EXPLORING THE PROCESS AND POTENTIAL OF PHOTOVOICE WITH CULTURALLY AND LINGUISTICALLY DIVERSE ADULTS WITH INTELLECTUAL/DEVELOPMENTAL DISABILITIES

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DEDICATION

This dissertation is dedicated to the memory of my father, John Clarence Bossler, who taught me the value of an education and in honor of my mother, Margaret Marie Buriak who taught me resilience and perseverance.
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Abstract

Research on the Photovoice process has been conducted with both culturally and linguistically diverse individuals and individuals with intellectual and/or developmental disabilities. However, few studies have explored the process and outcomes of Photovoice with individuals who are both culturally and linguistically diverse and have an intellectual and/or developmental disabilities. The purpose of this study was to expand on the paucity of research on the implications of using Photovoice as a method of facilitating communication among culturally and linguistically diverse adults with intellectual and/or developmental disabilities, community leaders, and decision-makers. More specifically, the Photovoice process was explored as a means of identifying the strengths and needs of a group to help its members communicate critical issues to community leaders.

Rather than relying solely on researchers and cultural outsiders to gather data, this research empowered the participants to reflect on their experiences with the chosen topic and share their knowledge and stories with people in their community. The research methods include both grounded theory and participatory action research. Specifically, the data collection and analysis methods of grounded theory were combined with a participatory action research method, Photovoice, to explore and develop a theoretical model of the experiences and perceptions of both culturally and linguistically diverse adults with intellectual and/or developmental disabilities using the Photovoice method and the perceptions of community members and decision-makers about using Photovoice as a tool for marginalized groups to communicate their strengths, issues, and needs.
The findings from this study suggest a positive reception from both the research participants and the community members. The Photovoice process created a space for culturally and linguistically diverse individuals with intellectual and/or developmental disabilities to explore, document, and communicate their strengths and concerns with their community members. The implications for researchers and service providers was that the Photovoice process provided a means for empowering people with I/DD to share their experiences and perspectives, encouraged the development of a sense of community, and cultivated the growth of new skills.
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CHAPTER 1

INTRODUCTION

This chapter presents the researcher’s predisposition to the topic, a brief background of the Photovoice process, the purpose of the study, the research questions, the organization of the dissertation, and the use of pseudonyms.

The Researcher’s Predisposition to the Topic

The topic of this dissertation has evolved over the course of many years. The ideas behind this project were first inspired by my experiences as a classroom educator on the leeward coast of O’ahu, Hawai‘i. As a new teacher, I was assigned to teach culturally and linguistically diverse students with disabilities. All of my students were a part of cultures that were different from mine and from anything I had encountered in my teacher training. As a result, I was faced with the reality of being a cultural outsider in my own classroom.

Based on the recommendations for practice of Stone (2005) and Lynch and Hanson (2006), I developed strong ties with my students and their families. Through my classroom experiences and my personal research, I learned to become more aware of the challenges my students faced. I learned to constantly reflect on the relevance of the lessons to my students’ daily lives, their progress, the overall classroom culture, and my position as their teacher. By stepping outside of my cultural comfort zone, and working with my students in culturally appropriate and responsive ways, I became able to connect with my students and better meet their educational needs.

Based on these experiences, I began to wonder about other educators and their preparation to work with students with disabilities in culturally and linguistically diverse (CLD) settings. I also wondered what strategies were relevant in CLD settings for students with disabilities. Through my research and with the encouragement of my master’s advisor, I learned of the Photovoice process as a way to encourage community involvement and change.
Photovoice

Photovoice promotes civic and educational engagement, using a visual, verbal, and participatory approach (Stevens, 2010). When implemented as a process for community action, Photovoice has the potential to engage participants in visually describing their realities, challenges, and obstacles to community leaders and decision-makers. Photovoice can be a powerful tool for women and marginalized communities who do not read and write. The concept of Photovoice was influenced by Paulo Freire’s theory of critical consciousness (1970), feminist theory (Wang & Burris, 1997), and documentary photography (Baker & Wang, 2006).

Developed in 1994 at the University of Michigan by Drs. Caroline Wang and Mary Ann Burris, Photovoice was initially intended to serve a means of achieving social justice and empowering women to understand and engage in problems they faced in rural China (Wang 1999). Through the use of Photovoice, female Chinese participants were able to identify forms of structural oppression and determine changes that needed to take place to positively impact their families and communities, including obtaining access to better health care for their children.

Beyond its initial purpose of empowering minority groups and marginalized peoples throughout the world (Castleden, Garvin, & First Nation, 2008; Janhke & Gillies, 2012; Kwiatkowshi, 2011; Moodie, 2010; Wang, 1999 & Wang & Burris, 1994, 1997), Photovoice has also been implemented in educational settings with students with disabilities (Carnahan, 2006). Thus, a convergence of research demonstrates how Photovoice can be used as a tool for empowering individuals with disabilities to advocate for their needs (Booth & Booth, 2003).

Purpose of the Study
Research on the Photovoice process has been conducted with both CLD individuals and individuals with intellectual and/or developmental disabilities (I/DD). However, few studies have explored the process and outcomes of Photovoice with individuals who are both CLD and have an I/DD.

The purpose of this study was to expand on the limited research on using Photovoice as a method of facilitating communication among CLD adults with I/DD, community leaders, and decision-makers. More specifically, the Photovoice process was explored as a means of identifying the strengths and needs of a group to help its members communicate critical issues to community leaders.

CLD individuals and those with I/DD have historically been marginalized by society (Kauffman & Hallahan, 2011; Winzer, 1993), and recent research documents that negative societal stigma and stereotypes for these groups still exist (Banks, 2008; Hosp & Reschly, 2003). Shifting the power dynamics between oppressors and the oppressed is a slow process, and inequities persist in the most enlightened of societies, even among those who possess a heightened awareness of the unacceptable nature of oppression (Freire, 2004). As a means of rectifying this situation, Photovoice creates a space for marginalized groups to explore, document, and communicate their strengths and concerns with those in positions of power (Wang, 1999). Rather than relying solely on researchers and cultural outsiders to gather data on a topic, Photovoice empowers community members to reflect on their experiences with the chosen topic and share their knowledge and stories with people in power.

**Research Questions**

The following research questions informed the study:

1. What were the participants’ experiences and perceptions of the Photovoice process?
2. What were the perceptions of local community members and decision-makers about the process of using Photovoice as a tool for CLD individuals with I/DD to communicate their strengths, issues, and needs?
Organization of the Dissertation

After this introduction, Chapter 2 begins with a discussion of the key terms: Photovoice, Developmental Disabilities, Intellectual Disability, and Intellectual and/or Developmental Disabilities (I/DD) and goes on to review several bodies of literature that relate and lead to the rationale for this dissertation research. Specifically, the literature review will provide a critique of the current knowledge about Photovoice, its use with CLD populations, and the use of Photovoice with persons with disabilities. The chapter will conclude with a discussion of common research methods used in Photovoice studies and the limitations of the Photovoice process. Chapter 3 presents an overview of the theoretical rationale for the methods selected for this study, the selection of participants and research setting, and specifics about data sources, collection protocols, data preparation, and methods of analysis used to answer the research questions. The chapter concludes with a review of the plan for disseminating the results of this study. Chapter 4 introduces the results from the Photovoice training, community presentations, focus group, participant interviews, and reports answers to the study’s two research questions. Finally, Chapter 5 provides a detailed discussion of the findings that emerged from the study in relation to the current Photovoice literature and knowledge, and presents implications for both service providers and future researchers in using the Photovoice process with CLD adults with I/DD.

Uses of Pseudonyms

To protect the confidentiality of participants, pseudonyms were used throughout the study. The main study participants chose their own pseudonyms during the first day of the Photovoice training. They were encouraged to choose any name by which they wanted to be known for the study. The participants laughed and joked with me as they chose their pseudonyms. This was the first of numerous bonding activities between the participants and myself. In addition, the decision to allow participants to
choose their own pseudonyms was made to encourage them to gain their own voices. Pseudonyms were assigned for the name of the community organization, the location of the research site, the state liaison, the community member participant, and my research assistant.
CHAPTER 2
LITERATURE REVIEW

This chapter includes definitions of key terms and a review of the history of the process of Photovoice and its theoretical underpinnings, including how it has been used to empower marginalized populations. More specifically, studies that included people of indigenous descent, immigrant cultures, and individuals with disabilities are highlighted. In addition, the methods used to study the implications of Photovoice are described. Finally, I demonstrate how past research contributed to the development of this study with CLD adults with intellectual and developmental disabilities.

Definition of Terms

The definitions of the following terms follow: Photovoice, developmental disabilities, intellectual disabilities, and intellectual/developmental disabilities (I/DD).

Photovoice. Photovoice refers to the process by which groups of participants collect photographs on previously determined themes and then apply a group process to develop narratives that convey the strengths of their community and an issue or need. Participants first share their photographs and narratives with other members of the group and engage in a process of feedback and reflection. They subsequently share their selected photographs with community leaders, persons in power, or decision-makers to give voice to their community strengths, concerns, and issues (Wang, 1999).

Developmental disabilities. This term has multiple meanings and interpretations. Currently, there are no standardized federal guidelines or explicit criteria to assess and diagnose developmental disability (Parette & Peterson-Karlan, 2008). Because the U.S. government does not operationalize the term, there is room for different interpretations. As a result, each state is left to devise its own definition. The participants included in this research study are limited to CLD adults who report having
an intellectual and/or developmental disability. Therefore, a definition of how developmental disability is defined within the context of this study is provided.

According to the Developmental Disabilities (DD) Assistance and Bill of Rights Act of 2000, developmental disabilities are severe, life-long disabilities attributed to mental and/or physical impairments that manifest before the age of twenty-two. Moreover, individuals with DD must have substantial limited function in three or more of the seven following areas: (a) capacity for independent living, (b) economic self-sufficiency, (c) learning, (d) mobility, (e) receptive and expressive language, (f) self-care, and (g) self-direction. (S. Res. 1809, 2000)

A definition of developmental disability is essential to assessment, diagnosis, and service attainment. The definition provided by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 will be the definition of developmental disabilities used in this study.

**Intellectual disability.** An intellectual disability is characterized by a below-average cognitive ability. Characteristics of an intellectual disability include an intelligence quotient (I.Q.) of 70-75 or lower, significant limitations in adaptive behaviors (self-care, socializing, communicating, etc.) that occur before the age of 18 (“Intellectual Disability,” 2014).

**Intellectual and/or developmental disabilities (I/DD).** According to the American Association of Intellectual and Developmental Disabilities, *developmental disabilities* is a term that includes intellectual disabilities but also other disabilities that are apparent during childhood (“Frequently Asked Questions on Intellectual Disabilities,” 2013). As intellectual and developmental disabilities can and often do co-occur, many disability professionals and service providers work with people who have both intellectual and developmental disabilities (“Frequently Asked Questions on Intellectual Disabilities,” 2013).
The participants in this study are part of an organization of individuals with intellectual and/or developmental disabilities aimed at leadership development, advocacy, and education for persons with intellectual and/or developmental disabilities. Therefore, the study will use the term I/DD to include individuals with one or both types of disabilities.

**The Literature on Photovoice**

Originally termed *photo novella*, the Photovoice model was developed by Wang and Burris (1994), who defined it as “a process by which people can identify, represent, and enhance their community through a specific photographic technique” (p. 369). Since its creation, Photovoice has been referred to in various ways, such as a concept, an approach, an educational tool, a process, and a participatory action research (PAR) method (Wang, 1999; Wang & Burris, 1994, 1997). PAR is rooted in the empowerment of people through their involvement in the design and implementation of the research. As such, the Photovoice method is an example of PAR.

The various terms used to describe Photovoice suggest its flexibility and potential to be used in a variety of ways and settings. The primary aim of this model is to encourage community members to think critically about a problem in their community, and use the medium of photography to represent and document the issue. A seminal article authored by Wang and Burris (1997) described the three objectives of Photovoice as a means to, (a) enable people to record and reflect on their community’s strengths and concerns, (b) promote critical dialogue and knowledge about important issues through large and small group discussion of photographs, and (c) reach policy-makers and decision-makers to enact change.

Photovoice has been used to give voice to marginalized populations around the world, such as women in rural China, Mayan women living in Guatemala, Latino immigrants in the Southern region of the United States and adults with intellectual and developmental disabilities in Midwestern area of the
United States (Jurkowski & Paul-Ward 2007; Streng et al., 2004; Wang & Burris, 1997; Williams & Lykes, 2003), to name a few. It has been used primarily in the health care field and in anthropological research (Catalani & Minkler, 2009).

**Theoretical Approaches Related to Photovoice**

The theoretical underpinnings of Photovoice are drawn from literature on empowerment education, feminist theory, and approaches to documentary photography (Wang, 1999). In the next section, I will discuss each theory and its intersections with the Photovoice model that was developed by Wang and Burris (1994).

**Empowerment education.** The first theory to explain the theoretical grounding of Photovoice is Paulo Freire’s theory of empowerment education. Freire’s (2004) ideas about education were developed in the late 1950s as a result of his work with Brazilian peasants who were illiterate. Freire maintained that in typical classrooms, students passively receive the content, memorize, and recite information. He described this type of education as *banking education* (p. 84), and claimed it was similar to what one would do when training animals. Instead of following the traditional banking model, Freire argued for the liberation and empowerment of students, allowing them to critically consider the world around them. In summary, Freire’s model of empowerment education encourages students to share their educational experiences, reflect on the roots of social problems in their communities, and take social action against these problems.

The Photovoice model exemplifies Freire’s theory of empowerment education. Empowerment begins with a discussion of the problems participants face and an agreement to focus on a specific issue, such as gaining physical access to their communities (Newman, 2012). After the participants identify an issue of focus, the next step involves them going into their communities, schools, or homes to collect data; that is, take photos. The photographs may be spontaneous or staged. Yet, the majority of studies
opt to use staged photos, as staged photos can be a very effective means of depicting a sensitive problem or issue. For example, the participants in Newman’s study (2012) staged photos of themselves wheeling their chairs down cramped aisle in stores, navigating unleveled sidewalks, and exiting their vans in tight spaces that were reserved for handicapped stalls. While these photos were staged, they visually depicted issues and barriers to community involvement that were commonly experienced by the study participants.

Once the participants have collected data on an issue they experience, they meet to discuss the meaning depicted in each photograph and more clearly identify the problem or issue. Following the process of identifying and agreeing on an issue, collecting data through photographic documentation, and analyzing the photos to ascertain a need or problem, the participants then take on the role of community or self-advocates and participate in a process of getting their message out to the decision-makers. Usually, this takes the form of participants presenting their photographs to stakeholders who have the power to make changes in their community. In the school setting this may be the principal, the school board or a student’s individual education planning (IEP) team. Through the process of developing a Photovoice project, participants work to create positive change within their communities. The most powerful part of this process is how it works to shift individuals’ self-image and sense of empowerment.

Another example of a staged Photovoice was implemented in a study conducted by Skouge and Kelly (2012). The subject of the study, Chef Ryan, was a young man with cerebral palsy living in an independent living center on the Big Island of Hawai‘i. While Ryan enjoyed being with people, he spent a large amount of time alone. He expressed a wish to learn to cook and host a party for his friends. Skouge partnered with Ryan to brainstorm the project and identify the issue. They concluded that the challenges Ryan encountered were barriers that made it difficult for him to independently shop for food
and cook. Skouge assisted in staging photos of Ryan shopping for groceries and cooking in his
“kitchen.” Together, the pair discussed each photo and how Ryan wanted to share his photos with his friends. After dinner, Skouge projected the photos and Ryan narrated them for his guests. Later, Ryan stated, “I want to have more parties … It is fun to work together” (Skouge & Kelly, 2012, p. 57). As a result of using the staged Photovoice model, Ryan was ultimately empowered to host numerous parties for his friends.

To summarize, Skouge and Kelly’s (2012) work with Ryan provides an example of how Photovoice intersects with Freire’s theory of empowerment education. Through the process of developing a Photovoice project, Ryan became his own advocate for change. He wanted to be included with his friends and host parties. Using staged photographs, Ryan was able to share his concerns with the stakeholders, who were his friends. Finally, Ryan demonstrated empowerment education by being able to demonstrate a problem, discuss how to fix the problem, and work with his friends to make a positive change.

Castleden et al. (2008) and Streng et al. (2004) provided an example of spontaneous Photovoice projects. In both studies, participants went out into their communities and took pictures of real and un-staged situations. In the Castleden et al. study, environmental changes and community concerns about the environment and health risks led to a Photovoice study collaboration between a PhD student from a Canadian University and Huu-ay-aht First Nation. Community members were asked to take photographs of places and events that exhibited environmental and health threats. Participants collected photographic data on: historic fishing boats, cedar baskets, mat weaving, graffiti, and pictures of the traditional lands. The participants in the Streng et al. (2004) study also took pictures in real life situations. For example, some of the participants collected photographic data during cultural dances, while at work, and throughout the school day.
**Feminist theory.** The second theory that is foundational to the Photovoice process is feminist theory. Feminist theory attempts to understand gender-based biases. Feminist theorists recognize that community members who are marginalized by society can often shed valuable insight and expertise on their communities in a way that professionals and cultural outsiders cannot (Wang & Burris, 1997). As such, feminist theory provides a framework for understanding Photovoice through the experiences of women and sheds light on women’s roles in society.

Applying feminist theory, Wang and Burris (1997) developed the Photovoice model in their work with women from rural Chinese villages. Similar to feminist theorists, their research attempted to understand and honor women’s knowledge and experiences. In feminist theory, women are seen as the catalysts for social change. Likewise, the women in Wang and Burris’s (1997) study were encouraged to share their knowledge in hopes of better understanding their communities and the biased institutions affecting their lives.

**Documentary photography.** While documentary photography is not a theory per se, it is used to explain the essential framework of the Photovoice method. Documentary photography is characterized by the use of photos to represent a significant or historical event. In documentary photography, the photographer attempts to capture candid shots of a particular subject or event. The term *documentary photography* is distinguished as the social conscience that is represented in visual imagery. It is used to transform the knowledge and experiences of a population into the language of photograph (Wang & Burris, 1997).

Documentary photography has been used extensively to provide marginalized populations outlets to express their stories, experiences, and struggles. In a similar vein, Photovoice operates under the assumption that the researcher provides cameras for individuals who otherwise might not have access to such technology. These individuals then use the cameras to document, record, and share their
experiences to bring about positive changes for their communities. As such, the participants literally become documentary photographers. Populations that are typically categorized as vulnerable include women, children, the elderly, and those with disabilities. Through the use of their camera and the Photovoice model, the power to share their experiences, stories, and options is placed into the hands of the most vulnerable populations.

Baker and Wang (2006) provided a clear example of the connection between documentary photography, empowerment education, and feminist theory. In their study, which focused on adults over the age of 50 who experienced chronic sensory and emotional pain, participants used the Photovoice method to enhance an understanding of chronic pain and how it impacted the participants’ lives. Rather than being passive participants in their health care, the study participants became active agents of change and helped their health care providers better understand their experiences with chronic pain. In this example, the use of the Photovoice model and documentary photography became tools of empowerment for a marginalized community, elderly adults, and opened the discussion for social change. Thus, documentary photography was shown to support both the ideas of Freire’s empowerment education and feminist theory.

The following studies exemplify how the theory of documentary photography aligns with the Photovoice model in reference to disability studies. Photovoice has been used with people with a range of disabilities, including students with autism (Carnahan, 2006), adults with spinal cord injuries (Newman, 2010), mothers with developmental disabilities (Booth, 2003), and students with cognitive impairments (Skouge & Kelly, 2012). In these studies, the participants were trained in basic camera usage and then given the freedom to choose the topics or issues to address. Through the Photovoice model the researchers supported participants to voice the challenges they faced and self-advocate for their needs in the hopes of making positive social changes within their communities.
In summary, documentary photography is essential to understanding Photovoice because it is the means by which participants visually communicate their experiences and findings. Feminist theory accounts for valuing the knowledge and lived experiences of marginalized groups, such as individuals with disabilities, and Photovoice is the vehicle for documenting concerns. Participants are empowered to self-advocate as they share their photographs with people in power positions. In short, the photographs can provide the space for dialogue to take place and initiate the process of change.

**Photovoice With CLD Individuals**

The following section discusses the extent to which Photovoice has been studied with reference to improving the outcomes for marginalized populations, including indigenous and immigrant cultures and individuals with disabilities.

**Indigenous cultures.** Since its inception in the early 1990s, the Photovoice model has been used to promote community dialogue and advocacy with indigenous cultures (Wang, 1999; Wang & Burris, 1994, 1997). Primarily used in health research to empower marginalized people to communicate with those in power and create positive social change, Photovoice has served as a means of better understanding the environmental and health risk perspectives of the First Nation people of Canada in the Huu-ay-aht territory (Castleden et al., 2008).

In this study, an elected Huu-ay-aht council appointed an advisory committee to work with the researcher. The participants, who ranged from 19-75 years of age, were given a short training session and disposable cameras. Next, they were asked to take photographs on the community’s agreed-upon themes surrounding environmental and health risks and non-risks. After taking photographs, participants returned the cameras to Castleden and his colleagues, who subsequently met with each participant to conduct interviews, once the photos had been developed. At the conclusion of the
interviews, the participants were given copies of the photographs as a way of thanking them for their participation in the study.

