ask you any questions that you do not want to answer, please feel free to tell me so. The interview will last about 20-30 minutes.

1. First I want you to tell me what you think about being in TAP

2. What is helping you?

3. What is not helping you?

4. What do you like most about college?

5. What do you like least about college?

6. Now I would like you to tell me what you thought about being in this photo research project.

7. What was helpful?

8. What was not helpful?

9. What did you like most about being a part of this project?

10. What did you like least about being a part of this project?

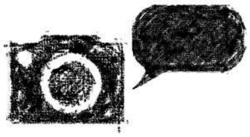
*Question prompting protocol will be followed (need to add-basically two prompts per question if participant does not understand, then question will be skipped)

# Appendix G

*Research Invitation*

## YOU are INVITED to be a part of TAP PHOTO RESEARCH GROUP

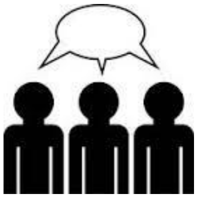
**What we are looking for:**



- Students who like taking pictures
- Students who want to learn more about research and have the chance to be a partner in a research project

**research partners**

- Students who want the chance to *share* their *college experience* with others?



**What you will do:**

- Take pictures about your college experience
- Meet every week during the fall semester of 2014 with Diane Clouse and a few of your peers on Tuesdays at 7pm to share and discuss your photos and the project
- Have the chance to share your pictures and ideas with others

**How do you sign up?**

- To learn more contact DIANE CLOUSE at 937-272-6671 or clousede@mail.uc.edu
- **Please note: only *6 people* will be randomly* chosen to participate**

*This means even if you want to participate you may not be picked.

- First meeting: TUESDAY SEPTEMBER 16th at 7pm

# Appendix H
## *Consent Form for Participant with Intellectual Disability*

**Adult Consent Form for Research**
**University of Cincinnati**
**Department:** CECH Division of Special Education
**Principal Investigator:** Diane Clouse
***Faculty Advisors:*** Anne Bauer, Steve Kroeger, and Lisa Vaughn

**Title of Study:** See Our Perspective: Using Photovoice to Document Students' College Experiences

**Introduction:**

You are being asked to take part in a study. Please read this paper and ask questions about things you do not understand.

**Who is doing this research study?**

The person in charge of this research study is Diane Clouse, a college student at the University of Cincinnati (UC). Anne Bauer, Steve Kroeger, and Lisa Vaughn professors at UC, are helping her. There may be other staff from TAP helping at different times during the study too**.**

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

The purpose of this study is help TAP students document their college experience.

**Who will be in this research study?**

About 12 people will take part in this study.

**What will you be asked to do in this research study?**

You will be asked to do the following:

| **Activity** | **Time required** | **What you will do** |
|---|---|---|
| Meet with Diane Clouse and other group members | About 1 hour every Tuesday for about 10 weeks | Meet weekly for about an hour from September to December 2014. See the attached weekly agendas for photo group meetings. |
| Take photos and talk about them. | Will vary | Take photos to share what you think about college and talk about your photos with the photo group. |
| Share with others | About 2 hours | You will have the chance to share your photos with your friends and other people interested in our program. |
| Final interview and survey with Diane Clouse | About 1 hour | You will complete a survey and interview with Diane at the end of the photo group meetings to share what you think about the program and what you thought about doing this study. Diane will write a poem for you based on what you share in the interview to make sure she understood what you shared. |

Other facts about you may be written down. Things like your age, if you are a boy or girl, where you are from, and other facts describing you.

**Are there any risks to being in this research study?**

Helping in this study should not change your daily life in TAP. If you want to talk to someone because part of this study makes you feel upset, you can tell Diane Clouse or any other TAP staff. If you don't want to help in the study, you will still be in TAP.

**Are there any benefits from being in this research study?**

By helping in the study, you may enjoy taking pictures and thinking about your college program.

**What will you get because of being in this research study?**

You will not be paid for helping in this study.

**Do you have choices about taking part in this research study?**
If you do not want to help in this study you do not have to. If you don't want to help in the study, you will still be in TAP.
You have a choice whether or not you would like your interviews to be video taped. There is a place at the end of this paper to mark your choice.