Additionally, after the interviews, the researchers and the Huu-ay-aht advisory committee hosted five potluck dinners to share their findings. As a result, informal community dialogue was generated, individual perspectives were shared to help clarify the issues raised in the photographs, and community action was instigated. For example, after one potluck meeting that highlighted the need for youth activities by showing photographs of an important community building defaced with graffiti, five youth were spotted cleaning graffiti from the village’s fire hall. When asked what motivated them to take this action, the youth responded, “We saw the poster” (Castleden et al., 2008, p. 1400).

Thus, the Photovoice method used here served as a means to balance the power between the researchers and the community. A sense of ownership resulted from having 50% of the community participate in the project. The findings also indicated that the project fostered a sense of trust between the researchers and the community because the participants determined the subjects of their photographs. In addition, by developing relationships with the community, the researchers built the capacity for future training and skill development within the community (Castleden et al., 2008).

While acknowledging the positive impact of Photovoice on enabling the community to express their concerns, Castleden et al. (2008) pointed to several limitations. First, the medium of photography was an important limitation because the findings were restricted to what was observable and tangible. For example, one participant expressed difficulty in capturing the social health issue of gossip in the community. Her solution was to take a photograph of the word spelled out on a Scrabble game board (Castleden et al., 2008). To gather information on the unobservable issues like gossip, interviews were purposefully used to clarify the participants’ perspectives beyond what was seen in the photographs.

Weather, accessibility to film development, equipment costs, and time were also listed as limitations.
Another major limitation of conducting this study was access to the photographic equipment and film development. Participants needed cameras to use for data collection and ways to develop the film. In addition to the cost of film development, the cost of purchasing cameras and potential replacements for lost or damaged cameras can negatively impact a research budget. Also, because the cameras may be similar in appearance, participants may unintentionally switch their camera with another group member, which can lead to frustration between the participants and the researcher.

Finally, Photovoice projects involved significant time commitments from both the participants and the researcher. Participants in a Photovoice study consented to doing much more than completing a survey or participating in an interview. In Photovoice, the participants agreed to camera and ethics training, taking photographs, participating in an interview about the photographs, and then participated in some action for change (Castleden et al., 2008).

To address the limitations of using photographic data, Castleden et al. (2008) suggested that future studies carefully document and report photographs and interview data so that others may evaluate the integrity and rigor of the analysis. The authors did not offer suggestions for alleviating the time commitment or the costs associated with conducting Photovoice projects. However, the study was conducted prior to the wide availability of digital technology. Utilizing digital cameras and computers may reduce the costs and time commitments associated with Photovoice projects.

As a result of this study, other First Nation communities have invited the research team to present their findings and train their community members to use the Photovoice method to address environmental and health concerns. The next section will discuss the uses of Photovoice with another CLD group, immigrants.

**Immigrant populations.** Photovoice has been employed throughout much of the world to give voice to those marginalized by society. Increasingly, Photovoice is being used with immigrant
populations seeking a voice in their newly adopted country. One group that is traditionally marginalized in the United States is Latino immigrants. According to the 2012 census, Latinos represented about 17% of the total population in the United States. They are the nation’s second largest racial and ethnic group (behind non-Hispanic whites). Therefore, it is not surprising that Photovoice projects focused on immigrant populations have been implemented with Latino immigrants, including studies by Schwartz et al. (2007) and Streng et al. (2004).

Many communities in the United States are experiencing an increase in the number of immigrants from Mexico. In response to problems faced by these migrant communities such as high drop out rates, poor health, and poor quality of life, Schwartz and his colleagues (2007) conducted a study with 10 (5 men and 5 women) newly-arrived Mexican migrant adults in Missouri. The participants decided upon the following research questions: (a) How is family planning viewed in your community? and (b) What is it like trying to obtain family planning services in your Midwestern community? The aim of the study was to enhance the understanding of the migrant needs and assets to improve family planning services.

The study followed Wang and Burris’s (1997) model for a Photovoice study, including engaging participants in PAR and encouraging the development of self-advocacy skills. It involved two training sessions, followed by equipping participants with disposable cameras to collect data. After the photos were developed, the researchers met with the participants to discuss the photos. Each participant chose two of their photos to display in the lobby area of the local health department and subsequently, along with the researchers, answered questions about the photos at an exhibit reception. The project resulted in a welcome kiosk in the health department lobby in Spanish, Mandarin, Korean, and Arabic (Schwartz, et al., 2007).
Through this project, health care providers learned about the barriers their patients face when attempting to access health care and family planning services, including language barriers and confusion. The participants also helped the public and the researchers appreciate how little free time recent immigrants have to contribute to a Photovoice project. One of the take-away lessons learned was that childcare should be provided for families when participating in a Photovoice project.

Photovoice has also been studied as a means of self-advocacy with Latino immigrant youth. Streng et al. (2004) worked with seven Latino immigrant youths, mostly boys, in rural North Carolina. The project engaged the youth in PAR to improve school conditions, enhance understanding of their needs and assets, and facilitate individual empowerment and self-advocacy. The Photovoice project allowed Latino youth to express the experiences and the challenges they faced as immigrant students and provided an insider’s view of the Latino adolescent experience in rural North Carolina.

Streng et al. (2004) followed the same model for data collection as in previously discussed Photovoice studies. However, because the participants were native Spanish speakers, each interview was conducted in Spanish and translated into English by native Spanish speakers. The photos were displayed as an exhibition for the participants’ families, community leaders, policy makers, service providers, school administrators, teachers, and counselors (Streng et al., 2004). The photo themes included: sense of limited future, limited use of English, school and institutional racism, valuing Latino identity, desire to have adult and community support, and the importance of role models.

At first, the school and community leaders in attendance were resistant to the exhibit. However, because the project was driven by photographs and themes generated by the participants, the principal and other teachers could not disqualify the findings. The researchers believed this type of conflict was necessary in order for communal change to take place (Streng et al., 2004).
This study illustrates one of the challenges in developing a Photovoice project with marginalized students in school settings. While the project was a partnership between the school, student club, and University of North Carolina, and although the school administration was aware of the research questions, the principal and teachers were unhappy to learn that the findings were critical of the status quo. This unfortunate outcome could potentially have impeded future partnerships between the University of North Carolina and the local high school. In future projects of this kind, it may be more appropriate to conduct controversial projects independent of the school setting. Another possible solution would have been to present the findings to the school administration instead of in a public forum. The administration may have felt blindsided, surprised, and embarrassed at learning such sensitive information publicly.

These findings also shed light on the critical responsibilities of the researcher and the research team. In some situations, the researchers may want to advise participants to present the material in ways that will be acceptable to stakeholders. That is, rather than alienating persons in power, Photovoice participants should consider ways to gain the support from those who hold power positions in the community. Friction may be necessary to spark discussion, but partnerships and community building are necessary to inspire meaningful and lasting changes in any community. Researchers need to be sensitive to the needs of the communities they work with and the information uncovered during Photovoice process.

**Photovoice With Individuals With Disabilities**

Recently, Photovoice has been making its way into classrooms and has been used with both elementary-aged children and adolescents to develop self-advocacy skills (Foster-Fisherman, Nowell, Deacon, Nievar, & McCann, 2005; Goodhart et al., 2006). Working in educational settings presented challenges and, in some cases, special considerations had to be made. For example, Goodhart et al.
(2006) noted that some students were more invested in the project than others, which may have impacted the outcomes. Additionally, students expressed concern about getting consent forms signed and, as a result, many chose to take photos of inanimate objects instead of live subjects. Finally, the participants were concerned with the potential unintended consequences of taking a picture of underage drinking or illegal drug use.

Based on their experiences working in the classroom, Goodhart et al. (2006) recommended working in small-group settings, meeting regularly, and gaining support from persons in power. The researchers concluded by noting that Photovoice was a way for students to take knowledge beyond the classroom and see how and where it could be applied to their communities.

Carnahan (2006) described the successful use of Photovoice in the development of verbal communication skills of students with autism as well as fostering reflection in teachers on their teaching practices. The project consisted of two phases. Phase 1 was the teacher Photovoice project. During an eight-week period, five teachers in Ohio were trained to use Photovoice and implemented their own projects. Through their Photovoice projects, the teachers expressed their concerns and development in teaching students with autism. During Phase 2, two male kindergarten students with autism and five of their general education peers participated in a teacher-driven Photovoice project. The goal of this phase was to increase the classroom participation of the students with autism.

The researchers found that Photovoice increased student involvement by removing language barriers, structured learning tasks, and incorporated student interests (Carnahan, 2006). The teachers attributed these positive findings to that fact that this process focused on the strengths of the students with autism to process visual information.
Photovoice is still relatively new to the educational setting, and further research is needed to better understand the impact and potential implications of Photovoice (a) in the classroom and (b) with students with disabilities.

**Photovoice Research Methods and Data Analysis**

Similar to the Goodhart et al. (2006) and Carnahan (2006), the majority of Photovoice studies have followed community-based action research approaches (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009). These approaches have included both the researcher and participants in the data collection and data analysis. The level of participant involvement in the data analysis varies between the studies.

Current researchers using the Photovoice process have reported using coding, content analysis, grounded theory, ethnography within-case analysis, cross-case synthesis, and critical reflection for their data analyses (Hergenrather et al., 2009). Multiple Photovoice studies conducted with people with disabilities have used the grounded theory approach (Beart, Hardy, & Buchan, 2003; Carnahan, 2006; Jurkowski, 2007; Jurkowski & Paul-Ward, 2007).

**Grounded theory approach.** Grounded theory refers to the study of social phenomena for the purpose of systematically collecting and analyzing data in order to generate substantive theory (from the participants’ perspectives). These theories further the understanding and explanation of social and psychological processes at work in the situation being investigated (Stauss & Corbin, 1998). By bridging the gap between theory and practice, the theory that is developed may be used to identify how the Photovoice process can be directed. Grounded theorists ask questions that attempt to reveal what is going on in a particular situation (Strauss & Corbin, 1998).

**Grounded theory and photovoice.** While multiple Photovoice studies have included people with disabilities using the grounded theory approach (Beart et al., 2003; Carnahan, 2006; Jurkowski,
2007; Jurkowski & Paul-Ward, 2007), few have been conducted with CLD individuals with I/DD. A review of studies applying a grounded theory approach to generate explanatory models for “what is going on” within the process of experiencing specific aspects of using Photovoice with CLD adults with I/DD revealed two studies that met the search criteria.

Jurkowski (2007) conducted a study on the health disparities of four Mexican-American adults with intellectual disabilities living in Chicago. Jurkowski and Paul-Ward (2007) also conducted a study with Mexican-American adults with intellectual disabilities to understand the health beliefs of people with intellectual disabilities, their health needs, and interests related to health promotion. These studies used grounded theory methods to generate theoretical models that explained how specific processes operate and affect the lives of CLD adults with intellectual disabilities.

**Limitations of the Research on Photovoice**

While Photovoice is a widely accepted technique, empirical data on the process are inadequate. That is, data used to support claims of the effectiveness of Photovoice typically come from case studies and anecdotal evidence (Gant et al., 2009). Thus, data are needed to rigorously assess the effectiveness of Photovoice as an intervention and in considering topics beyond issues of empowerment. Commonly found limitations to Photovoice include vague descriptions of the Photovoice projects and the analysis methods. In addition, of the 44 published studies reviewed, only 9 were conducted with people with disabilities (Baker, 2006; Bert et al., 2003; Booth & Booth, 2003; Carnahan, 2006; Jurkowski, 2007; Jurkowski & Paul-Ward, 2007; Newman, 2010; Newman et al., 2009; Tompson, 2008). Further, of these nine studies, only four were identified as being conducted with people who were culturally and linguistically diverse and had I/DD (Jurkowski, 2007; Jurkowski & Paul-Ward, 2007; Newman, 2010; Newman et al., 2009).
Future studies should be conducted with people who are CLD and have I/DD. Finally, future studies should include ways to evaluate the Photovoice projects and their impact on participants and their communities. Although Photovoice is a community-based intervention, to date, its impact at the community level has not been well described or assessed.
CHAPTER 3

METHODS

The following chapter provides an overview of the theoretical rationale for the methods selected for this study. The selection of participants and research setting are described. Specifics are given about data sources, collection protocols, data preparation, and methods of analysis used to answer the research questions. Lastly, the plan for dissemination of the results is reviewed.

Purpose of Study

The purpose of this study was to address the paucity of research on the implications of using Photovoice as a method of facilitating communication among CLD adults with I/DD, community leaders, and decision-makers. More specifically, the Photovoice process was explored as a means of identifying the strengths and needs of a group and to help them communicate critical issues to community leaders.

While research on the Photovoice method has been conducted with both CLD individuals and individuals with I/DD, to date only two published studies (Jurkowski, 2007; Jurkowski & Paul-Ward, 2007) have explored the process and outcomes of Photovoice with individuals who are both CLD and have an I/DD. Historically, CLD individuals and those with I/DD have been marginalized by society (Kauffman & Hallahan, 2011; Winzer, 1993), and recent research documents that negative societal stigmas and stereotypes for these groups still exist (Banks, 2008; Hosp & Reschly, 2003).

The shifting of power dynamics between the oppressors and the oppressed is a process – even in the most enlightened of societies and among those who possess a heightened awareness of the unacceptable nature of oppression (Freire, 2004). Photovoice is a process that creates a space for marginalized groups to explore, document, and communicate their strengths and concerns with those in positions of power (Wang, 1999).
Research Questions

1. What were the participants’ experiences and perceptions of the Photovoice process?

2. What were the perceptions of local community members and decision-makers about using Photovoice as a tool for CLD individuals with I/DD to communicate their strengths, issues, and needs?

Research Approach and Rationale for Research Methodology

The following sections include a brief discussion on the research approach of this dissertation, to include how the Photovoice process and methods of grounded theory are applied together within this study.

Research approach. It was impossible for me, the researcher, to know exactly what would be studied and learned by the participants in this project, for both were completely dependent upon what the participants identified as issues they wished to address. This knowledge was unnerving as a researcher because I did not have the feeling of control that typically accompanies studies using other educational research approaches.

However, this research was not about my feelings of comfort as a researcher. Rather, by completing this research, I hoped to gain a better understanding how CLD adults with I/DD perceive and experience the Photovoice process. I also hoped to gain insight into the perceptions of local community leaders and decision-makers about using Photovoice as a tool for this group to communicate individual and group strengths, issues, and needs.

Rationale for research methodology. The research methods used to gain insight into the two research questions included both grounded theory and participatory action research (PAR) (Merriam, 2009; Strauss & Corbin, 1998). Specifically, I used data collection and analysis methods of grounded theory combined with a PAR method, Photovoice, to explore and develop a theoretical model of the
experiences and perceptions of CLD adults with I/DD using the Photovoice method. In addition, I used the grounded theory methodology to uncover the perceptions of local community leaders and decision-makers about using Photovoice as a tool for marginalized groups to communicate their strengths, issues, and needs.

The qualitative data analysis was conducted using grounded theory research techniques. Grounded theory is the study of social phenomenon. The ultimate goal of grounded theory studies is to build theories based on participants’ perspectives (Strauss & Corbin, 1998). In grounded theory studies, participants become co-researchers, and the principles of PAR can be followed. Arguing that PAR methods (like Photovoice) and grounded theory research complement each other, Dick (2003) suggested that PAR can improve the “efficiency of data interpretation and theory building” in a grounded theory study (p. 10).

**Grounded theory.** A grounded theory approach was selected as the primary analytic method for several reasons. First, grounded theory offers an in-depth way to explore and record participants’ subjective experiences for purposes of analysis and discussion. Second, it allows participants to express their own thoughts and use their own voices. Third, the goal of grounded theory is to build a theoretical model that is grounded in the participants’ explanations (Strauss & Corbin, 1997). Finally, grounded theory is aligned with the mission of the Council on Developmental Disabilities (DD) to support people with I/DD to control their own destiny and determine the quality of life they desire (“About the DD Council,” 2001).

As mentioned, grounded theory data collection and analysis methods were used in combination with the Photovoice process, which is a participatory action research (PAR) process. The purpose was to provide a forum for participants to describe their experiences as CLD adults with I/DD and develop a
theoretical model of how their needs are perceived to be met and addressed from the perspectives of CLD adults with I/DD.

**Participatory action research.** Photovoice is grounded in PAR. The goal of PAR is to understand certain phenomena and the meaning they have for the participants. According to Merriam (2009), PAR is used not only to understand the phenomena and their place in society, but also to critique and change society. This type of research is based on several traditions and approaches, including Marx’s analysis of socio-economic class and status (Marx & Engels, 1998), Habermas’s approach to emancipatory knowledge (Habermas, 1966), and Freier’s empowerment education (Freier, 1970). This style of analysis attempts to reveal the power dynamics within a social and cultural setting and understand how they are reinforced as the status quo.

**Photovoice.** On a practical level, using the Photovoice process involved participants taking pictures of their lives, reflecting on these pictures, and sharing their stories in a discussion format. On a theoretical level, Photovoice became a process of participatory action research whereby the individuals attached meaningful narratives or stories to the pictures they took. The participants then shared their photographs and stories with each other to encourage discussions of the themes within the images and stories. The photographs were used to educate others about the experiences of the group to bring wider awareness of the issues being studied.

In summary, to address the research questions on using Photovoice with CLD adults with I/DD, this study employed a PAR method, Photovoice, combined with data collection and analysis methods of grounded theory to explore and develop a theoretical model of the experiences and perceptions of CLD adults with I/DD. The grounded theory research methodology for data collection and analysis provided insight into the experiences and perceptions of CLD adults with I/DD who participated in the process.
In addition, the Photovoice process was explored as a means of identifying the strengths and needs of a group and to help them communicate critical issues to community leaders. Table 1 illustrates the connection between each research question, the activities in which the participants took part, the research approach, data source, means of data analysis, and who collected the data.

Table 1

*Research Questions and Corresponding Activities*

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Activities</th>
<th>Data Source</th>
<th>Data Analysis</th>
<th>Data Collector</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What were the participants’ experiences and perceptions of the Photovoice process?</td>
<td>Photovoice Training, Participant interviews, Observations, Field Notes</td>
<td>Participant Action Research (PAR), PAR, PAR</td>
<td>Amy, Amy &amp; Louise, Amy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Photo Analysis, Observations, Focus Groups</td>
<td>PAR, PAR</td>
<td>Amy &amp; Louise, Amy &amp; Louise, Amy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community Presentation, Participant interviews, Observations, Focus Groups, Field Notes</td>
<td>Grounded Theory (GT), GT, GT, GT</td>
<td>Amy &amp; Louise, Amy, Amy, Amy</td>
<td></td>
</tr>
<tr>
<td>2. What were the perceptions of local community leaders and decision-makers about the process of using Photovoice as a tool for CLD individuals with I/DD to communicate their strengths, issues, and needs?</td>
<td>Community Presentation, Community member questionnaire, Community member interviews, Observations</td>
<td>GT, GT, GT</td>
<td>Amy, Amy</td>
<td>Amy &amp; Louise</td>
</tr>
</tbody>
</table>
Research Setting and Recruitment Procedures

The research participants were recruited from one agency, O’ahu Advocate (OA), for people with disabilities living in the Hawaiian Islands. OA is a subgroup of the DD Council of the State of Hawai‘i. The DD Council is federally mandated and funded through P.L. 106-402 as well as state mandates (Chapter 333E, Hawaii Revised Statues). The mission of the DD Council is to support people with I/DD to control their own destinies and determine their own quality of life (“About the DD Council,” 2007). As such, the Council plans, coordinates, evaluates, monitors, and advocates on behalf of individuals with I/DD and their families (“Who We Are,” 2007). It also ensures that individuals with I/DD and their families participate in the design of culturally competent services and supports that promote community inclusion.

The DD Council is made up of approximately 30 people appointed by the Governor of the State of Hawai‘i. To ensure the voices of people with I/DD are heard, at least 60% of the Council members are persons with disabilities or their family members. The remaining 40% are made up of service providers, community members, and representatives from state service agencies (“About the DD Council,” 2007).

While OA has chapters on all of the major Hawaiian Islands, participants were selected from the O’ahu chapter due to budget and time restraints. The O’ahu chapter has a total membership of 77. The members include those of Hawaiian, Samoan, Chuukese, Filipino, Japanese, Chinese, and Irish-American backgrounds. All of the participants had received advanced training in self-advocacy and were considered leaders within their community. The participants regularly volunteered at schools and in helping other individuals with I/DD gain access to services and supports.

O’ahu advocates. Working with the OA organization allowed me to build upon an existing relationship between the state liaison, the OA members, and myself. I was previously introduced to Ms.
Takao, the OA state liaison, in 2013 at the Pacific Rim International Conference on Disability and Diversity (PacRim). At both the 2013 and 2014 PacRim conferences, I presented and facilitated mini-Photovoice workshops for both CLD and non-CLD adults with I/DD. Through this relationship and the interest the mini-workshops sparked in OA members attending the PacRim conference, I was invited by Ms. Takao to present a proposal to conduct a study with the OA members.

In order to accommodate participants’ transportation limitations, all study events (Photovoice training, focus groups, and interviews) took place at the OA office. Ms. Takao generously offered to reserve their conference room for our use. This location provided the participants with a quiet meeting room with plenty of space to move around. It was easily accessible by public transportation and located on the first floor of a climate-controlled building.

**Partnership with the O’ahu advocates.** A brief informational presentation about the study was made at the OA general meeting in June 2014. I was then invited to present the proposed study to the OA officers in July 2014, at which time OA officer approval was obtained. Potential participants from the OA membership were suggested and most of the officers expressed interest in participating in the proposed study. During this meeting, OA officers identified potential areas of interests and concerns that may be addressed in a Photovoice study.

**Access to participants.** Ms. Takao, the OA state liaison, and the OA officers facilitated access to the research participants. Ms. Takao and the OA officers helped identify “information-rich” cases or participants who can illuminate on a topic and were able to provide appropriate data given the purpose of the research. They identified OA members who were CLD adults with ID or DD and who would be willing to participate in a Photovoice project. Additionally, the OA officers invited me to a follow-up meeting with potential participants during their October 2014 general member meeting.
**Inclusion criteria.** Participants were considered for the study if they met the following criteria: (a) 18-60 years old, (b) current OA members, (c) identified as having an intellectual/developmental disability, (d) able to communicate verbally, and (e) able to read and write. The OA officers and I collaborated to extend an invitation to participate in the project to all people meeting the inclusion criteria.

**Recruitment.** Ms. Takao and the OA officers facilitated the initial recruitment by allowing me to present at their July 2014 member meeting. In addition, Ms. Takao suggested other names of people who might provide “rich information” and who met my research criteria. During the next information session held in October 2014, I meet with 10 potential participants. At this meeting, I reviewed the consent form (see Appendix A) and an informational fact sheet on the Photovoice project (see Appendix B). I answered questions about participation, invited interested participants who were legally responsible for themselves to sign consent forms, and set dates for their Photovoice training sessions. I also gathered contact information so as to be able to follow up with formal invitations and to send reminders about the training. While families did not take part in the actual study, I encouraged each participant to share their consent forms with their families and provided the participants with my contact information so they could reach me if they had further questions. I also gave them a copy of the consent form that we reviewed as a group.

**Research Assistant**

Shimshock (2008) suggested including multiple facilitators in the development of a successful Photovoice project as a means of producing a more meaningful Photovoice project. While this research did not have funding available for additional leadership, I was able to locate a volunteer research assistant. The research assistant, Louise, recently completed her PhD in Education specializing in exceptionality studies at the University of Hawai‘i at Manoa. She was committed to empowering
students and persons with disabilities to advocate for their educational and personal needs.

Louise and I were part of the same PhD cohort and have worked together on previous projects. Most notably, we co-presented at the 2013 PacRim conference and co-facilitated the 2013 PacRim mini Photovoice workshop with CLD adults with I/DD. Through these experiences, Louise became familiar with the Photovoice goals and process.

Prior to conducting the Photovoice trainings, Louise reviewed the training materials to ensure they were appropriate for the participants, written in plain language, and free of grammatical and syntax errors. Further, during the training portion of the project, Louise conducted observations of the participants and myself, led small-group discussions of the participants’ photos, and debriefed with me after each session. I took notes on our debriefings in my research field notes. Finally, Louise was present at the final community presentation and conducted observations on the community leaders’ perceptions of the Photovoice process.

**Researcher Position**

One of the major goals was to build a strong relationship between the OA members and myself in this first partnership between us. With their support, future Photovoice projects will be planned with the OA members. For this first project, I was responsible for initiating the meetings to discuss the potential research partnership. The OA members and I defined the purpose of the Photovoice project collectively. I was responsible for managing the project and procuring the necessary technology (iPads). The participants were responsible for participating in the Photovoice process and sharing their findings with their local community leaders.

As a proponent of the Photovoice process, and particularly its potential in educational settings and with CLD adults with I/DD, I needed to critically consider my role in the research process. Thus,
my interest in Photovoice combined with the support of the OA officers and Ms. Takao may have caused the participants in this study to become more inclined to use the Photovoice process.

**Participant Sampling and Theoretical Sampling Procedures**

The study adhered to Merriam’s (2009) recommendations for determining the appropriate number of participants based on the questions posed in the purpose statement. The goal is to find saturation. In this study, a purposeful sample was used to maximize information, provide rich descriptions, and build a substantive theory related to participants’ everyday-world situations (Merriam, 2009).

**Participant sampling.** A substantive theory was developed on the everyday experiences of CLD adults with I/DD in order to create a group that matches, generally, the overall population demographics in HI. OA officers, Ms. Takao, and I identified potential participants who vary in cultural background, age, gender, and ability. The goal was to be able to observe the commonalities as well as the differences in the process of developing a Photovoice project with diverse CLD adults with I/DD living on O’ahu.

As there is not a set rule for sample size in qualitative studies (Merriam, 2008), the number of participants is dependent on the purpose of the study (Patterson, 2002). Therefore, because the intent of this study was to explore the experiences and perceptions of CLD adults with I/DD using the Photovoice process and to collect rich, thick contextual data, which requires more time and resources than a quantitative study, the sample size was purposefully small, 5 participants (Wang, 1999). The number of interested participants who attended the initial informational session and met the research criteria was 10. This number was consistent with other Photovoice research studies (Catalani, 2010). In addition, the limited number of participants allowed for rich, thick descriptions and in-depth discussions.
Theoretical sampling. As this is primarily a grounded theory study, data were collected, coded, and analyzed at each step in the process in order to determine what data to collect next to develop a theory (Glaser & Strauss, 1967). This process is known as theoretical sampling. Strauss and Corbin (1998) also referred to theoretical sampling in qualitative research as including participants who will bring rich experiences and data, which will lead to the development of codes and theory. For example, my research assistant and I conducted observations of the participants while they were participating in the Photovoice training to gain insight into their experiences and perceptions of the Photovoice process. I then share the themes identified from the observations with study participants during the focus groups. The participants discussed the categories and themes as a community and raised more categories and themes.

Participant Characteristics

The following section provides detailed descriptions of each participant. This includes age, ethnicity, type of disability, and motivation for joining the Photovoice research.

Pink Monkey (Pink). Pink Monkey identified herself as being a twenty-two year old of Hawaiian, Japanese, and Black heritage. She self-identified as having both developmental and physical disabilities. Pink relied on the use of a manual wheelchair for mobility. While completing her background questionnaire Pink told me that she earned a high school certificate and did not have any advanced training at the time of the research project. Issues that were important to her were transportation and bullying. She explained that she wanted to be a part of the Photovoice project so that she could learn to use iPads and to help other people.

Pink was the youngest participant in the group and was very shy around new people. She explained that she did not enjoy speaking to groups of strangers. Pink was very quiet throughout the research process. While, she was willing to share her thoughts, help take pictures, and be an active part
of the group, Pink needed a lot of prompting. She answered in simple sentences of one or two words. Pink often used body language (head nods or shakes, eyebrow raising, and pointing) to express herself. I was originally concerned with her participation. However, after speaking with Ms. Takao I learned that Pink had hardly spoken in the six months she was working with her. The fact that she was speaking to me was a major accomplishment in Ms. Takao’s mind.

**Princess.** At twenty-nine years old, Princess was the second youngest participant in this study. Princess identified herself as being Samoan and also having a developmental disability. She was a wheel-chair user, but was also able to walk with the use of supports. Princess explained that she earned a high school diploma and had received advanced training in self-advocacy. Princess was interested in issues concerning her struggles with the Handivan, bullying, and “uncomfortable feelings when receiving services.” She explained that she wanted to be part of the Photovoice project because she wanted to learn more about the process, to help teach other people with disabilities about Photovoice, and to be a role model for others.

Princess was very outspoken and articulate. She was able to clearly express herself and share her thoughts and ideas with the group. Princess was the unspoken leader of the group and often prompted others when they struggled to answer questions. Princess was also the vice-president of the OA and during the study took over the role of acting president.

**Scanner Chief (Chief).** Chief was a 33-year-old man who identified as being German, Irish, Korean, and American Indian. Chief self-identified as having a pervasive developmental disability. He explained that he had a high school diploma and was a self-advocate. Chief also worked as the state legislative liaison for OA. He had an aid assist him during the training. Chief was not sure what issues he wanted to address, but hoped to use Photovoice with his job.
Chief was able to express himself verbally and in writing. While he only participated in two of the five Photovoice sessions, Chief did call to tell us he was not able to attend due to his job. According to Ms. Takao, calling to explain his absences was one of the leadership goals he was working on. Chief participated in the up-date presentation for the OA members, but was not actively involved in the community presentation. However, he was present and observed the presentation.

**Swimmer.** Swimmer was a thirty-nine-year old woman with Down syndrome. She identified herself as being White and of Irish descent. Swimmer grew up in California and later moved to Hawai’i with her family. She earned a high-school certificate and had received advanced training in self-advocacy. Most notably, Swimmer is a *Feeling Safe Being Safe* trainer. Bullying on the Handivan was the main topic Swimmer wished to address. She stated that she wanted to be part of the Photovoice project to help others.

Swimmer was articulate. She was also artistically expressive. During our discussion on bullying she participated in the conversation, but also started drawing without being prompted. After completing her drawing, she exclaimed, “this is a definition of bullying.” Swimmer had drawn a picture of a person getting punched in the eye by another person. Her message was very clear and easy to understand. While she was able to verbalize her thoughts and feelings, I also encouraged Swimmer to use drawings to express herself. These images added richness and meaning to our conversation.

**Vyper.** Vyper was a thirty-six-year old man of Hawaiian, Chinese, and Filipino descent. He identified himself as having a developmental disability, but was not sure of his exact disability classification. Vyper graduated with a high school diploma and had attended some college. He was also trained as a self-advocate. Vyper had hoped to complete a Photovoice project on jay-walking, traffic safety, or teenage driving. They were all important issues for him. In addition, Vyper stated that he wanted to be part of the Photovoice project because he “loves taking pictures.”
From our discussions in the Photovoice training and our time working on the presentation I realized that Vyper was much more articulate when allowed to write his thoughts and feelings down first. He had a difficult time responding to questions verbally and would say “I don’t know,” to avoid further questions. From my observations of Vyper’s participation during the training and focus group, I decided to email him the interview questions ahead of time and asked him to write out his responses to share with me prior to the interview.

**Group Dynamic**

All participants were members of O’ahu Advocates (OA). Through their membership in OA, they received training in self-advocacy and were considered leaders within their community. The participants regularly volunteered at schools and in helping other individuals with I/DD gain access to services and supports. Each year, OA members elect the officers of president, vice-president, secretary, treasurer, meeting officer, state legislative liaison, timekeeper, and historian. The flow of the OA meetings loosely followed *Robert’s Rules of Order* (Kennedy, 1997) such as a call to order, a review of the last meeting notes, treasurer’s report, and a call for new business. Ms. Takao served an advisory role for the group. She offered support to members and assisted the officers in scheduling meetings, leading meetings, developing their newsletter, and hosting yearly events. She did not have a developmental or intellectual disability. However, Ms. Takao worked diligently to ensure that the officers were able to conduct the meetings without her presence. I had the opportunity to witness a meeting in which Ms. Takao could not attend. The meeting flowed as normal with very little interruptions her absence.

While each participant was part of the general OA membership, they were also part of other day programs for adults with disabilities. Swimmer and Pink Monkey were part of the same program. However, Princess, Vyper, and Scanner Chief were participants in other programs. In addition, prior to this research study, the participants had little interaction with each other. The OA members meet
monthly for their full-membership meetings. This meant that most participants would only see each other once per month for the two-hour meetings. While participating in the Photovoice project, the participants met every week instead of every month to allow for better continuity and shorter research duration. Of the seven sessions, the first two sessions were researcher-driven and were devoted to Photovoice training, three sessions focused on sharing and discussing the data (photographs) collected by the participants, and the final two sessions were devoted to developing their presentation, scripts, and practicing public speaking.

Throughout the research, Princess and Swimmer dominated the conversations. They eagerly participated in discussions, asked clarifying questions, and volunteered to share their stories and experiences with bullying. While both women were eager to express their opinions, they were also very aware of the needs of their fellow participants. Both women supported Vyper and Pink as they struggled to come to terms with their own experiences with bullying and to interpret the photographs. For example, when Princess shared her photo and story of a bus driver who regularly bullied her, Pink and Vyper were silent. They shrugged their shoulders when asked what they thought was happening in the photographs or if they had experienced something similar in their lives. Swimmer thoughtfully turned to Pink and asked her how Princess’s story made her feel. Pink shared that the story made her feel sad. In response, Swimmer nodded her head and said that it made her feel sad too (Researcher Journal, Entry 1).

Group interactions such as the one described above, relationship building between the participants and myself, and the weekly sessions eventually empowered Pink and Vyper to share their own experiences with bullying (Follow-up conversations with Pink and Vyper, 3/3/15). At the fifth Photovoice session, Vyper disclosed to the group that he had been bullied throughout his life. He shared his story of being bullied on the Handivan and how it made him feel scared and angry. When he was finished we all offered encouraging words to him and thanked him for his courage to share such an
emotional experience. Later that session, Pink pulled me aside and personally shared her story. She spoke of being bullied by her teachers and service providers. When Pink finished, I shared my own story of being bullied in an educational setting. She smiled after my story and we hugged. When we practiced our presentation for the community, Pink decided to share her story with our Photovoice group. However, she chose not to share her story during the community presentation.

**Protection of Human Subjects**

Interview protocols, training materials, Photovoice project materials, and consent forms were submitted and approved by the University of Hawai‘i Human Studies Program Institutional Review Board (IRB), at the University of Hawai‘i Manoa Campus (see Appendices ). IRB approval was secured for all of the protocols and materials that were adapted and developed for this Photovoice study.

**Research Procedures**

The study consisted of four phases: training, community presentations and interviews, focus group interview and personal interviews. The first phase of the study included a two-day workshop on implementing the Photovoice process and observing the process of creating a Photovoice project with CLD adults with I/DD. Through these observations, I collected data on how using a PAR method, the Photovoice process, works with this community. In the second phase of the study, I observed the final Photovoice project presentation and conducted a questionnaire with OA community members who observed the Photovoice presentations to gain insight about the Photovoice process for communicating the issues and needs of the participant community.

During the third phase of the study I facilitated a focus group with the research participants to understand their experiences and perceptions of the Photovoice process. I immediately analyzed the data from the focus group and used the themes that emerged to inform and guide the final phase of the study. In the fourth phase I conducted semi-structured personal interviews with each participant, Ms.
Takao, and one community leader. From these interviews, I gained more in-depth knowledge on their individual experiences and perceptions of the Photovoice process.

**Phase 1: Photovoice training sessions.** Ten potential participants were invited to attend the Photovoice training sessions. While I had already met the participants, one of the primary goals for the training was to develop rapport with them, consistent with Kvale and Brinkmann’s (2009) suggestion that the relationship between the interviewer and the interviewees is critical to the knowledge produced by the research. Because I worked with participants who have been marginalized by society, it was important and necessary that they felt comfortable and safe, that they trusted me, and more important, that they felt that their experiences and knowledge were validated and heard (Kvale & Brinkmann, 2009; Skouge & Kelly, 2012). Throughout the Photovoice training, therefore, I endeavored to build a strong relationship of trust between the research participants and myself, including encouraging them to ask questions as needed and share their experiences.

The Photovoice training sessions curriculum was adapted from Katie Shimshock’s *Photovoice Project Organizer & Facilitator Manual* (2008), developed through the University of Michigan School of Social Work Good Neighborhoods Technical Assistance Center. The manual included a sample Photovoice project timeline and a list of supplies/materials needed to complete a Photovoice project. I adapted the materials to plain language to better meet the needs of the participants in the current study. As a double-check, my research assistant reviewed the training materials to ensure they were free from error and written in plain language appropriate for the participants.

The following steps make up the Photovoice process:

1. Define the purpose of the Photovoice research
2. Recruit Photovoice participants from OA
3. Conduct the Photovoice training /discuss risk/obtain informed consent
4. Conceptualize the “issue” with participants
5. Develop themes for taking pictures
6. Distribute iPads to participants for picture taking
7. Facilitate group discussions
8. Select specific photographs for discussion
9. Develop context and storytelling related to the pictures
10. Invite local community leaders to attend a presentation of the findings
11. Prepare the photos and captions for presentation to community leaders
12. Reach local community leaders who are in the position to be able to make change

(Wang, 1999; Wang, Yi, Tao, & Carovano, 1998).

The Photovoice training was held at the OA conference room at a time that was convenient for the participants. Two days prior to the training session, I called the participants to remind them of our training and determine if there were any food allergies or sensitivities. I also made note of any participants who were diabetic. Food and the sharing of food is an important part of cultures throughout the Pacific. Additionally, our training sessions were held in the morning, a time of day when the participants may have gotten hungry. I had healthy snack options available to ensure the participants were comfortable and able to actively participate. The snacks were also a reminder for the group to take a break mid-way through the training sessions.

On the first day of training, I met and greeted participants individually and offered them some healthy snacks (fruit and vegetables) and drinks (water and hot tea). While the participants were arriving and enjoying the refreshments, I distributed a questionnaire designed to collect background information on gender, age, disability type, ethnicity, level of education and/or advanced training, work experience, and topics they would like to address with their Photovoice. The topics of interests
disclosed in the questionnaire were presented to the participants later in the session as possible themes from which they could select one to work on as a group.

After everyone was settled, I began the training by formally welcoming everyone to the Photovoice training session. I introduced participants to my research assistant and reviewed the agenda for our first training session. As a group we then participated in a photo “ice-breaker” activity. Next, we progressed into a PowerPoint discussion of the history and goals of Photovoice, and the Photovoice process (Wang, 1999). We discussed the power dynamics, ethical considerations, and legal/safety issues involved with photography (Wang, 1999).

Specifically, we discussed questions like: *What does the word ethics mean to you? What does the word responsibility mean to you? What does it mean to carry a camera? What is an acceptable way to approach someone when taking his or her picture? Should someone take pictures without the knowledge of the person being photographed? What do you not want to be photographed doing? To whom might people wish to give photographs, and what might be the implications?* (Shimshock, 2008, p. 33).

As part of this discussion, participants reviewed and discussed the acknowledgment forms (see Appendices B-D), which required them to obtain informed consent from any person they wished to take pictures of prior to taking any photographs. We discussed ways of obtaining informed consent, how to approach strangers, how to assess personal safety when approaching others, and how to minimize risks for both the photographer and the subject (Wang, 1999). With partners, we practiced obtaining informed consent and approaching strangers (see Appendix C). The participants struggled asking for consent so as a group we wrote scripts for them to use when they took their pictures. Following this section of the training, the participants signed ethics consent forms stating that they agreed to follow the ethics of Photovoice and photo release forms (see Appendices D and E).
After the ethics discussion and informed consent partner practice, each participant was assigned an iPad. I chose to use the camera function of iPads as opposed to traditional cameras because they are exciting new technology, easy to use, do not require film development, have screens large enough for multiple individuals to view the photographs without having to print the photos, have the potential to allow people with physical disabilities to take photographs, and do not limit the number of photographs each participant can capture.

Once each participant had an iPad, we reviewed a basic handout for successfully taking pictures (how to turn the iPad on, how to turn on the camera, how to turn on the flash, how far to stand from the intended subject, where to stand in relation to the sun, etc.) (see Appendix F). The participants then took their iPads and their acknowledgment forms home, ready to start taking photos related to the Photovoice theme. They were expected to each bring back 5-10 photos that provided insight into their collective Photovoice theme.

As the project facilitator, I provided examples of possible themes (from their background questionnaires), but as a group the participants brainstormed and decided on a common theme. They were also asked to fill out a photo log (see Appendix G) for each photo. The participants discussed these photos and photo logs using the SHOWED method (see Appendix H) in the second training session.

During the second Photovoice training session, we first reviewed participants’ experiences and challenges in taking photographs. We then discussed each of the participants’ photos, the stories they told, and why the participants chose to share them. Each participant chose 5-10 of their “best” photos to share during the group discussions. The photos were meant to inspire in-depth discussions, but also included semi-structured open-ended questioning (Shimshock, 2008; Wang & Burris, 1997). The photo discussion questions were based on the SHOWED acronym, as follows:
1. What do you SEE in this picture?
2. What is HAPPENING here?
3. How does the problem relate to OUR lives?
4. WHY do these problems exist?
5. How can we become EMPOWERED by our new knowledge and understandings of these problems?
6. What do we DO to address these problems?

(Shimshock, 2008; Wang & Burris, 1997)

This process prompted the participants to critically consider the photographs on a deeper level and determine what actions could be taken to address their needs (Wang, 1999; Wang & Burris, 1997). Additionally, this type of questioning allowed participants to identify themes that emerged from the photos and facilitated discussions and brainstorming of steps to be taken to address some of the issues raised in the discussions. At the completion of the group discussions, the participants and I summarized the themes that emerged and, as a group, decided what to do with the photographs.