**Will your information be shared with other people?**
No. Your name will not be used in the study. You will be given a pretend name so no one will know who you are. Information from the study will be saved to a on a flash drive, Dropbox file, or stored in a locked file. Any tapes of the interviews will be erased as soon as the information is typed up. The pictures taken belong to you. Diane will use her copies to learn about your experience and may describe them in her study. She will not print copies of the pictures or share with anyone else without your permission. Any audiotapes of the interviews or group meetings will be erased as soon as the interview information is typed up.

The information from the study will be kept in a locked file for up to three years. Then any papers or pictures will be cut up; files deleted, and flash drive destroyed. What is learned from this study may be printed in an educational magazine, but your name or pictures will not be shared without your permission.

People who work for the University of Cincinnati may look at information from the study to make sure all of the UC rules are followed.

Diane Clouse will ask staff involved in the study not to talk about it with anyone, but they might talk about it anyway.

Diane Clouse cannot promise that information sent by the Internet or email will be not seen by other people.

**What are your legal rights in this research study?**
You do not give up any legal rights by signing this form. The researcher, Diane Clouse, and UC are still responsible for their actions if they treat you unfairly.

**What if you have questions about this research study?**
If you have any questions or concerns about this research study, you should contact Diane Clouse at clousede@mail.uc.edu or 937-272-6671.

The UC Institutional Review Board reviews all research projects that involve human participants to be sure the rights and welfare of participants are protected.

If you have questions about your rights as a participant or complaints about the study, you may contact the UC IRB at (513) 558-5259. Or, you may call the UC Research Compliance Hotline at (800) 889-1547, or write to the IRB, 300 University Hall, ML 0567, 51 Goodman Drive, Cincinnati, OH 45221-0567, or email the IRB office at irb@ucmail.uc.edu.

**Do you HAVE to take part in this research study?**
No one has to be in this study. You will NOT get in trouble if you do not want to help. If you don't want to help in the study, you WILL still be in TAP. You may start and then change your mind and stop at any time. To stop being in the study, you should tell Diane Clouse.

**Agreement:**
Oral presentation of the consent was given to the participant, who may not have been able to fully comprehend the

written consent by reading it independently. By signing, I certify that the oral presentation was consistent with this written document.

____________________________________________________________________
Impartial Witness Signature (oral presentation only) Date

I have read this information and had all my questions answered. By signing this form I am consenting to:
☐ participating in the weekly group meetings
☐ ask permission before taking photos of people and follow other picture taking guidelines discussed
☐ allowing some group meetings to be audiotaped or videotaped
☐ Diane or research assistants taking notes during group meetings
☐ having my interview audiotaped and the transcripts transcribed
☐ allowing results of the process to be written up for a study

By checking the box in front of each item, I am agreeing to participate in that procedure and by signing below I agree to participate in this study. I will receive a copy of this signed and dated consent form to keep. I understand that I may withdraw my consent at any time, for any reason.

Participant Name (please print) ____________________________________________

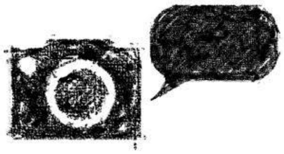
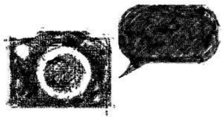
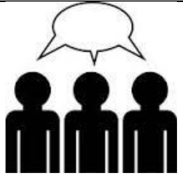
Participant Signature ____________________________________________Date _______

Signature of Person Obtaining Consent ______________________________Date _______

## Appendix I

*Pictorial Consent Form for Participants with Intellectual Disability*

Consent form with pictures

| | |
|---|---|
| <br>Be part of a Photo Research Project | You have been asked to take part in a photo research project. |
|  <br>Meet every week on Tuesday at 4pm | We will meet every week during the fall term. |
| <br>Take pictures | You will be taking pictures to describe your college experience. |
|  <br>Ask permission | You need to ask before taking pictures of people. You also need to ask before sharing your pictures with others. |
| <br>Discuss and analyze your photos | You will pick some of your pictures to share. Then you can talk about them with others in the project. |
| Share your  photos | You will be able to share your pictures with other people interested in learning about TAP. |
| | You will answer questions about what you think |

| | |
|---|---|
|  Answer a survey | about college and being a part of the project. |
|  Interview | You will talk to Diane to tell her what you think about college. You can also tell her what you think about being a part of the project. She will tape record the interview. |
|  Receive a poem | Diane will write a poem about what you shared to make sure she understood you. |
|  Remove pictures and files | You can throw away any pictures you don't want. Diane will throw away her copies of the pictures and files from the project in three years. |
|  Get a gift | You will receive a "thank you" gift from Diane. |
|  Diane Clouse<br>937-272-6671 or<br>clousede@mail.uc.edu | You can tell Diane or any of the TAP staff at anytime you don't want to be in the project any more. |
|  Publish | Diane may write about this project in an educational journal. She will not use anyone's "real" names and will only use photos that you say are ok. |

# Appendix J

## *Consent form for Support Peers*

**Adult Consent Form for Research**
**University of Cincinnati**
**Department:** CECH Division of Special Education
**Principal Investigator:** Diane Clouse, M.Ed.
**Faculty Advisors:** Anne Bauer, Ed.D., Steve Kroeger, Ed.D, and Lisa Vaughn, Ph.D.

**Title of Study:** Visualize Our Perspective: Using Photovoice to Document Students' College Experiences

**Introduction:**
You are being asked to take part in a research study. Please read this paper carefully and ask questions about anything that you do not understand.

**Who is doing this research study?**
The person in charge of this research study is Diane Clouse, a doctoral candidate in the University of Cincinnati (UC) Department of Special Education. Anne Bauer, Ed.D, Steve Kroeger, Ed.D., and Lisa Vaughn, Ph.D., professor at UC, are guiding her in this research. There may be other people on the research team helping at different times during the study**.**

**What is the purpose of this research study?**
The purpose of the study is to document, describe, and analyze the perceptions of students with intellectual disability regarding the post secondary educational program they are enrolled in through the use of photographs, interviews, questionnaires, and focus groups.

**Who will be in this research study?**
About 12 people will take part in this study.

**What if you are an employee where the research study is done?**
Taking part in this research study is not part of your job. Refusing to be in the study will not affect your job. You will not be offered any special work-related benefits if you take part in this study.

**What will you be asked to do in this research study, and how long will it take?**
You will be asked to assist TAP students while they are taking photos for the study. The dates and times of these photo sessions will be determined based on your personal schedule. This may involve explaining the study or getting permission from people TAP students want to take pictures of. You may also need to remind TAP students about taking appropriate photos. Photos may be taken in multiple settings on or off UC campus based on the TAP student's academic, vocational, and social schedule. You will also be asked to participate in weekly focus group meetings by attending or taking notes to document TAP students perspectives. The study will last about 12 weeks. Focus group meetings will be weekly for about one hour. You will also be invited to attend a final dissemination where the TAP students will share their photos with others.

**Are there any risks to being in this research study?**
It is not expected that you will be exposed to any risk by being in this research study.

**Are there any benefits from being in this research study?**
You will probably not get any direct benefit because of being in this study. But, being in this study may help you better understand the perspectives of TAP students and the impact the program is having on them. You will also gain experience in being part of a participatory research study involving participants with intellectual disability.

**What will you get because of being in this research study?**
You will be given a $100 gift card or equivalent compensation for taking part in this study.

**Do you have choices about taking part in this research study?**
If you do not want to take part in this research study you may simply not participate.

**How will your research information be kept confidential?**
Information about you will be kept private because your input will remain anonymous. Information from the study will be saved to a on a flash drive, Dropbox file, or stored in a locked file.

The data from the study will be kept for up to three years. Then any papers or photos will be cut up, files deleted and the flash drive destroyed. What is learned from this study may be printed in an educational magazine, but your name will <u>not</u> be shared.

Agents of the University of Cincinnati may inspect study records for audit or quality assurance purposes.

The researcher will ask people to keep any information confidential, but they might talk about it anyway.

The researcher cannot promise that information sent by the internet or email will be private.

**What are your legal rights in this research study?**
Nothing in this consent form waives any legal rights you may have. This consent form also does not release the investigator, Diane Clouse, the institution, or its agents from liability for negligence.

**What if you have questions about this research study?**
If you have any questions or concerns about this research study, you should contact Diane Clouse at clousede@mail.uc.edu.

The UC Institutional Review Board reviews all research projects that involve human participants to be sure the rights and welfare of participants are protected.