The SHOWED photo discussions lead the participants into brainstorming possible community leaders with whom they wanted to share their photos. They then discussed additional photos and scenarios they might want to photograph. As a group, we set a time to meet to discuss the next round of photos. Participants had one week to take photographs on their themes and reflect on the photographs by completing their photo summary sheets. We then met to discuss the Photovoice process, participants’ experiences and challenges, and the photos. As a group, the participants decided, based on the SHOWED method, which of the photos told the best story related to the common theme. To ensure all participants had a chance to share and be a part of the Photovoice project, each participant was asked to contribute at least one photo for the community presentation. The participants decided with whom
they wanted to share the problems or conditions they photographed and how to best contact these individuals. They then created an action plan for contacting the community leaders and plan for the Photovoice presentation and community celebration. This included tasks such as arranging the time and date for the celebration, arranging the conference room for the celebration, and determining how the photos would be presented (gallery walk, Power Point presentation, etc.). The group needed to set up additional meetings to work on their presentation and Photo analysis.

iPad safety. One major concern related to using iPads is that the participants may lose them or the iPads may be a target of theft when used in public. During the training sessions, we reviewed ways to keep participants and the iPads safe. For example, I discouraged participants from leaving their iPads unattended, giving away the security passwords, and using their iPads alone in public spaces (e.g., sitting in the bus alone) (Romano, 2013). In addition, Apple Inc. suggested that iPad users might reduce the risk of theft by keeping their iPad in a bag or secure location (Apple Support Community, 2012). “Find My iPad” software was installed so that an iPad could be tracked if lost. Additionally, the iPads carried visible deterrents in the form of engravings and nametags. If an iPad was lost, stolen, or damaged, I took responsibility for handling the issue. Specifically, I asked the participants to report any problems to me immediately so that I could take appropriate steps to recover the iPad or repair the damage.

Phase 2: Community presentation and community member interviews. In this phase, the participants presented their Photovoice projects to their local community leaders. I was present to observe and support the participants during their presentation as well as observe the responses from the local community members. Immediately following the presentations, I conducted a short questionnaire with the local community leaders and members on their perceptions of the Photovoice process for communicating the issues and needs of the participants.
Phase 3: Focus group interview. During the third phase of the study, I facilitated a focus group interview with the research participants as a means of gaining an understanding of their experiences and perceptions of the Photovoice process. I immediately analyzed the data from the focus group interview, used the themes that emerged to inform and guide the final phase of the study, and to began to build a substantive theory of the Photovoice process.

Phase 4: Personal interviews. Semi-structured interview questions were generated using the categories and themes discovered in Phase 3. The goal was to gain more in-depth knowledge about participants’ individual experiences and perceptions of the Photovoice process.

Following the personal interviews with the research participants, I conducted interviews with a community member who was present at the Photovoice presentation and with Ms. Takao. Through the interviews, I attempted to understand their perceptions of the Photovoice process for communicating the issues and needs of the participant community.

Sources of Data and Data Collection

Data sources included the following: Photovoice training sessions (recorded), project field notes and observations, community member questionnaire, community member interviews, focus group, and personal interviews. Table 2 lists each research question and the data sources used to help answer it.

Table 2

<table>
<thead>
<tr>
<th>Research Questions</th>
<th>Data Sources</th>
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<tbody>
<tr>
<td>1. What were the participants’ experiences and perceptions of the Photovoice process?</td>
<td>• Participant interviews</td>
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<td>• Focus groups</td>
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<td></td>
<td>• Observations</td>
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<tr>
<td>2. What were the perceptions of local community members and decision-makers about the process of using Photovoice as a tool for CLD individuals with I/DD to communicate their strengths, issues, and needs?</td>
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| • Community presentations
| • Community member interviews
| • Researcher journal and observations
| • Community member questionnaire |

In the following, I describe each data source, the protocol used to collect the data, and how data from each source was prepared and analyzed to answer the two underlying research questions.

**Participant interviews.** During October 2014, participants attended the Photovoice training sessions. They presented their project to local community leaders and members in November 2014. Following these experiences, I conducted purposeful interviews consisting of semi-structured, open-ended questions with each participant. As the interviews were my primary data source, I prepared and used an interview guide.

The use of the interview guide suggested that there was some structure to the interviews, even though the interviews were treated as conversations during which the participants shared detailed information and comments. Rubin and Babbie (2009) suggested using an interview guide to provide structure to the interview process, but also to allow for flexibility. The interview guide also eased the task of organizing and analyzing the data.
The decision to conduct interviews at the conclusion of the research project was to allow participants time to reflect on their experiences with Photovoice over the entire Photovoice process. With participant permission, the interviews were audio recorded and transcribed. The personal interviews were used to help answer Research Question 1.

**Observations.** With participant permission, I recorded the two Photovoice training sessions. The data from these sources were useful for reviewing the dynamics of the training, gaining insights on how to adjust the Photovoice process for CLD adults with I/DD, and beginning to build a theory on the Photovoice experiences on CLD adults with I/DD. In addition, I used these data to inform and guide the focus group to be conducted with participants following their local community member presentation.

**Focus group interview.** The focus group included the research participants to gain insight into their experiences and perceptions of the Photovoice process. I shared the themes and theories that arose from the community member presentation and observations from the trainings with the participants to gain further insight from their perspectives. Themes that emerged from the focus groups were used to build a substantive theory of the Photovoice process and shed light on the participants’ perceptions and experiences with the process. This data source helped answer Research Question 1.

**Community member questionnaire.** Immediately following the participants’ community presentations, I administered a semi-structured questionnaire with the community members. In particular, the questionnaire gathered information on how they felt about using the Photovoice process as a way to communicate the needs of CLD adults with I/DD and their perceptions of their overall experience. The community member questionnaire helped answer Research Question 2.

**Community member interviews.** Purposeful interviews consisting of semi-structured, open-ended questions were conducted with Ms. Takao and one community member. An interview guide was prepared based on data collected during the community presentation and the community member
questionnaire. The goal of the community member interviews was to gain detailed information and comments on the community members’ perceptions of the Photovoice process as a way to communicate the needs of CLD adults with I/DD and their perceptions of their overall experience. With participant permission, the interviews were audio recorded and transcribed. The community member interviews were used to help answer Research Question 2.

Researcher Journal. The final data source was the compilation of my journal. Keeping in-depth and thorough field notes (a) allowed me to record my thoughts and observations on specific events and ideas, which were useful for developing an interview protocol; (b) provided insight into the various stages of data collection; and (c) provided an audit trail to document my decisions and reflections pertaining to the project (Lincoln & Guba, 1985). Specifically, the audit trail of the journal notes included contextual, methodological, analytical, and personal/reflective notes (Rodgers & Cowels, 1993).

Contextual documentation consisted of the journal notes I wrote to describe the accounts and factors related to the context and process of the project. Methodological documentation, in turn, included descriptions of all methodological decisions made during the study. Analytical documentation included details of my thoughts as they occurred during the analysis of the data. Tracing my steps in the analysis process like this demonstrated the rigor of the procedures used. Finally, personal/reflective documentation provided a means to reflect on my opinions and possible biases. Because the credibility of the study relies on the procedures used during data collection and analysis, the documented reflections allowed for assessing the decisions I made in light of the biases that may have come into play given what I brought to the study (Rodgers & Cowels, 1993). In summary, the field notes provided further insight into both research questions and addressed issues of trustworthiness and bias.

Data Preparation and Data Analysis
All data collected through personal interviews and focus groups were organized in a binder and a file in my home office. To protect their identities, participants were assigned pseudonyms. Within one day of each interview and focus group, I reviewed the recording and inserted my notes or reflections (e.g., body language, emotions expressed, and voice inflections) (Huberman & Miles, 1994; Sandelowski, 1995). After I reviewed the recordings, I transcribed them to use for analysis. The rationale behind this quick timeline is that I hoped to transcribe the interviews while the information was fresh in my mind and I was more likely to remember additional details from the interview.

In addition, the data analysis adhered to the grounded theory procedures described by Strauss and Corbin (1998) and included three stages of coding: open, axial, and selective.

**Open coding.** The first stage of analysis involved open coding. This included a line-by-line examination of the transcripts and the generation of codes that categorized these data. After the transcripts were coded, both the codes and transcripts were reread in order to group codes together to create categories. The categories also incorporated the stories and photos of the participants.

**Axial coding.** During this second stage of analysis, I generated categories as part of an attempt to begin moving towards a theoretical understanding of the data. According to Strauss and Corbin (1998), in axial coding, the categories are related to subcategories, which will form more complete explanations of the social phenomenon under study (i.e., communication between CLD adults with disabilities and their local community leaders). The axial coding process involved written descriptions of each category and the creation of a diagram to represent the relationships between the categories and the subcategories.

The next stage of axial coding was to discover a way to present the findings as a set of related concepts. To that end, I reread the transcriptions to confirm that the concepts and categories accurately represented the interview responses. In addition, I explored how the concepts and categories were
related, what conditions influenced the concepts and categories, and what were the social and political contexts and the associated outcomes.

**Selective coding.** During this stage I combined all the categories identified as “core” categories that were central to phenomenon of the study. To determine the core categories, I considered how one might conceptualize the findings in a few sentences and how the variation between and among the data could be explained.

**Establishing Trustworthiness**

Lincoln and Guba (1985) proposed four criteria to determine the trustworthiness of a qualitative research study: transferability, credibility, dependability, and confirmability. Trustworthiness is the process and condition that the research study had undergone to ensure that the findings are worth “taking account of” (Lincoln & Guba, 1985, p. 290). Comparable terms used in quantitative research are: external validity, internal validity, reliability, and objectivity (Babbie, 2010).

**Credibility.** The credibility criteria were involved to establish that the results were credible or believable from the participants’ perspectives. Qualitative research seeks to describe and understand a phenomenon through the eyes of the participants. Additionally, the research participants determined the credibility of the results. As mentioned, during the training process and interviews, I built rapport with the participants in order to create conditions that were conducive to honest and open responses. Transcriptions of the interviews were provided to the participants for affirmation of the statements. Member checks were completed after the study was complete by sharing all of the findings with each participant. This allowed the participants to critically consider the findings and comments concerning their participation. The participants affirmed the accuracy of the findings giving the study results credibility. Member checking also served an important role in ruling out possible misinterpretation of participant meanings and perspectives, and to identify possible researcher biases.
**Triangulation.** In qualitative research, data triangulation is used to establish credibility by analyzing the research questions from multiple perspectives. During the data analysis in this study, the participants’ feedback was compared to that of their council liaison and the community members present at their Photovoice project presentation to determine areas of agreement as well as of divergence.

In addition to data triangulation, the study included investigator triangulation. The data were compared and crosschecked by two analysts. A colleague in the College of Education at the Leeward Coast Community College and I independently analyzed the same data and compared our findings. Merriam (2009) suggested that if our independent analyses arrived at the same conclusions, we can have confidence in the findings. Yet, often two analysts do not look at the data in the same way. The benefit of having two analysts review the data was the conversation about the differences they found in the data. Reconciliation of differences could help deepen the understanding of both researchers, and of the research itself.

The inclusion of multiple data sources increased the credibility of the study. These consisted of personal documents in the form of the participants’ Photovoice project, in-depth personal interviews, interviews with the community members, focus groups, field notes, and observations.

The benefits of triangulation include increased confidence in the study as a result of the diversity and quantity of the data used for analysis. One disadvantage of triangulation is that the process is time-consuming. Collecting more data led to the need for additional planning and organization. To assist in this data collection, I developed a procedure for conducting the interviews to include a set of previously determined interview questions.

**Transferability.** *Transferability* refers to the degree to which the results of the study can be generalized to other circumstances: setting, people, and time. To maximize transferability, I developed
rich, thick descriptions about the setting, participants, training sessions, and findings. Additionally, adequate evidence was presented in the form of notes and quotes from the interviews and documents.

**Dependability.** In quantitative research, the term *reliability* refers to the repeatability of the study. That is, whether the study can be repeated by somebody else and still produce the same results. In qualitative research, on the other hand, the emphasis is on describing the changes that occur in the setting and how such changes impact the study (Yin, 2009).

Dependability is difficult to establish due to the nature of qualitative study and ever-changing human behavior. That is, one participant’s experience with Photovoice may not be the same as that of another. Additionally, the experience of multiple participants is not necessarily more reliable than that of a single person. Therefore, replication of the study will not necessarily yield the same results.

In order to ensure consistency and dependability, an audit trail was implemented in addition to the use of triangulation, peer examination, and the investigator’s position. Lincoln and Guba (1985) suggested the use of an audit trail to explain how researchers arrived at their results. I established an audit trail in the form of recorded memos and a research journal. These documents included reflections on the research, my questions, and decisions I made with regard to the challenges, issues, and ideas I encountered while collecting and analyzing the data.

**Confirmability.** While quantitative researchers strive for objectivity, qualitative research recognizes that each researcher brings his or her unique perspective to a study. In qualitative research, therefore, confirmability refers to whether the study results may be confirmed by others. I attempted to increase the confirmability of the study by documenting the study procedures and checking the data throughout the study. At the conclusion of the study, I conducted an external data audit and examined the data collection and analysis process to look for potential biases in the procedures. External audits involve having a researcher, not otherwise part of the research process, examine both the process and
product of the research study. The purpose is to evaluate the accuracy and evaluate whether or not the findings, interpretations, and conclusions are supported by the data (Creswell, 2003; Lincoln & Guba, 1985) and to provide an opportunity for an outsider to challenge the process and findings of the research.

**Data Dissemination Plan**

The data were shared in two major ways: (a) a community celebration and (b) the opportunity to co-present at the May 2015 Pacific Rim International Conference on Disability and Diversity.

**Community presentation.** In hopes of inspiring change in their communities, the study participants hosted a community presentation for local community members, leaders, and the participants’ family members. The participants elected to present to their OA community members, officers, and service providers. They based this decision on the hope that they might share important and helpful information with other members. The goal for the community celebration was to (a) disseminate the information to local leaders; (b) share information about CLD adults with intellectual disability or developmental disabilities; (c) develop relationships between the community leaders and the research participants; and (d) encourage and develop next steps to address the needs the participants identified.

**Dissemination opportunities.** Information about this study and its findings were shared via publications (e.g., OA newsletter, OA website summary, published manuscript, and presentations to the OA members, officers, and community leaders). In addition, the participants presented their Photovoice project at the 2015 “Day at the Capitol” and at the May 2015 Pacific Rim International Conference on Disability and Diversity.
CHAPTER 4

RESULTS

Grounded theory analysis was conducted to answer the two research questions underlying this study: What were the participants’ experiences and perceptions of the Photovoice process? What were the perceptions of local community members and decision-makers about using Photovoice as a tool for CLD individuals with I/DD to communicate their strengths, issues, and needs?

Qualitative data were collected from seven data sources: one participant focus group transcript, nine telephone interview transcripts, one in-person interview, observations from three photo discussion sessions, questionnaire feedback from 28 community members, one observation of the community presentation, and 24 pages of field notes. This chapter presents the themes and subthemes that emerged for each research question and how they relate to the research questions.

To stay true to a participatory approach to research, member checks were conducted with all interview transcriptions and data analysis write-ups. This chapter discusses how statements made by the participants provided significant feedback regarding the research questions and concludes with a discussion about how the data address the research questions.

Research Question One: Participants’ Experiences of Photovoice

In response to the first research question, this section provides insight into participants’ experiences and perceptions of the Photovoice process. Specifically, the discussion includes researcher observations and the themes that were uncovered in the focus group, interview processes and the Photovoice presentation.

Researcher Observations

Observational data were collected from the Photovoice training and the photo discussions. The data were later used in the development of the focus group interview questions and personal interviews.
The following section provides insight from the observational data.

**Photovoice training.** During the Photovoice training sessions, the participants were engaged in the materials and the training. Vyper participated actively, asking questions and offering anecdotal information. Princess was also engaged, asking other participants if they understood the concepts. During the ethics discussion, she offered examples and demonstrated that she was competent with the material. She also shared her experiences of being bullied and repeatedly expressed that she hoped sharing her experiences would help others.

Like Princess, Swimmer was an active participant, always willing to share her ideas and experiences. Even when talking about her experiences with bullying, she remained positive and attempted to assist other participants in developing their understandings of bullying. Pink appeared to be engaged in the training sessions, but was less vocal than Vyper, Princess, and Swimmer. She made eye contact, nodded her head, and appeared to be listening intently. Over the course of the sessions, Pink began to share more of her thoughts and experiences. Chief was quiet during the presentation portion of the training sessions but engaged in the information and demonstrated understanding of the concepts presented during the discussions and iPad practice. While he did not attend the photo discussion sessions, focus group interview, or personal interview, he did participate in the mid-project summary at the OA officers’ meeting and provided technical support during the Photovoice community member presentation.

**Photo discussions.** At the beginning of each Photovoice discussion session, I reviewed the process and checked for participants’ understanding. Then I encouraged them to share their photos on the project topic and any challenges they had encountered while taking the photographs.

All participants were able to articulate the Photovoice process and share the challenges they had encountered while taking photos, including difficulty obtaining signatures on consent forms, lack of
assistance at home, lack of time, fear of taking pictures alone, and forgetfulness.

Swimmer was always prepared for the discussions, bringing her photos and completed photo analysis sheet. She shared that she and her sister, Lydia, would take walks in the evening together to take photographs – Lydia assisted her in taking photographs and completing her photo analysis sheet. Prior to each session, she also proofread Swimmer’s writings. In addition, Swimmer had her own journal in which she wrote her thoughts and ideas. She shared these writings with the group during our discussions.

Through the photo discussions, Swimmer was able to explain and analyze her photographs using the SHOWED questions (see Chapter 3) from Shimshock (2008) and Wang and Burris (1997). Swimmer was able to evaluate her photos and express which photo she felt best supported the topic. She was also able to independently produce a script to read during the community presentation.

Princess brought photographs, but she did not complete her photo analysis sheet. When asked why, she responded that it was difficult for her to write out her answers on paper and that she preferred to express herself verbally. She added that she was very busy with work and additional committee memberships. I offered to meet with her to assist her with her writing. Despite multiple phone calls and emails from me, she did not respond until the night before the last photo discussion session.

While she did not complete her individual photo analysis, Princess verbally shared her analysis in the small group setting. With assistance, she was able to use the SHOWED mnemonic to help the group understand the stories and meanings she attached to her photos. In order to promote independence and self-advocacy, I also introduced the PHOTO mnemonic: “Describe your Picture.” “What is Happening in your picture?” “Why did you take a picture Of this?” “What does this picture Tell us about your life?” “How can this picture provide Opportunities for us to improve life?” (Graziano, 2004). Using the PHOTO questions, Princess was able to evaluate the quality of her photos and create
plans for how they could be used in the community presentation. During the discussions, she also
prompted others to share their thoughts on her photographs.

The PHOTO questions also helped Pink and Vyper participate in the discussions, as both
struggled with the photo analysis. Pink brought photographs to the first photo discussion session, but
brought neither photographs nor her completed photo analysis sheet to subsequent sessions. When
asked why she did not take additional photographs or complete her photo analysis sheet, she answered
that she had no one to help her. She elaborated that it was difficult for her to operate the iPad and ask
potential subjects to sign consent forms. I offered to meet with her during the week to assist with taking
photographs and completing her photo analysis sheet, but she did not respond to my calls or emails. At
the conclusion of the project, Pink said she would like to have a partner for her next Photovoice project,
noting that if she had a partner, one person could operate the iPad and the other could ask the subject to
sign the consent form if applicable.

Pink attended every session, brought her binder and iPad, and appeared to be actively engaged in
the sessions. Yet, she was often quiet and had to be prompted to participate in the discussions. She
struggled with the SHOWED questions, but was able to answer the PHOTO mnemonic questions.
During the second-to-last session, she was able to share her stories of bullying with me, and later that
session with the rest of her group. Pink shared that her teachers had bullied her in school and made her
feel like she was “not smart.” She also shared that her teachers told her she could never go to college
and that it had made her feel bad. After Pink disclosed such a personal and emotional story, I shared my
own experience with educational bullying. I saw her experience as a teachable moment and helped her
understand that almost everyone has been bullied at some point and that she is not alone.

Vyper, similar to Pink, only shared photographs during the first photo discussion session and did
not complete his photo analysis sheet. His photos from the first session were very dark, and the other
participants were unable to identify the subjects or the composition of the photos. He explained that he took his photographs late at night. When asked why he was taking photos in the dark, Vyper explained that he was uncomfortable taking photographs alone during the day and was afraid neighborhood kids would bully him. He said that he would try to take photos during the daylight. However, he did not bring photos to the second discussion session. I offered to meet with Vyper and assist him in taking photographs. He was excited about meeting with me and said, “That would be great.” Nevertheless, he did not return my phone calls or emails and we never met.

While he did not share additional photographs, Vyper was still an active participant in the photo discussions. When listening to other participants share their photos, Vyper was able to analyze the photos using both the SHOWED and PHOTO mnemonics. He was articulate and able to evaluate which photos would be best shared during the community presentation. He was also able to suggest what additional photographs were needed for the presentation. However, throughout most of the training and photo discussion sessions he was unable to discuss how the photos related to his life or discuss his experience with bullying. During Session 6, Vyper was inspired to share his experiences of bullying with the group members. He explained that he had been bullied his entire life: in school, in the park, and on the bus. In a follow-up conversation he stated, “If I didn’t do a Photovoice, I wouldn’t have been comfortable talking about bullying.” When asked what specifically helped him to feel comfortable to talk about his experiences, he responded, “The project, the group and you helped me feel safe and supported to talk about bullying.” Vyper did not separate the Photovoice process from the support of the group or the researcher. To him, the entire Photovoice experience allowed him to share his story.

The following table contains the images of the photographs the participants shared during their photo discussions and in their community presentations. The table includes the corresponding discussion themes that emerged through their photo discussions. The themes are posed as questions,
which were participant generated. The table also includes examples of participant comments from the photo discussions.

Table 3

*Photograph Discussions*

<table>
<thead>
<tr>
<th>Participant Photographs</th>
<th>Themes From Discussions</th>
<th>Story Shared/Supporting Statements</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>What is bullying?</td>
<td>“Bullying means someone who treats others like they are weak, not strong enough to speak up, and makes them feel like they don’t belong” (Princess).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“The definition makes me feel sad” (Pink).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“We should tell people how they make us feel and tell them what they are doing is wrong” (Vyper).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I speak up for myself” (Swimmer).</td>
</tr>
</tbody>
</table>
What do bullies do?  

“Bullies pick on people they think are weak” (Princess).

“Bullies pick on the weak” (Pink).

“They think you won’t talk back or you won’t tell someone” (Vyper).

“Bullies tease you, hurt you, steal things on the computer, swear at you, say you can’t go to college, make you feel stupid, say I can’t do things, and make you feel less than them” (Pink).

“Bullies do it and they know what they are doing is wrong, they do it anyway” (Swimmer).

“This is a picture of a boy getting bullied by another student. The bully punches the boy in the eye. This is what bullies do. It makes me sad when people are bullied. It is not very nice. I want to make them stop it” (Swimmer).
<table>
<thead>
<tr>
<th>How does bullying make you feel?</th>
<th>“People want to run away from home and cut themselves too” (Princess).</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“Sad … want to fight back … bad … and makes you feel down” (Pink).</td>
</tr>
<tr>
<td></td>
<td>“Other people commit suicide because of being bullied” (Vyper).</td>
</tr>
<tr>
<td></td>
<td>“When you get teased, you feel alone and helpless” (Swimmer).</td>
</tr>
</tbody>
</table>
Where does bullying happen?

“Bullying can happen anywhere. It can happen on tennis courts, basketball courts, the playground, and at school” (Swimmer).

“It can happen on the bus, Handivan, and at work” (Princess).

“I was bullied a lot. On the bus, they cut in front of me” (Vyper).

“Bullying happened in school” (Pink).

“I was bullied by my teacher when I ate my lunch. She would make fun of me for eating too slow” (Princess).
Who helps stop bullies?

“My sister helps me” (Swimmer).

“My counselor stops bullies” (Princess).

“The bus driver, police, teachers, and other OA members” (Vyper).

“Family and friends” (Pink)

“Me” (Swimmer).
<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>How can we stop bullies?</td>
<td>“One way we can stop bullying on the bus is to put up a new sign. We can put a sign next to the others on the Handivan. It can show the word ‘bullying’ in the middle with a red line over it like the other signs. That way people will know that they are not allowed to bully people” (Swimmer).</td>
</tr>
<tr>
<td></td>
<td>“We can tell the bullies to ‘stop,’ walk away from them, and if they keep bullying ask an adult or teacher for help” (Pink).</td>
</tr>
<tr>
<td></td>
<td>“Another idea is to make a commercial on TV to get our voices heard. That way everyone in Hawai‘i can hear that bullying should stop. We can also make laws to stop bullying. That’d be a good idea. Maybe Photovoice can help” (Vyper).</td>
</tr>
</tbody>
</table>

**Focus Group Interview**

Observational data from the Photovoice training, the photo discussions, and the Photovoice presentation were used to guide the development of the semi-structured focus group interview guide. The focus group interview guide consisted of six open-ended questions: 1. *What did you like or dislike about the Photovoice project?* 2. *Could you tell me about a time when you faced a challenge while completing the Photovoice project? How did you resolve it?* 3. *Think about the times when you had to*
take pictures on your own, what was hard about taking the pictures? 4. What did you learn through the Photovoice photo discussions? 5. How will you use Photovoice in the future? 6. How did you feel about being a presenter during the community presentation?

The researcher, research assistant, and Ms. Takao, the OA state liaison, reviewed the discussion questions prior to meeting with the participants. This ensured the questions were free from biases and were written using appropriate language. With participant consent, the focus group was recorded, and the discussion was transcribed immediately following the focus group interview.

The focus group took place after the community member presentation in early November 2014. The participants were excited from presenting and the community members’ positive reception of the material. While I had permission from Ms. Takao to hold the focus group, individual program coordinators were rushing some of the participants to finish quickly. The program coordinators were given advanced notice of the focus group interview. However, they did not want to hold their vans for the participants. Pink was particularly distracted and kept watching the door and partially wheeling closer to the exit. Similarly, while Vyper and Swimmer actively participated, sharing their responses, they also seemed to feel rushed. They normally spoke in detail about their thoughts and experiences. However, during the focus group, they were more prone to give short responses.

In addition, Princess was not allowed to stay for the focus group interview. Her program decided after the community presentation that she needed to return immediately to her program site. I emailed her the focus group interview guide. However, Princess and I were never able to meet to discuss the focus group interview questions. Due to the sense of being rushed and Princess’s absence, I decided to address themes from the focus group interview in more detail during the personal interviews (see below).
**Focus group interview results.** Through the focus group interview I gained more information about participants’ experiences and perceptions of the Photovoice process through their participation in the Photovoice training, photo discussions, and community presentation.

Analysis of the focus group data as it relates to Research Question 1 revealed three major themes and numerous subthemes within each category (see Table 4). After completing the analysis of the focus group transcription, I met with the participants to review the themes and confirm my findings in order to stay true to the participatory action research (PAR) nature of this research and increase the credibility of the study. The participants confirmed the themes and subthemes that arose as major talking points in the focus group interview.

Table 4

*Focus Group Themes and Subthemes*

<table>
<thead>
<tr>
<th>Major Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Components of Universal Design for Learning</td>
<td>Representation</td>
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<tr>
<td></td>
<td>Expression</td>
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<tr>
<td></td>
<td>Engagement</td>
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<tr>
<td>Challenges of Photovoice</td>
<td>Photo composition</td>
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<tr>
<td></td>
<td>Obtaining informed consent</td>
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<tr>
<td></td>
<td>Fear of working alone</td>
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<tr>
<td></td>
<td>Unintentional consequences</td>
</tr>
<tr>
<td>Benefits of Photovoice</td>
<td>Sharing stories</td>
</tr>
<tr>
<td></td>
<td>Empowerment</td>
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<tr>
<td></td>
<td>Learning new skills</td>
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</table>
Components of Universal Design for Learning (UDL). As Princess was unable to participate, only three participants took part in the focus group interview. All three participants expressed that they had a positive experience with the Photovoice process, including independently identifying that they enjoyed learning about the principles of UDL, including representation, expression, and engagement. In particular, the participants shared how the Photovoice process supported them to represent their knowledge and learning through various media, express their knowledge and stories, and engage with the topic and material.

Representation. Photovoice and digital technologies, such as iPads, provided new opportunities for the participants to interact with the topic of bullying and connect it to their daily experiences. Vyper shared that he enjoyed the visual aspects of Photovoice and developing the community presentation. He specified, “I liked downloading the pictures and analyzing them. I liked putting the presentation and scripts together.” The Photovoice process enabled Vyper to engage with digital technology in the process of sharing his experiences and educating others about the harmful impacts of bullying. He was able to express his knowledge through digital photography and PowerPoint.

To Swimmer, who had previously disclosed that she was a visual learner, a favorite part of the Photovoice project was “taking the pictures and talking about them.” Swimmer also enjoyed drawing and, in fact, drew a picture to represent her understanding of bullying during a photo discussion session.

Image 1: Swimmer’s definition of bullying.
Expression. Each of the participants navigated the learning environment differently. Swimmer preferred to draw to express her knowledge. Vyper chose to write his ideas in paragraph format. Pink enjoyed taking pictures with her iPad. During the focus group discussion, Pink shared that she did not enjoy talking to groups of people. However, the iPad camera provided her with a means to represent her thoughts and knowledge in a new and exciting way. She stated, “I can hold the iPad to show my pictures.” That is, by using the iPad camera, Pink was able to connect with the topic of bullying and share her understanding of the concept in a way that was appropriate for her learning style.

Engagement. The iPads offered participants a chance to connect their life experiences to their Photovoice topic. Both Pink and Vyper enjoyed learning through photography and appreciated the visual aspects of the Photovoice project. In addition to taking photographs, Swimmer shared that she “liked the skits.” She explained that developing and acting in a skit helped her learn and share her knowledge with the other participants.

The idea of using Photovoice as a process of gaining voice led me to wonder more about the participants’ learning styles and which aspects of Photovoice helped them share their knowledge and stories. Gaining such insights proved to be helpful in answering Research Question 1 and led to the development of the interview questions.

I asked the participants what they liked about the Photovoice project at the beginning of the focus group interview because I wanted to start on a positive note with a question that would not be perceived as threatening or uncomfortable and give them a chance to share their immediate reactions to their community presentation.

Challenges of Photovoice. The following two questions addressed the Photovoice process. My hope was to gather further information on the participants’ experiences with the process and their
abilities to problem solve solutions to challenges they encountered while completing the project. The participants expressed four challenges that they encountered.

**Photocomposition.** All three participants identified challenges with photocomposition, including choosing which pictures to take and figuring out the best angle from which to capture shots. Swimmer shared that it was challenging to think about lighting and photocomposition. After discussing her challenges with the group, Swimmer decided to ask for help from her family. She explained, “I went back with my sister, she helped me.”

**Obtaining informed consent.** The participants also struggled with obtaining informed consent from their photo subjects. Pink noted, “It was hard asking people for their pictures and getting the consent forms.” While Swimmer stated that it was not difficult to get her consent forms signed with her sister’s help, she shared that “it was hard to get the objects in the pictures and get people in the pictures without their names on it.”

**Fear of working alone.** A third challenge related to working alone. Vyper stated, “There was no help. I was scared. I didn’t like taking the pictures alone.” Pink explained, “It was hard alone. Nobody could help me.” While the participants were encouraged to work with family, friends, and each other outside of the Photovoice sessions, only Swimmer chose to do so.

**Unintentional consequences.** Vyper brought up a final challenge: the unintentional consequences of taking photographs – his fear of being bullied during the Photovoice process. He explained, “I was scared a lot. I had the same shirt on today as in the photos. I was afraid they’d think I was the bully.” Vyper worried that wearing the same shirt in the photograph and at the presentation might have caused the participants to mistakenly believe he was a bully. He was representing a bully in the photograph and afraid the participants would not be able to distinguish between his acting for the photograph and reality.
**Benefits of Photovoice.** The final three questions explored the participants’ perceptions of what they had learned through the Photovoice process and how they would implement these skills in the future. Specifically, they noted that the Photovoice process had enabled them to share their stories, empowered them to share their voices, and supported them in learning new skills.

**Sharing stories.** The participants shared that they learned how to use the Photovoice process to share their stories and would like to use the process again. Pink indicated that she would use the Photovoice process to help her tell her stories and experiences. Vyper added that he would like to use the process to take pictures of challenges and problems he faces in his community. In addition to learning about sharing his own story, he also “learned about other people in the group through their stories.” Swimmer shared that she would use Photovoice to assist her in her advocacy work with other people with disabilities. She explained, “We could use it to share our voices to other people and in the ‘Feel Safe Being Safe’ training.”

**Empowerment.** All three participants indicated that the Photovoice process was an empowering experience. In addition, each articulated how he or she planned to use the process on a personal level. For instance, Swimmer recognized the flexibility of the Photovoice process, stating that she would try using Photovoice again with different topics to empower her to share her stories and experiences. An active self-advocate who regularly participates in trainings and presentations, she recognized that Photovoice empowered her to educate others on various topics and bring about change for people with I/DD.

**Learning new skills.** When asked what they learned through the Photovoice process, Swimmer and Pink shared that they learned how to use an iPad. In addition, they had learned about giving a presentation and leading a group discussion. Even though Swimmer and Vyper had previous experience presenting to groups, they both felt the Photovoice process helped them share their knowledge and work
with others. Vyper contributed that “It was good to share our work with the group.” Pink, on the other hand, had never spoken in front of an audience. She acknowledged that it felt good to present and share her stories, “People clapped and told me I did good.”

**Summary.** Data from the focus group interview revealed three major themes and numerous subthemes and allowed me to better understand the participants’ experiences and perceptions of the Photovoice process. In particular, the participants elaborated on their experiences with the Photovoice process as well as the challenges and perceived benefits of participating in the project. The themes that arose guided the development of the personal interview protocol.

**Personal Interviews**

In-depth purposeful interviews were another primary data source. According to Merriam (2009), interviews are needed to truly understand the phenomenon being studied. During the personal interviews, I hoped to gain more information about themes that arose in the participants’ Photovoice project, photo discussions, community presentations, and focus group interview. The interviews were semi-structured with a mix of nine flexibly worded and unstructured questions, including follow-up questions and questions seeking clarification. The plan was to limit the interviews to 60 minutes. However, all four interviews lasted 20-30 minutes.

As the participants were dispersed across the island of O’ahu, had transportation challenges, and led busy lives, I offered them the option to be interviewed in person or over the phone. All four participants requested phone interviews. The actual recording of the interviews was achieved with the GarageBand recording software. During the interviews, I kept notes of key points and main ideas. At the conclusion of the interviews, I completed verbatim transcriptions of the recorded interviews. In addition, to stay true to the PAR nature of Photovoice research, I included the participants in every step of the data analysis. After analyzing the interview transcriptions, I met with the participants to confirm
my findings and to offer them the opportunity to share additional information. This step was aimed at encouraging and supporting the participants to become co-researchers and also to increase the credibility of the study.

Statements made by the participants during their personal interviews provided significant feedback to theme development with regard to Research Question 1. The themes included empowerment, importance of trust, supporting others, and suggestions for improvement (see Table 5).

Table 5

*Personal Interviews*

<table>
<thead>
<tr>
<th>Major Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empowerment</td>
<td>Sharing stories</td>
</tr>
<tr>
<td></td>
<td>Developing community</td>
</tr>
<tr>
<td></td>
<td>Recognizing and addressing bullying</td>
</tr>
<tr>
<td>Importance of trust</td>
<td>Safety</td>
</tr>
<tr>
<td></td>
<td>Building trust</td>
</tr>
<tr>
<td></td>
<td>Teamwork</td>
</tr>
<tr>
<td></td>
<td>Learning through leadership</td>
</tr>
<tr>
<td>Supporting others</td>
<td>Video training</td>
</tr>
<tr>
<td>Suggestions for improvement</td>
<td>Partners’ modifications to presentation</td>
</tr>
</tbody>
</table>
these problems. The following sections show how Photovoice served as a means to empower the participants to share their stories and experiences, reflect on the challenges CLD adults with I/DD face, and take actions to address them.

**Sharing stories.** Vyper shared that the Photovoice process empowered him to share his story. “It just helped us to tell our stories. Tell what we do and care about.” While he seemed to be challenged when having to analyze the photos, he still felt that Photovoice was “really fun” and that he learned a lot from the discussions. Over the course of the study, Vyper was empowered to gain his voice and share his experiences with bullying. He also took on a lead role in the group presentation. He explained that he wanted to “give them the skills that we learned over the past six weeks.” In short, the Photovoice process empowered Vyper to talk about the challenges he faced in a safe environment, consider solutions with other participants, and share possible solutions with his community in the hopes of eliminating bullying. In a follow-up discussion, Vyper added, “This was empowered research. Ever since you talked about it, I can’t stop thinking about it. The word keeps spinning in my head. We were empowered to share our photos and stories.”

Princess also felt empowered by the Photovoice process. “Photovoice helped me show myself in pictures. It helped me to show myself to others.” Within the research group, Princess also recognized that she was becoming a role model for other participants because of her willingness to share her experiences. She explained, “I really opened my voice for others, for change. I’m going to be a voice for people like me. I’m going to help other people. I want to be their role model.” Following the community presentation, Princess shared an outcome that was exciting to her. She informed me that “the girl from Maui, who was at our presentation … said that I was a role model for her.” She added, “That is a blessing for me to get so much positive feedback.”
In addition, Princess shared an example of how she witnessed Photovoice empowering another research participant:

“Pink surprised me because she couldn’t really talk, but she tried her best to share her experience. This was her first time presenting herself, Photovoice. It gives people like Pink, who are really shy, a way to share their feelings and stories. It helped her and we as a group helped support her too.” Not only did Princess have first-hand experience with the empowering nature of the Photovoice process, she also identified how the process empowered other participants. Through the Photovoice process, Princess was able to share her stories, reflect on bullying in her life, take actions to address bullying with her community members, and witness how Photovoice helped other people in her community.

**Developing community.** When asked how Photovoice made her feel, Pink shared, “I felt like I was part of the group . . . I felt like my voice was heard. People listened to me.” Through the Photovoice project I also witnessed a substantial change in Pink’s participation and communication. In my first journal entry I wrote:

“I am concerned about whether this project is appropriate for Pink. She does not speak regularly during the group discussions. I have to ask her direct questions and wait patiently for her responses. She does not seem to enjoy talking. However, she does seem to like being part of our group: she comes to every session, smiles, watches the PowerPoint presentations, looks at the other participants when they speak, nods her head when she agrees with what they say, raises her hand when asked for an opinion on a topic, and occasionally shares a few word responses.”

Throughout the Photovoice project, the other participants and I attempted to encourage Pink to share her experiences and participate in the group discussions. Through these efforts at relationship building, positive reinforcement, and the empowering nature of Photovoice, Pink was inspired to share
her story with other participants and me. In a follow-up interview, she shared, “I liked it [Photovoice] and want to do another one. I can help teach others about Photovoice and bullying.”

In part, Pink’s progress can be attributed to the relationships she developed with the other research participants and the support and positive reinforcement she received. Princess and Swimmer took Pink under their tutelage and encouraged her throughout the project. Swimmer, a motivated and active self-advocate, regularly assisted Pink in photo discussions.

Throughout the interview, Swimmer repeatedly talked about how she enjoyed the Photovoice project and how she would use what she learned in future projects. When asked how Photovoice empowered her to share her stories, she talked about community and safety. “I felt safe to talk about anything.” Safety played a major role in her empowerment process. Through the Photovoice community, Swimmer felt safe in her surroundings. The community created by the other participants and me enabled Swimmer to share her experiences and stories. Swimmer also shared that the Photovoice process “made me feel stronger because it helps me share my voice.”

By developing a supportive community, the participants felt safe to participate in the Photovoice process. Through Photovoice, they were empowered to share their stories and voices and to recognize and address bullying in their everyday lives.

**Recognizing and addressing bullying.** Photovoice provided participants an avenue for recognizing and identifying bullying in their lives. Recognizing and accepting that they were victims of bullying was often an emotional experience. Some participants (Princess and Swimmer) were immediately able to share their experiences; for others (Vyper and Pink), it took much longer to process the fact that they were victims of bullying.

Princess was able to openly share her stories and experiences with bullying, including sharing how she experienced bullying on the bus and in school.
“What I liked the best about Photovoice was I liked to take pictures of how people bully others. Then we shared how others bully us. I liked sharing our experiences and stories with the other participants. Bullying happens everywhere, in schools and outside too. It helped me to share my experiences with bullying. It makes me feel that we can stop bullying.”

During the second photo discussion Princess showed the group a picture of the inside of the Handivan. She explained that she was not comfortable taking a picture of the bus driver because he bullied her each day. The group shared their thoughts and experiences around the photograph and helped Princess brainstorm solutions. At the conclusion of the study, Princess stated that the Photovoice project had helped her recognize that the bus driver was a bully and had empowered her to make a change. She shared, “one thing that happened right after I shared about my stories about the Handivan was that I changed my driver.” Through her experience with Photovoice, Princess was empowered to report her former bus driver to the Handivan dispatcher and now has a new driver who supports and helps her. She added, “I spoke up for myself and there are now more cameras in the vans … and I’m riding in a newer Handivan, too.”

Image 2: Princess’s former bus driver.
Like Princess, Swimmer was also eager to share her stories, take photographs, and write analyses of her photos. While she did not share one particular personal story about bullying, she pointed out an example of bullying that took place during the community presentation. She said, “during the Photovoice presentation one boy told us that he was bullied and hit. Everyone laughed at him. Ms. Takao made them stop.”

In a follow-up question, Swimmer added, “I was glad Ms. Takao stopped them. It made me feel bad. I told him I was sorry for that afterwards, too.” Through this spontaneous episode and the discussion that followed, the community members demonstrated that bullying was such a common experience in their lives that they could not recognize it and when they did, they just laughed it off. However, with the help of Ms. Takao and myself, the participants were able to use that teachable moment to help the community members recognize bullying in their lives and identify steps to keep them safe and stop bullies.

Similar to Princess and Swimmer, Vyper was eager to share his thoughts on other participants’ photos and add additional ideas for photographs. However, in the first five sessions, Vyper was unable to share his own experiences with bullying. He avoided my probing questions or stated that he had never been bullied.

Over the next month, Vyper slowly started to become more comfortable discussing bullying. Instead of avoiding my questions, he shared hypothetical scenarios. For example, when Princess talked about her experience with bullying in school, he described what he would do if that happened to him. Vyper also shared what he thought it might feel like to be bullied by a teacher.

In the final photo discussion session, Vyper was encouraged to write down his thoughts on each photo and how they related to his personal experiences with bullying. He ended up sharing a story about
a time when he was bullied. When asked what motivated him to share his story, he stated, “The project gave me courage. It took a lot of courage to talk about being bullied.”

Vyper experienced bullying in his everyday life and this was an emotional topic for him. Over the seven weeks of working on the Photovoice project and participating in the photo discussions, he learned how to identify bullying and the steps to safely address bullying. During a follow-up interview in March 2015, Vyper was able to recall these steps four months after the Photovoice community presentation and the completion of the study.