If you have questions about your rights as a participant or complaints about the study, you may contact the UC IRB at (513) 558-5259. Or, you may call the UC Research Compliance Hotline at (800) 889-1547, or write to the IRB, 300 University Hall, ML 0567, 51 Goodman Drive, Cincinnati, OH 45221-0567, or email the IRB office at irb@ucmail.uc.edu.

**Do you HAVE to take part in this research study?**
No one has to be in this research study. Refusing to take part will NOT cause any penalty or loss of benefits that you would otherwise have.

You may start and then change your mind and stop at any time. To stop being in the study, you should tell Diane Clouse at clousede@mail.uc.edu.

**Agreement:**
I have read this information and have received answers to any questions I asked. I give my consent to participate in this research study. I will receive a copy of this signed and dated consent form to keep.

Participant Name (please print) ____________________________________________
Participant Signature ______________________________________________ Date _______
Signature of Person Obtaining Consent _____________________________ Date _______

# Appendix K

## *Ongoing Consent Sign in Sheet*

Date:______________________

I am here at the Photo Group Meeting and, by writing or signing my name below, I am confirming I still want to be part of this research project.

________________________________ ________________________________

________________________________ ________________________________

________________________________ ________________________________

________________________________ ________________________________

________________________________ ________________________________

## Appendix L
### *Interviewing People with Intellectual Disability*

| Strategies and accommodations to design interviews with participants with intellectual disability identified in the literature | Application to the study |
|---|---|
| Select a setting (or allow participant to select setting) that is familiar, convenient, and comfortable for participant (Azmi eta al, 1997; Hall, 2013; Knox et al., 2000; McDonald & Patka, 2012). | Interviews will be scheduled in the social group house where participants were familiar with and frequently socialize. Researcher will be open to room change based on participant suggestion and availability of space. |
| Determine if presence of support persons or family members is desired or necessary for support or data triangulation (Azmi eta al, 1997; Hall, 2013), but be aware of their role or influence on participant response (McDonald & Patka, 2012). | All participants in this study are legal guardians of themselves. All participants are living independently on the college campus. Support persons of the program will not be included in the interviews as all participants are able to communicate verbally and have already established a relationship with researcher. |
| Setting should be quiet with minimal distractions and provide some privacy for participant but yet enough visibility to protect integrity of interviewer and participant (i.e. conference room with door open) (Hall, 2013) | Room in building is utilized as a study area or quiet social area, similar to a library setting. |
| Provide options for multiple means of expression during interview (write, draw, or act out response) and any other accommodations to support effective communication (Finlay & Lyons, 2001; Hall, 2013; McDonald & Patka, 2012) | Participants will be asked to respond orally, but given the option to respond in a different means if preferred. |
| Build rapport by meeting participants before first interview session to explain study by meeting on multiple occasions (Hall, 2013; Mactavish et al., 2000) and, if possible, provide materials in advance (McDonald & Patka, 2012). | Relationship with participants is established and we have been meeting for 12 weeks at point of interview. Consent forms (providing an overview of their role in the study and purpose of interviews) will be given to participants prior to signing consent and prior to interviews. |
| Schedule two different dates to meet in case interview is not completed in one session (Hall, 2013) | Meetings will be schedule in advance with participants based on their schedules. |

| | |
|---|---|
| Begin interview with personal discussion to get to know participant (help build rapport) and encourage them to relax (Hall, 2013) | Interviews will begin with small talk about their day or other known topic of interest to help participant relax. |
| Explain questioning protocol to participants (Hall, 2013) and emphasize that the goal is to gain the participant's perspective (McDonald & Patka, 2012). | Goals and interview questions will be printed for participant in simple language and explained orally. PI will also explain how she may be asking questions to better understand what they are saying as well as repeating what she heard for clarification. |
| Use a semi-structured interview script that includes open-ended questions to provide structure, but yet create a comfortable atmosphere that supports dialogue to disclose experiences (Azmi et al., 1997; Hall, 2013). Question sequencing may depend on participant response (Azmi et al., 1997). | Following an interview script, participants will be asked open-ended questions based on the goals of the interview followed up with wait time, repeating the question, providing examples, or re-directing questions for clarification as needed. |
| Determine how much effort will be put into supporting participant in providing answers and provide adequate processing time between questions (Finlay & Lyons, 2001; Hall, 2013; McDonald & Patka, 2012) | Following a questioning prompting protocol, Researcher will provide 2 prompts to support participant in understanding or answering a question. If these strategies are not successful then researcher will move on to next question. Researcher may repeat another variation of a question later on in the interview if she feels the participant may be able to more successfully answer the question at that point. Researcher wants to avoid frustration or boredom on part of participant (Hall, 2013) |
| Build rapport with participant by showing interest in their responses (Hall, 2013) | Researcher will make eye contact and focus on participant as they are responding. |
| Use simple language and state questions in an understandable way using as few words as possible (Azmi et al., 1997; Finlay & Lyons, 2001; Hall, 2013) | Questions will use as few words as possible and use simple language to meet needs of participants. |
| Avoid leading questions (Finlay & Lyons, 2001) | Following a questioning prompting protocol designed to solicit participant input and asking open-ended questions will avoid use of leading questions. |
| Use visual aids or manipulatives to help with comprehension of questions and concepts (Hall, 2013) | A printed copy of questions will be provided and additional visual aids can be if necessary based on participant needs during |