Pink was also resistant to sharing her experiences with bullying. Over the course of the study, Pink began to verbally participate in the photo discussions and share how the photographs or topics made her feel. In the final photo discussion session, Pink shared her experience with being bullied. Pink motioned for me to come to her side of the table. When I sat down next to her, Pink told me her experience of being bullied in school. In addition to students bullying her, Pink shared, “My teachers told me I was not smart and could never go to college.” With tears in her eyes, she added, “This really hurt a lot.”

Pink rarely volunteered information or spoke in sessions. After she shared her story and I apologized on behalf of the teacher and students who had bullied her, I shared my own story of being bullied. Through our short discussion and sharing of stories, I strengthened my bond with Pink and helped her understand that she was not alone in her experiences with bullying. This was obviously a very painful topic for her. Yet, as painful as it was, she decided to share her story with the rest of the Photovoice participants. The group quietly listened to her speak and then offered positive words and encouragement when she finished.

During a follow-up interview, I asked Pink why she chose to share her story. She responded, “I talked to you and the group because I know you. I trust you.” The Photovoice process and the stories
shared by the other participants helped Pink recognize how she has experienced bullying. Yet, the bond between Pink and me was necessary for her to share her experiences with the rest of the participants. The need for trust among the research participants and with me was clearly critical.

**Importance of trust.** Throughout the study I worked diligently to develop strong bonds with all of the research participants. The success of these efforts is reflected in the interviews. Each participant shared how he or she felt safe to share their stories with the other participants and me. They also shared that they trusted me and the other research participants.

**Safety.** When asked, “How does Photovoice make you feel?” Swimmer replied, “Well, I’d say that we first have to make sure that all the people are safe. The people in our group made me safe in my surroundings. I felt comfortable talking about anything.” For Swimmer, trust and safety were intertwined. Feeling safe allowed her to trust our group and fully participate in the meetings. Through the relationships we built as a Photovoice community, she felt comfortable sharing her personal stories and experiences with bullying.

**Building trust.** Pink did not share personal information with the group until Session 6. It took six weeks of working together for Pink to trust me enough to share her experiences with bullying. In an interview, I asked what inspired her to finally share her story with the group. She explained, “I don’t like talking to people I don’t know. I talked to you because I know you.” After she shared her story with me, she was also inspired to share her story with the other research participants.

Pink participated in the final presentation, but she did not share her personal story. Instead, she shared the group’s ideas on the impact of bullying. Pink recognized that presenting was “kind of hard” for her and noted that in future presentations she would prefer to hold up her pictures rather than speaking to the audience. While Pink was able to trust the research participants, she was still working on trusting others and overcoming her fear of speaking to unfamiliar people.
**Team effort.** Similar to Pink, Vyper shared that he had never been bullied and maintained this position through most of the study. While he was able to share his thoughts on the quality of other participants’ photos, he did not share his own photos or stories. During each session, the other research participants and I encouraged Vyper to share his opinions and experience with bullying. Gradually, he started to tell how the photos made him feel and eventually he acknowledged that he had been bullied most of his life – in school, on the bus, and in public places.

When asked what helped him share his stories, Vyper explained that Photovoice was a team effort. He added, “We all helped each other. We all worked together.” During the interview, Vyper explained, “I learned a lot from what we did. I learned about bullying too …The project gave me courage.” Vyper’s courage to speak up was based in the trust we developed over the Photovoice project and the knowledge that his “team” would support him. At the conclusion of the project, Vyper announced that he would like to become a Photovoice facilitator and help other people with disabilities develop the courage to share their voices.

**Learning through leadership.** From the start of the project, both Princess and Swimmer were inspired to share their voices to help others learn from their experiences. This research was an opportunity for Princess and Swimmer to take on leadership roles and share their voices with the other participants.

Over the course of the project, Princess and Swimmer became the unofficial leaders in our group. They shared their voices when others were afraid to and helped support other members when they struggled to understand a concept or participate in discussions. Princess noted, “I liked sharing our experiences and stories with other participants … It helped me to share my stories of bullying so that other people will know that they are also bullied.” By becoming a leader and sharing her stories with other members, Princess gained self-confidence. She acknowledged, “It helped me to help others.”
Princess and Swimmer also talked about learning from other participants. Both women indicated that they enjoyed hearing “about other people’s stories and making new friends.” Princess added that she was “touched by other people’s stories” and that the other participants gave her “good advice.” She concluded by saying that the Photovoice process had made her feel happy and that she hoped to participate in another project. Princess was motivated to share her experience with others and help more people learn about the Photovoice process.

**Supporting others.** Supporting others was another major theme throughout the study. From the very first training session in October 2014 all the way through the interview process in January 2015, the participants repeatedly stated they wanted to share Photovoice with other people with I/DD. This section includes the participants’ plans to use Photovoice in the future to benefit others with I/DD.

**Video Advocacy.** As previously stated, Swimmer was an energetic advocate for people with disabilities. She had participated in advanced training and travelled to Washington, DC, to advocate for people with disabilities. During the personal interview, I asked her how she would use Photovoice in the future. She stated, “I’d use Photovoice in my video for ‘Feeling Safe, Being Safe.’ It is a way for everyone to hear my voice and thoughts and feelings. That way everyone in the world can hear our voices.” Swimmer recognized that the data collected with the other research participants could be used in developing an advocacy video and training. Swimmer not only understood the Photovoice process, she was also able to share a potential way to adapt it to meet her needs and the needs of others in her community. Swimmer shared her desire to extend her message about bullying through the use of video technology. Through video, she believed that “more people will hear our voices.” While Swimmer wanted to share the knowledge she gained from the Photovoice experience through video technology, the other participants talked about helping others on a smaller scale.
**Transformation.** Pink and Vyper expressed their desire to complete another Photovoice project. Pink also wanted to be trained as a Photovoice facilitator. As a facilitator Pink wanted “help teach others about Photovoice and bullying.” Over the course of the six-week study, Pink shifted from being a shy, quiet participant to becoming an advocate ready to share her story with other people with disabilities and help others learn about Photovoice.

Vyper also went through a personal transformation. In the beginning he was unable to share his experiences with bullying, yet over the course of the project he began to gain confidence and slowly started to share his stories. On the Photovoice process, Vyper shared, “Working on the project gave me a lot to think about. I am excited to start another one and help train other members. I really want to do it … I want to give them the skills that we learned over the past six weeks.” Vyper explained that he would like to “give them courage” to share their voices, too.

**Suggestions for improvement.** After describing the Photovoice process, the participants were asked to describe any changes they would make to the process. In addition to learning more about their perceptions of the Photovoice process, this question was designed to support the participants in sharing their opinions about the challenges they faced in the Photovoice process.

All participants explained that they would like to work with partners in future Photovoice projects. Vyper shared that “Two people to a topic would have been much easier too … That would be perfect. We wouldn’t have to worry about bullies either.” The participants agreed that having a partner would ease their struggle with obtaining informed consent, their fear of working alone, and the fear of being bullied while gathering photographs.

Three of the four participants did not have support systems at home to assist them with the Photovoice process. Vyper stated, “I was on my own.” Princess added, “No one helped me.” Swimmer,
however, received the support of her family to assist her in the Photovoice process. She explained, “My sister helped me.”

Princess and Swimmer also shared that they would like to make modifications to the presentation style. Rather than writing in the photo logs, they would prefer to share their input through auditory processes. Princess explained, “Sometimes I don’t write because it’s easier for me to express myself verbally. Teaching me to record my thoughts on the iPad would help a lot.” Swimmer added, “I’d like to make more speeches and more drawings. That would help me share my stories.”

**Summary.** The themes of empowerment and improving Photovoice emerged from the personal interviews. The participants shared that through the Photovoice process they felt safe and like they were part of a community. They learned about photography, sharing their stories through photography, and helping others. They also gained courage through the process learned about the importance of trust and rapport. This trust helped them work together, feel safe, and support others.

Finally, the participants suggested that working with partners in the future would help mitigate the challenge of obtaining informed consent and reduce the chance of being bullied while taking photographs. Finally, Swimmer and Princess shared that they would appreciate more opportunities to express themselves verbally and through drawing.

**Summary of Findings Related to Research Question One: Participant Perceptions of Photovoice**

Overall, the focus group and interviews suggested that the participants had a positive experience with the Photovoice process. Four themes with relevance to the participants’ experiences and perceptions of the Photovoice process emerged: empowerment, the importance of trust, supporting others, and suggestions for improvement. The participants were able to elaborate on the themes by sharing personal examples and stories. The data supported Research Question 1 in that the participants’ shared their experiences and perceptions of the Photovoice process.
Research Question Two: Perceptions of Community Members

This section provides insight into the second research question related to the perceptions of local community leaders and decision-makers about using Photovoice as a tool for CLD individuals with I/DD to communicate their strengths, issues, and needs. Three data sources contributed to this question, (a) observations from the community presentation, (b) a brief community participation questionnaire, and (c) interviews with two OA community members.

Observations From Community Presentation

The Photovoice participants chose to present their project at the monthly OA full membership meeting. On the day of their presentation, approximately 30 community members and 15 service providers were present. The following table shows the nine slides presented to the community members and service providers.

Table 6

Photovoice Presentation
Princess introduced the participants and the Photovoice project to the community members in the first slide. She explained, “Photovoice is a process we learned how to take pictures of things in the community. Our Photovoice project is on bullying. We learned to take pictures of bullying in different places to try to stop it.” She also introduced the four steps of the Photovoice process: pick a topic, gather photographs on the topic, analyze the pictures, and present to the community.

Vyper then shared Slide 2, the research participants’ definition of bullying. Pink shared what bullies do to their victims and led a discussion on two examples of bullying on Slide 3. The photos used in the community discussion are included below.

Image 3: Bullying example 1.  Image 4: Bullying example 2.

Following the photo discussion, Pink shared Slide 4, how bullying makes people feel. Participants answered community member questions and one community member shared his personal experience with bullying. Vyper then presented Slide 5, examples of places where bullying can happen. He shared his experience being bullied on the playground and Princess shared her story of being bullied on the bus. Related to Slide 6, Pink discussed people who can help stop bullies and showed photographs of family members, her counselor, a friendly bus driver, and a police officer. She also shared her personal experience with bullying on Slide 7. This included a role-play activity in which she acted out a scene of her being bullied in school. Pink then shared her research on steps to follow when being
bullied. Through the final slide, Swimmer ended the presentation with a discussion of ways to stop bullying. She included her idea of a new anti-bullying sign on the bus and the creation of a service announcement about bullying.

The community members were engaged in the presentation. They reacted to the bullying pictures (e.g., “That’s mean,” “No way!”). When Swimmer asked for their definition of bullying, multiple members expressed their own definitions. Additionally, each time a question was posed, there were always several responses. In short, the community members were supportive of the Photovoice presentation and eager to share their thoughts with the Photovoice presenters.

**Community Member Questionnaire**

At the conclusion of the presentation, I distributed a short questionnaire to gather information on the community members’ perceptions of using Photovoice as a tool for CLD individuals with I/DD to communicate their strengths, issues, and needs. I deliberately chose to use a questionnaire, as the questionnaire format was familiar to the OA community members. After each meeting, the OA community members complete questionnaires on the information and presentation. In these monthly questionnaires the OA community members share what they learned, what they liked, and what they disliked about the meeting. By concluding the presentation with a questionnaire following this format, I was able to ensure our presentation followed their normal meeting routine and was able to gather insightful data on the participants’ perceptions of the Photovoice process.

The questionnaire included questions asking for biographical information, questions on what they enjoyed about the Photovoice presentation and what they did not like, a question on what they learned, and the option to volunteer to participate in a follow-up interview (See Appendix I for the entire questionnaire).

**Biographical Information**
The community participants represented a wide range of OA members. They were associated with four major service agencies on O’ahu for people with I/DD. They were from a range of locations on O’ahu, including Ewa, Ewa Beach, Haleiwa, Honolulu, Kailua, Kalihi, Kapolei, Makaha, Pearl City, Wahiawa, Waialua, and Waipahu. One member was visiting from the Maui chapter. Twenty-four community participants identified as having an I/DD, 2 were service providers, 1 was a parent, and 1 person identified as being both a service provider and a person with a disability. Some of the community participants needed assistance with reading the questions. Others needed help with spelling or in writing their answers. In an ideal situation, I would have been able to create an audio recording of the responses from OA members who were unable to write. However, because we were limited by the OA schedule, I was unable to offer this modification. Instead, my research assistant, the service providers, OA community members, and I assisted the members who required support in completing the questionnaire.

Finally, nine participants indicated that they were interested in participating in a follow-up interview. Six of them included contact phone numbers. Of those, I contacted three based on the information they included in the questionnaire and recommendations from Ms. Takao. One community member responded to my phone call and agreed to participate in a follow-up interview. The remaining two community members never responded to my attempts to set up interviews. The following section presents the responses to the community member questionnaires.

**What did you like about the Photovoice presentation?** Eight of 28 respondents expressed that they liked the information that was shared. One community member wrote, “I learned a lot. I liked the presentation.” Six indicated that they liked the pictures. One person wrote, “I liked that it showed pictures.” One responded that he/she had learned about his/her feelings. Four community members said that they learned not to bully others. Two said they liked the speeches. Two stated that they learned to
“speak out and what to do if they are bullied.” Two members also shared that they liked the activities and the opportunities to share their stories. One person shared her experience of being bullied by high school football players. Finally, somebody suggested making a video.

These results support the notion that Photovoice can support the principles of UDL. Sixteen community members shared that they appreciated the format, pictures, and activities. Photovoice provided the research participants various means to express, represent, and engage with the topic of bullying and the same UDL features supported the learning of the community members.

**What did you dislike about the Photovoice presentation?** Only 6 of the 28 participants responded to this question. Two indicated that they liked everything in the presentation. One stated, “I liked it all.” Another shared, “There was nothing I didn’t like.” The remaining responses reflected a surface-level understanding of the presentation. For example, respondents shared they did not like “bossy people,” “I don’t like fighting,” “I didn’t like it because I don’t like bullying and teasing,” and “don’t look pitiful.” I believe this response can be attributed to a misunderstanding of the question. Rather than explaining what they did not like about the presentation, the respondents shared what they did not like about bullying. My attempts to follow up by phone with the participants who misunderstood the question were unsuccessful.

In follow-up discussions with the Photovoice research participants and Ms. Takao, it was suggested that the failure of 22 community members to respond to this question could be interpreted as them liking all aspects of the Photovoice presentation. There was overwhelming support for the presentation. In addition, the community members were still talking about the Photovoice presentation when I attended their monthly meeting in February 2015 and several OA members have asked when the next Photovoice project will start and volunteered to participate.

**What did you learn?** Twenty-four of the 28 community members responded to this question.
Two major themes emerged: (a) how to recognize and stop bullies and (b) bullying is wrong and needs to stop. Nine responded that they learned how to stop bullying and what to say if they are bullied. One participant shared that the Photovoice presentation made her “flashback to the time that I was bullied and to think of positive ways of handling it.”

Eight participants supported the second theme, that bullying is wrong and should be stopped. One person stated that the Photovoice presentation “showed that everyone can be a bully, but they can stop.” Two shared that bullying hurts people’s feelings. Two of the other respondents shared that bullying can happen on the Handivan. One said he or she already knew all of the information, one stated that he or she wanted to be on the TV commercial, and one liked the skit.

The responses showed that the majority of the respondents understood the topic and the goals of the Photovoice presentation. However, some of the participants might not have understood the questions. For instance, a person responded “I want to be on TV,” clearly demonstrating that he or she either did not understand what was being asked or was rushing to complete the questionnaire.

The data from the community member questionnaire support some of the themes discussed in previous sections and provided insight into wording the questions and structuring the probes to match the instructional level of the community member participating in the project. In addition, they were useful for developing the protocol for the community member interviews.

Community Member Interviews

Following the Photovoice presentation and community member questionnaire, two community member interviews were conducted. The first was with a person with an I/DD and the second was with a program specialist. The interviews were conducted to gain a better understanding of the perceptions of local community leaders and decision-makers about using Photovoice as a tool for CLD individuals with I/DD to communicate their strengths, issues, and needs.
**Friendly.** Friendly was a 35-year-old Hawaiian/Chinese man living in a group home on the north shore of O’ahu. He was originally from Honolulu, but chose to move away from his family to live in the group home. Friendly is a greeter at a coffee shop and is training to work at a surf shop. He is an active community member and regularly attends town meetings. Friendly is also an OA member and would like to run for an elected officer position. He has received training as a self-advocate and is working on goals to become more independent. Friendly rides the bus to meetings and is beginning to take responsibility for his medical appointments. He has been diagnosed as having an I/DD, but he is unable to explain exactly what that means. For enjoyment, Friendly goes to church and a family fitness club where he likes to lead exercises. He chose the pseudonym “Friendly” because he likes making new friends. He was excited to be interviewed and asked to be a participant in the next Photovoice project.

**Learning Through Photovoice.** Friendly provided significant feedback with regard to Research Question 2: perceptions of local community members about using Photovoice as a tool for CLD individuals with I/DD to communicate their strengths, issues, and needs. Specifically, he was asked the questions to gain his perceptions about the process of using Photovoice as a tool for CLD individuals with I/DD to communicate their strengths, issues, and needs. The interview protocol was guided by the data collected from the community member questionnaire (see Appendix M). The questions were worded at a level appropriate for Friendly to understand. The interview took place at Friendly’s favorite breakfast diner near his home.

Overall, Photovoice made Friendly feel “happy because they showed me the pictures.” Friendly shared that he likes “taking pictures and talking about the pictures.” During the interview, Friendly mentioned the importance of pictures five times. He also felt the Photovoice process was beneficial for CLD individuals with I/DD in making and maintaining new friends. “I made new friends by talking to them during the discussion and afterwards. We talked more about bullying at program and at the
clubhouse.” This was an important issue for Friendly because he wants to make friends but sometimes has trouble talking to people. Friendly believed that Photovoice has the potential to help him learn problem-solving skills and how to better “talk to my friends and case manager.” He expressed a strong desire to learn more about Photovoice and participate in the next project. He wants to learn more about Photovoice, iPads, and photography.

In addition, Friendly felt the Photovoice process could be used to support CLD individuals with I/DD to communicate their strengths, issues, and needs through sharing stories. He explained that, “sharing feelings makes us stronger. We get one voice.” For Friendly, the opportunity to share his feelings and stories with other people with I/DD was a strength of the Photovoice process. He felt the process of sharing stories “brought us together. All the groups came together to talk.” The Photovoice process helped Friendly and other community members with I/DD “by sharing their feelings and talking about problems” they face as a community. He felt the pictures and acting helped him better understand the concept of bullying. “Pictures helped me learn about bullying. The skits helped me learn, too.”

Friendly also shared that he believed the Photovoice process has the potential to help CLD people with I/DD develop a sense of community through sharing stories. He shared that the Photovoice process brought groups of people together to share their stories and develop one common voice. Friendly explained, “It was good because it was sharing feelings and brought us together.”

In summary, Friendly was excited to be part of the Photovoice presentation. He felt the process helped him make new friends and share his feelings and stories with other community members. Friendly believed the Photovoice process can be used to support individuals with I/DD to communicate their strengths, issues, and needs through the sharing of stories and pictures. He believed that the process had the potential to bring the community together and make them stronger. In addition, the visual and verbal aspects of the Photovoice process aided Friendly in learning about bullying and talking
with new people. These were important skills for Friendly because he struggled to make and maintain friendships. Friendly is planning to participate in a Photovoice project this summer to learn more about the Photovoice process.

**Ms. Takao.** Ms. Takao is the current OA state liaison and program specialist for the Hawaii State Council of Developmental Disabilities. She has many years’ experience working with the OA members. She was previously the Director of the Best Buddies program for the state of Hawai’i and the Resource Developer for the Best Buddies program in California. Ms. Takao is passionate about working with people with disabilities. She has committed much of her career to supporting and training people with disabilities to advocate for their needs. The interview was designed for her to share her perceptions of the Photovoice process as a tool to support CLD individuals with I/DD to communicate their strengths, issues, and needs. Ms. Takao was present for the four of the six Photovoice sessions.

I first met Ms. Takao and the OA members at the Pacific Rim International Conference on Disability and Diversity in 2013. The following year I presented to the OA members again and had the opportunity to talk further with Ms. Takao. I was impressed with the wealth of her knowledge, the programs she was working on, and her commitment to CLD individuals with I/DD living in Hawai’i. From the moment I approached Ms. Takao about developing a Photovoice project with the OA members, she was supportive. She invited me to be a guest at the OA meetings and to present to OA officers. Further, she donated the meeting space for our Photovoice training and photo discussion sessions.

In addition to helping facilitate the logistics of the project, Ms. Takao assisted the research participants throughout the study. During the photo analysis discussions, she helped make modifications to the training material and assisted participants in writing their scripts for the community presentation.
She also assisted the participants in organizing and setting up the presentation space. [Without Ms. Takao’s support and guidance, this project would not have been possible.]

**Self-Advocacy Through Technology.** The main themes for the interview with Mrs. Takao were (a) interest in Photovoice, (b) enhanced skills, (c) sharing opinions, (d) new technology, (e) lessons learned, and (f) positive life changes as a result of using Photovoice. The following sections discuss each theme in detail.

*Interest in Photovoice.* To begin, Ms. Takao felt the level of participant interest in the Photovoice process was a major strength. She shared, “the members who did attend appeared to be very committed to it. They were there every single day. This meant that Photovoice was important enough for them to come.” Ms. Takao explained that the participants needed to go beyond what a “typical” person would have to do to attend the Photovoice training. Each participant needed to organize transportation and get approval from his or her caregiver to attend the sessions. To many people this may not seem very important, but responsibility is “something that they are very excited to have, but not always given. So, when you entrust someone with something or to show up to a meeting, they will and that is a huge feat for them.”

In addition to organizing a ride and obtaining caregiver approval, the participants also had to explain to their daily programs why they would not attend their sessions. By deciding to attend the Photovoice sessions, they had to learn to “navigate their supports and be able to communicate their priorities.” Ms. Takao expressed that this was an important aspect of the project. “I think it’s hard for people to understand that the small decisions that the members are making are actually really huge and significant for them.” Despite all the challenges the participants faced, “they made Photovoice a priority.”
**Enhanced skills.** According to Ms. Takao another strength of the Photovoice project was that it offered the research participants the “opportunity to enhance the current skills that they are working on in regards to leadership.” These skills included “being professional, coming to meetings, being prepared, organizing a ride, being able to provide input, and being able to share their experiences.” Additionally, the Photovoice process provided a venue for participants to practice their self-advocacy skills and develop new skills. Ms. Takao clarified; “members who never spoke in public were now speaking in public. Those who were already in a leadership role took mentor roles.” She felt this was the goal of self-advocacy.

Through the Photovoice process, the research participants were asked to discuss “different issues, concerns, and experiences on their own.” She felt the Photovoice process was overall an empowering experience for the participants and was a “good mechanism for people to address issues of change that they want in their lives.”

**Sharing opinions.** Another strength of the Photovoice process, according to Ms. Takao was that it asked CLD individuals with I/DD for their opinions. She explained that sharing their opinions might be difficult for people with disabilities because “we don’t ask them for their opinions.” She added that people with disabilities sometimes have trouble giving their opinions because they have never been given the opportunity to share their thoughts on what is important to them. She also explained that many of the OA members still do not have a voice and that our job as professionals is to “continue to teach them how to say what they really want.”

**New technology.** Combining iPads with the Photovoice process made the experience accessible to people with communication devices and physical disabilities. One OA member asked Ms. Takao how a person with a communication device could participate in a Photovoice process. She responded, “You don’t need to speak to say what you want because a picture can tell a thousand words.” The OA
member was excited to share her experiences and stories through photography. Unfortunately, she was unable to participate in this study due to other commitments. However, she is planning on participating in a future Photovoice project.

Ms. Takao also shared that the iPads appeared to work well for people with both physical and visual disabilities. “I think it’s a good avenue for iPads. It’s easy to use. Believe it or not, a camera is hard to use because the buttons are too small and it’s hard to maneuver.”

Not only were the iPads easier to use, they were also new and exciting technology. Using iPads in the Photovoice process gave the participants the chance to learn technology beyond what they learned in school. Ms. Takao explained that the participants were excited to use the iPads because most of them had little to no experience using digital technology. She felt it was “fun because our members get to feel pretty equal to the rest of the community. We’re all using iPads, we’re all using Internet, and phones, and it gives them a chance to be a part of the world as well.”

Finally, iPads and the Photovoice process have the potential to improve the connections between the OA members on O’ahu and chapters on other islands. Ms. Takao stated “technology is a way for OA to keep the spirit of what they are trying to do, which is making changes in their community.” She added, “iPads will definitely do it if each OA chapter has a set of iPads, they learn how to use them, and learn about the Photovoice process.”

*Lessons learned.* By observing the Photovoice process, Ms. Takao learned three main lessons: (a) bullying is a common experience for people with disabilities, (b) participants needed assistance in working through the emotional aspects of Photovoice, and (c) participants needed guidance in finding solutions.

Through this experience, Ms. Takao became acutely aware of the challenges people with disabilities face in recognizing and identifying bullying. “As professionals, what we learned is that
bullying is a very common everyday experience for people with disabilities.” In the photo discussion session, Ms. Takao and I also became aware of the internal struggles some participants had in regards to past experiences with bullies. Over the six weeks, we learned that “bullying is a challenging subject and that some members were really hindered by thinking about the past or trying to verbally express what they thought was important.”

Realizing that some of the participants were struggling with the topic, Ms. Takao and I helped the participants work through their difficult emotional experiences during the photo discussions. She explained that this is an area of advocacy that most people do not address. “We want change, but then we don’t really teach people how to work through the changes in an individual.” She added, “If you look at the purpose of Photovoice and its emphasis on people sharing experiences, I don’t know how you could avoid that.” Sharing experiences and the emotional aspects of advocacy, raised the question of “how do you emotionally or behaviorally move them to a more solution-based thinking?”

During the initial photo discussion sessions the participants were unable to offer solutions to bullying and needed guidance in finding solutions. Through the discussions it became apparent that the participants did not have an idea of what to offer in regard to a suggestion or resolution to the issue. They could talk about bullying and eventually learned the definition, but applying that definition to every day life and then suggesting what to do about it, that took some work. In supporting the participants to become more solution-oriented, Ms. Takao suggested to get to know the participants on a more personal level. This allowed her to creatively modify the Photovoice process to be “individualized to the participants’ needs.” With support, the participants researched state and national definitions of bullying, how local schools deal with bullying, and what approaches other islands are taking to eliminate bullying. The community presentation allowed them to share this knowledge with other OA members.
Prior to the presentation, the OA members saw bullying as a “normal event in their lives and therefore there wasn’t anything wrong with it.”

**Positive life changes as a result of using Photovoice.** In addition to learning about bullying, iPads, and the Photovoice process, Ms. Takao identified positive changes in each participant. For example, she saw a major jump in Pink’s participation. “Pink is a new member who never spoke, but now she presented to the group and made a phone call, without staff, to get information.” She added that Swimmer loves to participate in projects, but the Photovoice process “allowed her to shine and participate in a way that she is comfortable. She shined an awful lot. This was a much more personal project for her.”

Over the course of the Photovoice project, Vyper was also able to reveal his issues with bullying, “which was a major breakthrough.” Finally, even though Chief stopped coming to the Photovoice sessions, he “called to say he couldn’t come because of his job. And he returned the iPad, which is really huge.”

Overall, Ms. Takao felt the Photovoice process was “a very empowering experience.” She also felt that Photovoice was an example of true advocacy. In her work with the OA members, she explained that you start as a self-advocate. Then you expand to become a peer advocate. Finally, you become a community advocate. “Through the three stages you strengthen your character, strengthen your voice, and the skills that you need to change, not only for your life, but for those in your community.” She challenged the participants by asking them what they would do with Photovoice and how they would apply it to their OA members. Participants responded by expressing their desire to present a workshop and poster session at the 2015 Pacific Rim International Conference on Disability and Diversity and to become facilitators for future Photovoice projects. This, she shared, is the “start of empowerment and a voice for people.”

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Summary of Findings Related to Research Question Two

The data from the community presentation observations, community member questionnaire, and interviews with Friendly and Ms. Takao shed valuable insight into the perceptions of local community members and decision-makers about using Photovoice as a tool for CLD individuals with I/DD to communicate their strengths, issues, and needs. While there was much variation, two themes emerged from all four sources: the importance of using photography and the opportunities to learn new skills.

Both the community members with I/DD and Ms. Takao explained the importance of photographs in the Photovoice process as a means of supporting CLD individuals with I/DD to learn new skills, specifically, learning to take and discuss their pictures, learning new technology, and learning to share their stories and opinions with others. As such, the data supported Photovoice as a process that could be used as a tool to empower CLD individuals with I/DD to communicate their strengths, issues, and needs.
CHAPTER 5

DISCUSSION

The purpose of this grounded theory study was to add to the scant literature on the implications of using Photovoice to facilitate communication among CLD adults with I/DD, community leaders, and decision-makers. More specifically, the goal was to explore the Photovoice process as a means of providing insight into the experiences and perceptions of CLD adults with I/DD who participated in the study and develop a theoretical model of how they felt their needs were met and addressed through the Photovoice process. In addition, a community member questionnaire and semi-structured personal interviews were employed to uncover the perceptions of local community members and decision-makers about using Photovoice as a tool for marginalized groups to communicate their strengths, issues, and needs. The study was aligned with the mission of the Council on Developmental Disabilities (DD) to support people with I/DD to control their own destiny and determine the quality of life they desire (“About the DD Council,” 2001).

This chapter presents the findings, implications, and recommendations for future research.

Relationship of Results to the Related Literature

Multiple themes and subthemes emerged from the seven data sources. Four themes transcended the data sources: Photovoice as an example of universal design for learning (UDL), challenges of Photovoice, benefits of Photovoice, and the importance of trust. Table 8 shows the relationships between the themes, subthemes, participant quotations, and related studies that support the themes and subthemes.

Table 7

Common Themes/Subthemes From All Data Sources

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
<th>Participant Quotations</th>
<th>Related Studies</th>
</tr>
</thead>
</table>

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### Benefits of Photovoice as a Participatory Action Research Tool for Empowerment

| 1) Sharing Stories | “It helped us tell our stories. Tell what we do and care about” (Vyper). |
| 2) Understanding through the participants’ perspectives | “People listened to me” (Pink). “The project gave me courage” (Vyper). |
| 3) Photo Evidence | “The pictures were us acting but they were my experiences” (Princess). “The pictures helped me learn about bullying and talk to others” (Friendly). |

### Challenges of Photovoice Process

<p>| 1) Training and Consent | “It was hard asking people for their pictures and getting the consent forms signed” (Vyper). |
| 1) Unintentional Consequences | “We had to tell them that I am not a bully … I’m just acting” (Swimmer). |
| 2) Multiple Means of Representation | “I liked downloading the pictures and analyzing them. I liked putting the presentation and scripts together” (Vyper). |
| 2) Multiple Means of Representation (Acrey, Johnstone, &amp; Miligan, 2005; CAST, 2008) |</p>
<table>
<thead>
<tr>
<th>Importance of Trust</th>
<th>3) Multiple Means of Expression</th>
<th>“I can hold the iPad to show my pictures” (Pink).</th>
<th>(Acrey et al., 2005)</th>
</tr>
</thead>
<tbody>
<tr>
<td>4) Multiple Means of Engagement</td>
<td>“I liked the skits, acting, and staging the photos” (Swimmer).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Tool for empowerment.
Photovoice is based on Paulo Freire’s theory of empowerment education (Wang, 1999), which encourages students to share their educational experiences, reflect on the roots of social problems in their communities, and take social action against these problems. The following sections discuss how Photovoice empowered the participants in the current study to share their stories and experiences, reflect on their challenges as CLD adults with I/DD, and take actions to address these challenges. As such, the discussion shows that Photovoice can be a means of (a) empowering people with I/DD in sharing their stories, (b) providing photo evidence of their experiences, (c) gaining an understanding of the topic through participants’ perspectives, (d) developing community, (e) creating sustainable tools, and (f) learning new skills. By being empowered to share their stories and voices, the participants were able to identify and recognize bullying in their everyday life experiences.

### Sharing stories.
Throughout the study, participants expressed that the Photovoice process helped them share their stories. The culminating presentation in the Photovoice process of sharing stories is essential and enabled the participants to “share the knowledge they gained and thus strengthen
their voices” (Graham, 2011, p. 85). This experience was acutely important for Vyper and Pink. Prior to this study, neither of them was able to identify or address bullying in their lives. However, through the Photovoice process, after listening to the stories of the other participants and reflecting on their photos, Vyper and Pink were able to develop an awareness of bullying and how it impacted their lives. Pink, who had been silent throughout most of the process, shared that she will use Photovoice in the future “for telling my stories.” While Pink is still quiet and typically speaks in simple sentences, she now has a tool to assist her in sharing her voice.

In addition to raising awareness of the issues they face, the Photovoice process empowered the participants to make meaningful changes in their daily lives. For example, Princess used the knowledge she gained in the Photovoice process to address the bullying she experienced on the Handivan. She shared, “One thing that happened right after I shared about my stories about the Handivan was that I changed my driver.” Thus, as a result of her experience with Photovoice, Princess was empowered to report her old bus driver to the Handivan dispatcher and now has a new driver who supports and helps her. She added, “I spoke up for myself, and there are now more cameras in the vans … and I’m riding in a newer Handivan, too.” The Photovoice process enables people to share knowledge with others who might find it valuable and use this new knowledge to bring about change (Graham, 2011).
Understanding through participants’ perspectives. Newman et al. (2008) found that taking pictures allowed their participants to document and share their experiences. Streng et al. (2004) reported similar experiences when working with Latino adolescents in rural North Carolina. Thus, in the current study, the process of taking pictures offered an insider’s perspective of the experiences of CLD adults with I/DD.

The iPad cameras empowered participants to share and reflect upon their life experiences. That is, each of the participants used their photographs to document and express their experiences and knowledge of bullying. Thus, they staged photo examples of their definition of bullying, what bullying looks like, how it makes them feel, places where bullying happens, people who can help stop bullies, and their ideas on how to stop bullies. Table 8 shows examples of the participants’ perspectives as presented through their photography.

Table 8

Participants’ Perspectives

<table>
<thead>
<tr>
<th>What Is Bullying?</th>
<th>What Do Bullies Do?</th>
<th>How Does Bullying Make Us Feel?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Princess's photo of bullying on the Handivan.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Photography enabled them to share stories with each other and with community members (Jurkowski, 2008). As a result, through their photographs and photo discussions the participants created more awareness of the issue. Specifically, they demonstrated that bullying is a common everyday experience for people with disabilities.

**Photo evidence.** Through their photography, the participants were able to provide evidence of their experiences with bullying. Thus, they photographed challenges they faced and presented them to their community (Jurkowski, 2008). The photos provided them a means to show their everyday experiences with bullying in a way that others could not argue against.

In addition, the Photovoice process provided participants with intellectual disabilities a venue to reflect on their lives and share their perspectives. They developed their own awareness and understanding of bullying through photo taking, photo reflections, and discussions. Princess explained, “The pictures were us acting, but they were my experiences.” The community member participant, Friendly, also expressed the importance of photographic evidence, noting that the pictures helped him understand the topic of bullying and how it impacted the participants’ lives.

**Learning new skills.** The Photovoice process also has the potential to build capacity for new skill development (Haque & Rosas, 2010; Jurkowski, 2008). Through the Photovoice training, story sharing, relationship-building opportunities, and decision-making, the Photovoice process enhanced
participants’ skill sets and provided them with opportunities to develop new knowledge.

Across all of the data sources both the participants and the community members talked about the new skills they acquired through the Photovoice process. For example, in her interview, Princess mentioned learning from other participants. She enjoyed hearing “about other people’s stories and making new friends.” For Pink and Vyper, the Photovoice process taught them about bullying and helped them gain their voices. Both expressed the desire to share this knowledge with other people with disabilities. Through a conversation about future Photovoice participants, Vyper pointed out that he would like to “give them courage” to share their voices. Additionally, Ms. Takao felt that the Photovoice process provided a venue for the participants to practice self-advocacy and develop new skills. She clarified, “Members who never spoke in public were now speaking in public. Those who were already in a leadership role took mentor roles.” She felt the Photovoice process overall was an empowering experience for the participants and was a “good mechanism for people to address issues of change that they want in their lives.”

**Challenges of the Photovoice process.** Despite all the benefits, the participants’ struggled with the Photovoice process. During the focus group interview and personal interviews, three main challenges emerged: training and consent, individual work, and the unintentional consequences of Photovoice. These challenges are not unique to this study. Goodhart et al. (2006) and Jurkowski (2008) also noted their participants’ challenges with obtaining informed consent and the unintentional consequences of the Photovoice process.

**Training and consent.** Photovoice “entrusts cameras to the hands of people to enable them to act as recorders” (Wang & Burris, 1997, p. 369). Most of the Photovoice literature reports focusing on basic photography skills and technical approaches to photography in the training sessions, along with ethics and safety. However, great variability was found in the approach and scope of the training
sessions in the various studies. For instance, Wang and Burris (1997) included two days of training whereas Wilson, Minkler, Dasho, Wallerstein, and Martin (2006) incorporated “professional” training on photography and research techniques, which extended over several weeks.

Despite training and repeated discussions about the purpose of obtaining informed consent, all four participants in the current study expressed concerns over having potential subjects sign consent forms and continued to struggle to determine when it was appropriate to take photos and if they had to obtain informed consent. Jurkowski (2008) noted that people with intellectual disabilities might encounter difficulties in understanding when it is appropriate to take photographs and the purpose of obtaining signatures on consent forms. For example, two of the participants did not take photos outside of the Photovoice sessions. Referring to taking pictures of local schools, Vyper explained, “It’s hard to get the objects in the pictures and get people in the pictures without their names on it.” Similar to Goodhart et al. (2006), participants chose to photograph inanimate objects and staged scenes. Many of the photos were of buildings, objects, or vehicles. Princess shared, “It was hard asking people for their pictures and getting the consent forms.”

The review of the literature suggested that persons with intellectual and developmental disabilities have largely been excluded from the research as the issues listed above proved challenging both for me to teach and for my participants to learn. Thus, an apparent shortcoming of the extant Photovoice literature is its failure to describe the actual “nuts and bolts” of Photovoice training, including teaching photographic techniques (lighting, setting); teaching storyboarding; obtaining signed releases; and overcoming trepidations related to “public” documentation (e.g., photographing people).

Unintentional consequences of Photovoice. While the ethics training included a discussion of protecting privacy, personal space, not placing someone in a false light, and not using a person’s likeness for commercial gain (Wang & Redwood-Jones, 1997), the participants were concerned about
the potential unintended consequences of taking pictures of bullying. Photographer safety and the ethical considerations for Photovoice came up repeatedly during the discussion sessions. Throughout the project and in the focus group interview and personal interviews, the participants expressed fear of being targeted by bullies while taking photographs or of being mistakenly labeled as a bully from their appearances in the staged photographs.

The participants in the Goodhart et al. (2006) study also feared the unintended consequences of taking pictures. To address their fear, Goodhart et al. (2006) instructed their participants not to photograph any activity that may have caused them or their subjects harm. Likewise, the participants in the current study were instructed to only take pictures in safe environments. As a result, they chose to photograph inanimate objects and staged scenes of bullying. Staging scenes involved the participants working together to share their personal experiences with bullying, deciding how to represent these stories visually, designating the roles of actors and photographer, and determining which photos told the most powerful story.

**Photovoice as UDL.** Throughout the data sources, study participants and community members noted positive experiences with the Photovoice process. For example, they described the importance of photography in helping them understand the topic of bullying and share their stories. Study participants, in particular, independently identified features of the Photovoice process that they enjoyed. The features that they chose to discuss were principles of UDL as described below.

The Center for Applied Special Technology (CAST, 2008) has devoted more than 10 years to researching learning sciences in the development of their UDL guidelines and framework. To better understand the variance in human learning, CAST research has included the fields of neuroscience, cognitive psychology, and multiple intelligences. Based on their findings, CAST has generated three primary principles of UDL: (a) provide multiple means of representation, (b) provide multiple means of
action and expression, and (c) provide multiple means of engagement. The goal of these principles is to encourage the development of teaching methods that enable all students to have equal access to an excellent education (CAST, 2008). The follow section explains how the participants’ responses can be interpreted as examples of the principles of UDL.

**Representation.** Photovoice and digital technologies, such as iPads, provided new opportunities for the participants to interact with the topic of bullying and connect it to their daily experiences. Acrey, Johnstone, and Miligan (2005) found that visual aids helped students recognize the relationship between class content and their lives. Similarly, Vyper shared that he enjoyed the visual aspects of Photovoice and putting together the community presentation. Specifically, the Photovoice process enabled Vyper to engage with digital technology to share his experiences and educate others about the harmful impacts of bullying. That is, through the Photovoice process and visual aids (pictures), he was able to connect his personal experiences to the topic of bullying and express his knowledge through digital photography and PowerPoint.

**Expression.** Throughout the study it was evident that the participants navigated the learning environment differently. As mentioned, Swimmer preferred to draw to express her knowledge. Vyper, on the other hand, chose to write his ideas in paragraph format. Princess favored verbally expressing her ideas or using the iPad to share her stories. Finally, Pink preferred to use the iPad to share her stories.

CAST (2014) encourages using teaching materials and techniques that all learners are able to interact with. During the focus group discussion, Pink shared that she does not enjoy talking to groups of people. She found the iPad camera provided her with a means to represent her thoughts and knowledge in a new and exciting way. “I can hold the iPad to show my pictures.” By using the iPad camera, Pink was able to connect with the topic of bullying and share her understanding of the concept
in a way that was appropriate for her learning style. While she struggled to participate verbally, Pink was able to participate in the Photovoice project and express her ideas through her photography.

**Engagement.** Many Pacific island students and community members come from oral and visual traditions in which they are taught through the observation of and participation in story telling, dancing, singing, modeling, and guided experiences (Iding et al., 2008). Pink, Princess, and Vyper were from Pacific Island backgrounds. Digital technologies such as iPads offered them the chance to celebrate their cultural wisdom and connect it to their Photovoice topic through photography and role-playing.

All of the participants shared that they enjoyed learning through photographs. Even though she was not from a Pacific Island background, Swimmer also reported benefiting from the visual aspects of the Photovoice project. The Photovoice process offers multiple means of engaging with the topic, which optimizes individual choices and allow participants choices about how they interact with the topic (CAST, 2014). Swimmer explained that developing and acting in a skit helped her learn and share her knowledge with the other participants.