| | |
|---|---|
| | interview or interview rescheduled and redesigned to address those needs. |
| Ask more probing questions based on participants initial response if a more comprehensive response is desired (Hall, 2013) | Researcher will provide redirecting “W” questions (who, what, where, when, why) to prompt a more comprehensive response or if further clarification is necessary. |
| Ask the same question in multiple ways or rephrase to increase participant understanding, minimize acquiescent responses, and strengthen accuracy of data (Azmi et al., 1997; Hall, 2013) | Researcher will repeat a question with an example or rephrase a question to support participant in understanding or answering a question |
| Rephrase questions if needed (Hall, 2013) | Researcher will rephrase a question to support participant in understanding or answering a question |
| Provide concrete examples to help participants understand concepts (Hall, 2013), but be aware that some may be used in participant’s response (Finlay & Lyons, 2001) | Researcher will repeat a question with an example, rephrase questions as necessary, or provide redirecting “W” questions (who, what, where, when, why) |
| Use multiple probing questions in multiple contexts when needed to obtain more information or more in-depth responses or to clarify responses given (Hall, 2013) | Researcher will provide 2 prompts to support participant in understanding or answering a question. If these strategies are not successful then researcher will move on to next question. Researcher may repeat another variation of a question later on in the interview if she feels the participant may be able to more successfully answer the question at that point. |
| Present issues that are easy for participants to respond to or of relevance to them and words that are common to them (Hall, 2013; Finlay & Lyons, 2001; Knox et al., 2000). | Interview questions involve participant’s current experiences in college and their recent participation in this research project so they should be very familiar with the topic. |
| Begin with more concrete concepts first and then move to more abstract ideas. (Hall, 2013) | Questions will all be related to participant’s current experiences. |
| When asking about more abstract concepts, interviewers should provide examples and then ask participant to state their understanding. This will clarify comprehension and also provide interviewer with vocabulary to use that participant relates to (Hall, 2013). | Researcher will provide 2 prompts to support participant in understanding or answering a question. Once participant provides an answer, researcher will repeat her interpretation of what she heard from the participant for clarification. |

| | |
|---|---|
| Provide time at the beginning of successive interviews to review and clarify data from previous sessions (check for inaccuracies or misinterpretations) and determine how this information will be presented (read transcripts or provide pictures or graphic organizers) (Azmi eta al, 1997; Hall, 2013; Jones, 2007) | Researcher plans for only one interview and member checking will be presented via found poem (Reilly, 2013). |
| Keep interview sessions brief (~30-60 minutes); be flexible in session duration and number of sessions; and provide breaks as needed to accommodate needs of participants (Azmi eta al, 1997; Hall, 2013; McDonald & Patka, 2012). | Interview sessions will be schedule for one half hour but researcher will be flexible and accommodate the needs of the participant. |
| Be cognizant of non-verbal signals or slower, shorter responses that may indicate participant needs a break or the session needs to end (Hall, 2013). Also, review with participants how they can request a break or end a session if needed (Hall, 2013). | Researcher will watch for signs of stress or behaviors that indicate participant may need a break. Researcher will also periodically ask participant if they need a break and discuss ways they can request a break or stop the session if needed. |
| Include participants in changes during research process to incorporate their ideas and experiences (Hall, 2013) and ask for their feedback about how to improve the process or make it easier for participants (McDonald & Patka, 2012). | Researcher will solicit participant input in all aspects of this study as part of the inclusive, participatory design. |
| Interviewers should resist sharing personal ideas or understandings to minimize impact on participant response (Hall, 2013) | PI will not provide personal ideas during interview. |
| Audiotape transcribe interviews (Hall, 2013) | All interviews with be audiotaped and transcribed. |
| Obtain feedback regarding interview protocol from other professionals in the field of special education (Hall, 2013) | Interview protocol will be reviewed by PIs doctoral committee. |

# Appendix M
## *Found Poems*

**CBAGGS**
**"Confident Friend"**

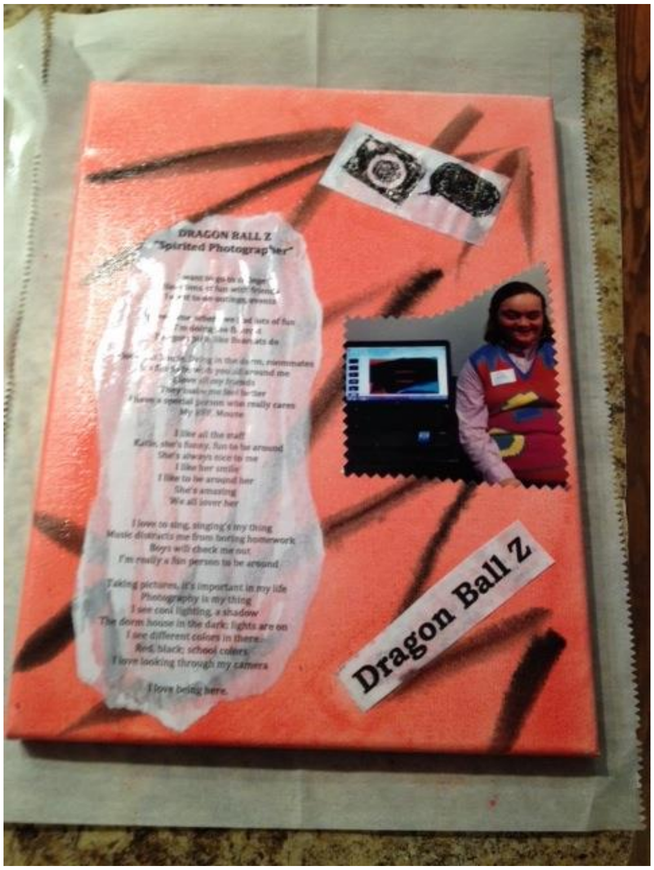
I want to show kids what I'm made of
I like modeling
I like to smile
I like to take pictures of myself

I'm spirited
I was voted 'most spirited' over 470 students
Bearcats are cool
It gets me out, going to more activities
So I'm not cooped up in the house

Having awesome friends who care about me
I love Dragon Ball Z
She's taught me ways to be with friends
Mouse is like a second sister to me
I am helpful when my friends are down

Meeting new people outside of TAP
Hanging around, social group, homework
Relaxation, studying, peace and quiet

Go to college, learn more
People will say 'oh you can't go to college'
Look at us now we are in college
We can do whatever the other UC students can do
It doesn't matter who you want to be,
Just do it!
Keep Calm and Just Dance!



DRAGON BALL Z
"Spirited Photographer"

[illegible]

[illegible]

[illegible] living in the dorm, roommates
[illegible] around me
I love all my friends
They make me feel better
I have a special person who really cares
[illegible]

I like all the staff
Katie, she's funny, fun to be around
She's always nice to me
I like her smile
I like to be around her
She's amazing
We all lover her

I love to sing, singing's my thing
Music distracts me from boring homework
Boys will check me out
I'm really a fun person to be around

Taking pictures, it's important in my life
Photography is my thing
I see cool lighting, a shadow
The dorm house in the dark: lights are on
I see different colors in there
Red, black: school colors
I love looking through my camera

I love being here.

[illegible]
[illegible]

Classes
Getting homework done
Academic mentors, helping in different ways
Calm you when you're stressed
Professors, help you if you don't understand

Dorm
Live and experience living independent
Laundry, chores
Shopping for items you need
Living with best friends, like my sisters and brothers

Activities
Going to sporting events
Football games, soccer games
T-shirts, support the team
Show spirit, I love going

Friends
Meeting new people
Excited, glad
Hangout, walk

College
Living independently
Being successful

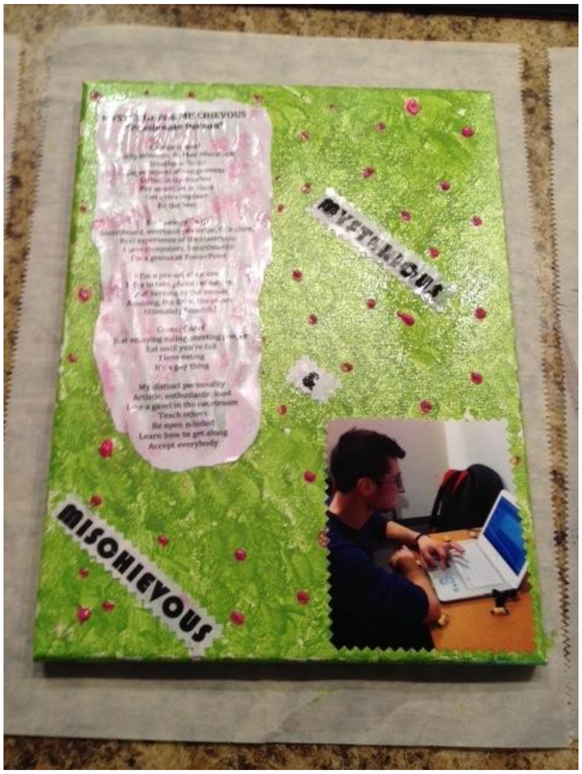
MOUSE
"Delightful Soul"

College
Taking classes
Being with mentors
Having help from staff
Doing homework, too much homework

Having friends
Having a boyfriend
Hanging out
At the Bearcat game
School spirit
Being silly and fun

Drinking Coffee
Starbucks
I love coffee
Wake up, warm up
Feel energized

Inspirational
Different, unique
Someone Special


MYSTERIOUS
&
MISCHIEVOUS


RICKY
"Determined Advocate"
RICKY
Need to explore the whole kingdom
A chance to grow, be free
Many do not know what it is to be in our shoes
They grew up with no condition
Regular school, regular kids, regular social events
We're not 'learning disabled'
We're highly functioning individuals with different exceptionalities
People are just ignorant
Just need accepted for who we are
Tell them
I run this, not you
No matter where you are from
If you have to go far to achieve something
Just do it

SIMONE
"Balanced Achiever"

College
Isn't as scary as you think
Come in with low expectations
Seeing something completely different

Classes, homework, books, degrees
I like to do stuff different
Put my own spin on things
Strive for more
But not too much to get overworked

Balance
social life
Take a break, have some fun
Have fun AND learning

Done
Meet people
Get welcomed to college
A good place to get adjusted
Interact with people my own age, hang out
Don't see ability, just a person

SIMONE

Strive for something bigger than what everyone is telling us
Bigger, taller, confident
Leave a mark on the way
Strive to be bigger and achieve more

We're different or unique
We're not tied down to what everybody thinks of us
People like us can have a business
We're just like everyone else
We just do it at a different speed

Strive for what we can see
Strive for the goals we set
Not what everybody expects for us

Better to go after what you're searching
Than just sitting by
Go out and grab what you want

# Appendix N

## *I.R.B. Approval*

**Institutional Review Board - Federalwide Assurance #00003152**

**University of Cincinnati**

Date: 12/6/2013

From: UC IRB Committee

To: Principal Investigator: Diane Clouse
CECH Educ Criminal Justice & Human Srvcs

Re: Study ID: 2013-7728
Study Title: Empowerment Evaluation: Using Photovoice in a Participatory Qualitative Design to Document Students with Intellectual Disabilities' Perception of their Post-Secondary Experience

The Institutional Review Board (IRB) acknowledges receipt of the above referenced proposal. It was determined that this proposal does not meet the regulatory criteria for research involving human subjects (see below). Ongoing IRB oversight is not required.

Consent form for TAP participants: The document seems complex and may not be appropriate for students with rather limited academic skills. The IRB does not require use of an informed consent document for this project. If one is used, however, the IRB recommends that it be simplified significantly to be more appropriate for this population. All reference to consent, research and research study should also be removed, and replaced by other non-research words such as agreement, project, etc.

Consent form for peer supporters: The IRB does not require use of an informed consent document for this project. If one is used, however, all reference to consent, research and research study should also be removed, and replaced by other non-research words such as agreement, project, etc.

**Please note the following requirements:**

**AMENDMENTS: The principal investigator is responsible for notifying the IRB of any changes in the protocol, participating investigators, procedures, recruitment, consent forms, FDA status, or conflicts of interest.** Approval is based on the information as submitted. New procedures cannot be initiated until IRB approval has been given. If you wish to change any aspect of this study, please communicate your request in writing to the IRB providing a justification for each requested change.

Statement regarding International conference on Harmonization and Good clinical Practices. The Institutional Review Board is duly constituted (fulfilling FDA requirements for diversity), has written procedures for initial and continuing review of clinical trials: prepares written minutes of convened meetings and retains records pertaining to the review and approval process; all in compliance with requirements defined in 21 CFR Parts 50, 56 and 312 Code of Federal Regulations. This institution is in compliance with the ICH GCP as adopted by FDA/DHHS.

*Thank you for your cooperation during the review process.*

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**45 CRF § 46.102(d):** Research means a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge.

**45 CRF § 46.102(f):** Human subject means a living individual about whom an investigator (whether professional or student) conducting research obtains:

1. data through intervention or interaction with the individual, or
2. identifiable private information.

**Intervention** includes both physical procedures by which data are gathered (for example, venipuncture) and manipulations of the subject or the subject's environment that are performed for research purposes.

**Interaction** includes communication or interpersonal contact between investigator and subject.

**Private information** includes information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place, and information which has been provided for specific purposes by an individual and which the individual can reasonably expect will not be made public (for example, a medical record). Private information must be individually identifiable (i.e., the identity of the subject is or may readily be ascertained by the investigator or associated with the information) in order for obtaining the information to constitute research involving human subjects.

**FDA regulations** apply whenever an individual is or becomes a participant in research, either as a recipient of a FDA-regulated product or as a control, and as directed by a research protocol and not by medical practice. FDA-regulated activities involve individuals, specimens, or data, as patients or healthy controls, in any of the following:

a. any use of a drug or biologic, other than the use of an approved drug or biologic in the course of medical practice
b. any use of a device (medical or other devices, approved or investigational) to test the safety or effectiveness of the device
c. any use of dietary supplements to cure, treat, or prevent a disease or bear a nutrient content claim or other health claim

d. the collection of data or other results from individuals that will be submitted to, or held for inspection by, the FDA as part of an application for a research or marketing permit (including foods, infant formulas, food and color additives, drugs for human use, medical devices for human use, biological products for human use, and electronic products.)
e. activities where specimens (of any type) from individuals, regardless of whether specimens are identifiable, are used to test the safety or effectiveness of any device (medical or other devices, approved or investigational) and the information is being submitted to, or held for inspection by, the FDA.

**See Research Policy R-03: Research That Must be Reviewed by the IRB for the complete definition of Human Subject Research for further information.**

Clouse, Diane (clousede)

Tue 4/29/2014 9:27 AM

Sent Items

To:Norman, Claudia (normancr) <normancr@mail.uc.edu>;

Bcc:Bauer, Anne (baueram) <BAUERAM@UCMAIL.UC.EDU>;

Great! Thanks- yes, the purpose is still the same, to document student perceptions for TAP program enhancement.

Diane Clouse
Doctoral Candidate
University of Cincinnati,
CECH-School of Education
clousede@mail.uc.edu

"Treat people as if they were what they ought to be and you help them become what they are capable of becoming." -- *Goethe*

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**From:** ePAS@cchmc.org <ePAS@cchmc.org>
**Sent:** Tuesday, April 29, 2014 8:31 AM
**To:** Clouse, Diane (clousede)
**Subject:** IRB: Email Study Staff

**Subject:** 2013-7728 Not Human Subjects Research

From: Claudia Norman

To: Diane Clouse

Re: Study ID: 2013-7728
Title: Empowerment Evaluation Using Photovoice

Diane, the purpose of your project was determined to be improvement of UC's TAP program, not generalizable/research, which is what made it "not human subjects research". As long as your purpose does not change, you do not need to submit any additional information. Repeating the activities with more people and different activities does not require IRB approval. If you have questions, give me a call. Claudia.Norman@uc.edu 558-5784