**Importance of developing trust.** Finally, the significance of developing rapport with the participants was a major theme throughout the data sources. Trust and partnership between the researcher and the participants ensures collaborative development of the research and a positive impact the participants and their communities (Hergenrather, Rhodes, & Bardhoshi, 2009).

**Between the researcher and the participants.** Kvale and Brinkmann (2009) suggested that the relationship between interviewer and interviewees is critical to the knowledge produced by the research. Because I worked with participants who have been marginalized by society, I believed it was especially important and necessary that they felt comfortable and safe, that they trusted me, and, more important, that they felt that their experiences and knowledge were validated and heard (Kvale & Brinkmann, 2009; Skouge & Kelly, 2012). Throughout the Photovoice project, therefore, I endeavored to build a strong
sense of trust between the research participants and myself, including encouraging them to ask questions as needed and share their experiences. I purposefully planned numerous meetings and information sessions with the participants prior to beginning the study. The following table is a breakdown of the activities and approximate amount of time I spent with the research participants.

Table 9

_Activity Summary and Time_

<table>
<thead>
<tr>
<th>Activity</th>
<th>Time Spent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Photovoice project at PacRim, 2013</td>
<td>3 hours</td>
</tr>
<tr>
<td>Photovoice project at PacRim, 2014</td>
<td>3 hours</td>
</tr>
<tr>
<td>Introduction meeting at Oahu</td>
<td>1 hour</td>
</tr>
<tr>
<td>Advocates meeting, June 2014</td>
<td>30 minutes</td>
</tr>
<tr>
<td>Officers meeting, July 2014</td>
<td>1 hour</td>
</tr>
<tr>
<td>Oahu advocates meeting, July 2014</td>
<td>1 hour</td>
</tr>
<tr>
<td>Introduction/interest meeting</td>
<td>3 hours/day = 6 hours</td>
</tr>
<tr>
<td>2 days of Photovoice training</td>
<td>3 hours/day = 6 hours</td>
</tr>
<tr>
<td>Update/participants present at Oahu Advocates October meeting</td>
<td>1 hour</td>
</tr>
<tr>
<td>3 days of photo discussion and analysis</td>
<td>9 hours</td>
</tr>
<tr>
<td>1-day presentation preparation</td>
<td>3 hours</td>
</tr>
<tr>
<td>1-day presentation to Oahu advocates and community members</td>
<td>2 hours</td>
</tr>
<tr>
<td>Focus group discussion</td>
<td>30 minutes</td>
</tr>
<tr>
<td>Individual interviews</td>
<td>30 minutes/participant = 2 hours</td>
</tr>
<tr>
<td>Final wrap-up, thank-you party with the participants</td>
<td>2 hours</td>
</tr>
<tr>
<td>Follow-up interviews and data analysis</td>
<td>30 minutes/participant = 2 hours</td>
</tr>
<tr>
<td>Total time spent with participants</td>
<td>37 hours</td>
</tr>
</tbody>
</table>

According to my research journal, which is reflected in Table 9, I spent approximately 9½ hours with the participants prior to beginning the study. The only exception was Pink. As she was a new OA member, she did not attend the PacRim presentations. Prior to beginning the project, Pink had spent approximately 3½ hours with me in information sessions and OA meetings. On the first day of training, all of the participants knew me by name.
Through my previous research and experience leading Photovoice projects, I knew that developing rapport with the research participants was vital. Ms. Takao took note of my efforts to build rapport with the participants, commenting that presenting to the members at PacRim and attending the OA meetings was a “good transition into the group.” She also noted that the participants were comfortable with me. She shared, “they trusted you. I think that’s really huge. The advocates won’t work with just anyone.”

In addition, my efforts to develop rapport with the participants were reflected through the interviews with all four participants. Participants shared that they felt safe to share their stories with the other participants and myself and that they trusted me and the other research participants. The following example with Pink highlights the importance of trust.

During most of the Photovoice project, Pink was very resistant to sharing her experiences with bullying, but slowly she began to verbally participate in the photo discussions and share how the photographs or topics made her feel. In the final photo discussion session, she shared her experience with being bullied. Pink motioned for me to come to her side of the table. When I sat down next to her, she told me that she had been bullied throughout her educational career. In addition to students bullying her, Pink shared, “My teachers told me I was not smart and could never go to college.” With tears in her eyes, Pink added, “This really hurt a lot.”

Pink rarely volunteered information and was hesitant to share her opinions in the photo discussion sessions. Her opening up to me was a huge breakthrough. After she shared her story and I apologized for the teachers and students who bullied her, I shared my own experience with educational bullying.

**Developing community.** Streng et al. (2004) saw community building as a strength of the Photovoice process. Specifically, they found that the process enables participants to provide
information on the “hidden transcripts” and critical discourse. In the current study, the Photovoice process aided in developing a trusting community and relationships among the participants and me. The following example from Viper’s experiences sheds further light on this. In the Photovoice training, Vyper struggled to come to terms with his experiences of bullying. Each session, Princess, Swimmer, Ms. Takao, and I encouraged him to share his opinions and experience with bullying, and gradually, he started to share how the photos made him feel. With encouragement from the group, he became more and more vocal to the point that he eventually acknowledged that he had been bullied most of his life – he was bullied in school, on the bus, and in public places. As he spoke about his experiences, it became clear that this was an agonizing and scary topic for Vyper. It took a lot of trust for him to openly share his personal struggles.

When asked what helped him share his stories, Vyper explained that Photovoice was a team effort. He added, “We all helped each other. We all worked together.” During our interview, Vyper explained, “I learned a lot from what we did. I learned about bullying, too … The project gave me courage. It took a lot of courage to talk about being bullied.” Vyper’s courage to speak up was based in the trust we developed over the Photovoice project and the knowledge that his “team” would support him. At the conclusion of the project, Vyper commented that he would like to become a Photovoice facilitator and help other people with disabilities develop the courage to share their voices.

To summarize, multiple themes and subthemes emerged and were discussed through the study. Four themes transcended the eight data sources, including the principles of UDL, challenges of Photovoice, benefits of Photovoice, and the importance of trust. Through these themes, the study revealed the experiences and perceptions of CLD adults with I/DD using the Photovoice process. In addition, the Photovoice process provided a means for empowering people with I/DD to share their stories, provide photo evidence of their stories, gain an understanding of the topic through their insiders’
perspectives, encourage the development of a community, and cultivate the growth of new skills.

Finally, the themes illustrate the perceptions of local community members and decision makers about using the Photovoice process as a tool that enables CLD individuals with I/DD to communicate their strengths, issues, and needs.

**Contributions of the Study**

This study contributed important information on two weaknesses in the Photovoice literature. It provided data on conducting a grounded theory Photovoice study with CLD individuals with I/DD, an area on which there is limited previous research. In addition, this study included both short-term and long-term follow-ups with the research participants to better understand the outcomes of Photovoice with CLD individuals with I/DD.

**Use of grounded theory Photovoice with CLD adults with I/DD.** While multiple Photovoice studies have included people with disabilities using the grounded theory approach (Beart et al., 2003; Carnahan, 2006; Jurkowski, 2007; Jurkowski & Paul-Ward, 2007), few have been conducted with CLD individuals with I/DD (Jurkowski, 2008; Jurkowski & Paul-Ward, 2007; Newman, 2010; Newman et al., 2009).

The results of the current study demonstrated how the Photovoice process can empower CLD individuals with I/DD to record and reflect on their experiences and perspectives on the strengths, needs, and issues their community face. In addition, it revealed potentially empowering aspects of the Photovoice process for CLD individuals with I/DD, including sharing stories, providing their insider perspectives, generating photo evidence, and learning new skills to express their experiences and perspectives. Yet, this research only brushed the surface of this issue and is not generalizable to all CLD individuals with I/DD because the data are based on only four main participants and two community member interviews. Additionally, the results of this study were not meant to be generalized to other or
larger populations.

**Short-term follow-up.** Previous studies have not included short- or long-term follow-up to assess the impacts or sustainability of the Photovoice process (Catalani and Minkler, 2010). This study conducted follow-up interviews two months after the completion of the study. All four of the participants indicated that they were interested in learning to train others with I/DD on the Photovoice process. Further, they presented their work to legislators, service providers, and other individuals with I/DD at the “Day at the Capitol” in March 2015. The following photos were taken of the participants’ display at the Hawai‘i state capitol.

Image 6: Photovoice display.  
Image 7: Photovoice display close-up.

In addition, the participants decided to co-present a 60-minute workshop and a poster session with me at the May 2015 Pacific Rim International Conference on Disability and Diversity, six months after the study. We collaborated on the proposals and the content of the presentations. Active participation in the research process and in the professional presentation development is important for CLD individuals with I/DD because they have been traditionally treated as research participants rather than research partners (Ward & Trigler, 2001). During the PacRim presentations the participants took on the roles of co-presenters and provided first-hand knowledge of their experiences and perspectives of
the Photovoice process. At the conclusion of the presentation, a researcher from Harvard School of Education invited the participants to participate in interviews for a short video about people with I/DD. They expressed excitement for this opportunity to represent their community. The interviews were filmed at the conclusion of the conference.

**Long-term follow-up.** From my experience conducting this Photovoice study, it was apparent that the Photovoice process enabled a sense of ownership among the participants. They were excited to share their photographs and stories with education professionals and eager to help others better understand their experiences with bullying. Further, they expressed an interest in sharing the Photovoice process with other individuals with I/DD and learning to conduct Photovoice trainings. Realizing they did not have money to fund their trainings and purchase the necessary cameras or iPads, the participants and the OA officers decided to write a grant proposal to fund the project. The participants contacted a successful grant writer at the University of Hawai‘i at Manoa to assist them in learning how to write a grant proposal. They are currently planning a grant-writing workshop for the OA officers and the Photovoice participants. The group intends to submit their grant proposal by the September 2015 deadline.

The group also asked Ms. Takao and me to modify the Photovoice training materials and train them to be Photovoice trainers. A date has not been set for this training. However, we anticipate the training will occur over the Fall of 2015. The Photovoice participants plan to conduct their first Photovoice trainings on O‘ahu with interested OA members in the Spring of 2016, and they expect to conduct trainings with the Maui chapter the following summer.

Through this research, the participants provided me with insights into their experiences and perceptions of the Photovoice process. At the same time, they also taught me about their passion and desire to make changes in their community. In fact, they not only wanted to make change, they have
actively taken steps to ensure their work with Photovoice is passed on to other OA members. They are working to raise funds for their project and following-up with key individuals to guarantee their success.

Based on the existing literature, I expected the participants would enjoy the Photovoice process and express interest in conducting future projects (Castleden et al., 2008; Newman, 2010; Newman et al., 2009). However, I did not expect that they would be interested in becoming trainers and leading their own Photovoice trainings and projects. None of the previous research reported such a participant response. I attribute this reaction to the nature of the current group and the continued support and follow-up from Ms. Takao and myself. Both Ms. Takao and I have assisted the participants in their quest to lead future Photovoice projects and attain funding for iPads. I expect long-term follow-up in future studies to discover similar reactions from the participants.

**Limitations**

There are two major limitations to the present study: lack of generalization and possible research bias. To begin, the study was conducted with one organization for adults with I/DD – an organization that was highly motivated to promote self-advocacy, community outreach, and advanced leadership training for its members. According to Strauss and Corbin (1998), the aim of grounded theory research is to build a theory. Therefore, generalizability was not an aim of the methodology. In addition, the participants were purposefully selected from a list of potential candidates identified by the OA officers and Ms. Takao; true random assignment was not possible.

The study offers a theoretical model built on the experiences of 4 CLD adults with I/DD, 28 CLD community members with I/DD, and 1 community decision maker, who were all part of the OA organization. Therefore, the study does not claim to offer explanatory power for the experiences or perceptions of the large number of self-advocates in the United States of America. However, the model offers a starting point for developing further understanding of the experiences and perceptions of CLD
adults with I/DD living on O’ahu who participate in OA. The model was grounded in examples to help readers judge my interpretations of the data. By grounding the study in the participants’ experiences and words, the study was intended to gain a new understanding of CLD adults living on O’ahu who are members of OA.

Including only members from a self-advocacy organization for adults with I/DD limits the study to adult individuals with I/DD who have indicated interest in self-advocacy. Additionally, this may exclude individuals with more severe disabilities as the self-advocacy group was generally composed of individuals who were actively participating in their communities. However, the intent of the study was not to gauge how well each individual within the OA organization was able to function within his or her community or his or her guardianship status.

Furthermore, no data were collected on the exact disabilities of each individual. Instead, the study relied on information provided by the participants and OA officers. I chose not to pursue their exact diagnoses because I was more interested in what the participants had to say regardless of whether they had an intellectual disability, a developmental disability, or both. Some researchers may feel that this drastically affects the generalizability of the findings. Nevertheless, the results should be of interest to individuals with I/DD, their service providers, and families or guardians, as well as other researchers who are interested in using the Photovoice process with CLD adults with I/DD.

Finally, as a former teacher, I had experience working with students and adults with disabilities and other at-risk populations. I also had prior knowledge of the overrepresentation of students from culturally linguistically diverse backgrounds who receive special education services (Harry & Klinger, 2014). As a result, I may have developed a sympathetic bias towards the participants and, therefore, may not have had the ability to remain completely neutral. In addition, I was the sole researcher on this project and, consequently, the only person to analyze and interpret the data collected in this study. Thus,
although Photovoice training materials from Shimshock (2008) and interview protocols were used, the research was open to researcher interpretation.

**Implications**

Empowered to share their stories and voices, the participants were able to identify and recognize bullying in their everyday life experiences. This is important for researchers and service providers because the Photovoice process provided a means for empowering people with I/DD to share their stories, provide photo evidence of their stories, provide an understanding of the topic through their insiders’ perspectives, encourage the development of a community, and cultivate the growth of new skills.

Additionally, the study uncovered several special considerations when conducting the Photovoice process with CLD adults with I/DD. Similar to the findings of Newman et al. (2008), the study demonstrated the need to consider transportation and conflicts with other programs/service providers when planning a Photovoice process with CLD adults with I/DD. While the project took place at a central location and a convenient time, the participants still needed to go beyond what a “typical” person would have to do to attend the Photovoice training. Thus, they had to organize transportation multiple days in advance, get approval from their caregivers to attend the sessions, and explain to their daily programs why they would not attend their normal sessions. That is, as a result of deciding to attend the Photovoice session, the participants had to learn to “navigate their supports and be able to communicate their priorities” (Takao personal communication, November 26, 2014). Coordinating transportation and service provider supports were important aspects for the success of this project and scarcely discussed in previous studies. The study implies that it is necessary for future Photovoice researchers, project facilitators and service providers to discuss these areas with CLD individuals with I/DD when designing future studies.
Recommendations for Future Study

The outcomes of this study clearly indicate that the Photovoice process is beneficial in supporting CLD adults with I/DD to share their strengths, concerns, and needs. Yet, a larger sample size would enable generalization of the findings to the larger population and thereby help fill a void in the literature.

In addition, future grounded theory Photovoice studies should include ways to evaluate the impact of Photovoice projects on participants’ communities. Although Photovoice is a community-based intervention, to date, its impact at the community level has not been well described or assessed. While anecdotal evidence has been used to suggest that Photovoice can be an empowering process for the participants and their communities and it can have long-term impact on communities, few attempts have been made to evaluate the impact of the Photovoice process on the participants and their communities.

Another important recommendation for future studies is to support participants in sharing and discussing their learning needs. Understanding one’s strengths, needs, interests, and learning styles is the first step towards self-advocacy (Abery, Rudrud, Arndy, Schauben, & Eggebeen, 1995). The Photovoice process is rooted in Paulo Freire’s theory of empowerment education (2004), which encourages students to share their educational experiences, reflect on the roots of social problems in their communities, and take social action against these problems. However, in order for this process to take place, the participants must be taught in a way that maximizes their strengths and interests.

Ms. Takao addressed this idea in her interview. She suggested that at the beginning, time be devoted to building rapport with the participants and encouraging them to share how they learn. Such information helps “establish that everyone can be encouraged to say what they need. Not in a way that says I have a disability, rather this is the best way for me to do my best job.”
Many individuals with disabilities do not understand their strengths and needs well enough to explain the accommodations they need beyond school life (Izzo & Lamb, 2002). Wehmeyer, Agran, and Hughes (1998) defined self-advocacy as skills individuals need to speak up or defend a cause (p. 20). Wang (2006) noted that Photovoice has three main goals: to enable individuals to record and reflect on their everyday experiences, to promote critical dialogue about their personal or community strengths and concerns, and to inspire change by presenting to policymakers (p.148). Through the Photovoice process participants are taught to recognize and identify the strengths of their community and advocate for their needs.

**Conclusion**

Photovoice is an emerging research method, which has the potential to be an empowering experience for people with I/DD. The use of photography, critical discussions, and community member presentations provide the participants with opportunities to bring light to the strengths of their communities and advocate for their needs.

In this study, the Photovoice process enabled the CLD individuals with I/DD to become co-researchers. They were able to bridge cultural and learning differences through the use of photography and sharing stories. Additionally, they were given the opportunity to share their expertise based on their personal experiences and knowledge. Although creating lasting changes in communities and in policies can be a slow process, the Photovoice process enabled the research participants to identify strengths, needs, and issues and empowered the participants to advocate for changes in their community. The process also enabled them to provide photographic evidence of their concerns and proved to be helpful in sharing their concerns with their community members and leaders.

In closing, it is my hope that the new knowledge generated by this study will support future Photovoice research on the experiences and perceptions of the Photovoice process from the perspective
of CLD individuals with I/DD. While the participants in this study reported positive benefits from the Photovoice process, future studies are needed to determine the educational impact of the process with CLD individuals with I/DD. The study also attempted to uncover the perceptions of local community members and decision-makers about using Photovoice as a tool for CLD individuals with I/DD to communicate their strengths, issues, and needs. Again, the findings suggest a positive reception from the community members. Yet, further research is needed in this area and on the role of Photovoice as a tool for empowerment education. In the words of Vyper, “If there was no empowerment, why join? We need to be empowered by our photos and stories” (personal communication March 5, 2015). The Photovoice process has the potential to be a tool for empowering CLD individuals with I/DD and their communities to highlight their strengths and advocate for their needs.
Appendix A: Photovoice Participant/Guardian Consent Form

**Participant Consent Form**

*Exploring the Process and Potential of Photovoice with Culturally and Linguistically Diverse Adults with Intellectual and/or Developmental Disabilities*

My name is Amy Bossler. I am a PhD candidate at the University of Hawai’i at Manoa (UH) in the College of Education. I am leading a research project on Photovoice. The purpose of my study is to explore the process and potential of Photovoice with culturally and linguistically diverse adults identified as having an intellectual and/or a developmental disability.

**Activities and Time Commitment:** If you decide to participate in this project you will receive photography training and will take photographs of your lives that have meaning for you. The photographs are taken as part of project to identify issues and educate others about the issues that people with intellectual and developmental disabilities face. Once you take your photographs, you will meet as a group with me to discuss stories related to your photographs. These discussions may be audio recorded and will be followed by short individual interviews to help me better understand your experiences. The recorded group discussions and interviews will last between thirty minutes and one hour. As a group, you and the other participants will decide which photos to share in public exhibits, presentations, or publications. You will only be asked share photos you consider appropriate and comfortable. The entire project will last approximately 4 weeks.

**Benefits and Risks:** You will receive a copy of your photographs and meet with community leaders. You will be able to tell your stories as they relate to your photographs, express your feelings and opinions, and promote community change. I believe there is little risk for you in participating in this research project. However, if you become stressed or uncomfortable answering any of the interview questions, we can skip the question, take a break, stop the interview, or withdraw from the project.
iPad Use: Once you complete the Photovoice training you will be assigned an iPad to use to collect photographs. You will be expected to keep the iPad safe while it is in your possession. If the iPad is lost/stolen it must be reported to me immediately. All iPads are equipped with tracking software, which will be used to locate missing iPads. I will recover the lost iPad once the location is identified. However, if necessary the Police will assist in recovery. If the iPad is damaged it must be reported to me. I will repair the iPad and have it returned to you as soon as possible. You will not be held responsible for lost, stolen, or damaged iPads.

Privacy and Confidentiality: During this research project, I will keep all of the photographs, focus group records, and interview records in a safe place. Only my University of Hawai‘i advisor and I will have access to the data. After I transcribe the interviews, I will erase/destroy the audio-recordings. When I type and report the results of my research project, I will not use your name or any other personally identifying information. Rather I will use pseudonyms (fake names) and report my findings in a way that protects your privacy and confidentiality to the extent allowed by law. It is good to remember that there is always the chance that somebody may recognize you in the photographs.

Voluntary Participation: Your participation in this project is completely voluntary. You may stop participating at any time without any penalty or loss. Should you wish to continue to participate but not have your photographs or stories included in the project, you may do so. There are no negative consequences for withdrawing from the project.

If you have any questions about this research project, please call me at (570) 259-4379 or email me at bossler@hawaii.edu. If you have any questions regarding your rights as a research participant, please contact the UH Committee on Human Studies at (808) 956-5007, or uhirb@hawaii.edu.
If you agree to participate in this project, please sign and date this signature page and return it to:

Amy Bossler  
2355 Makanani Drive  
Honolulu, HI 96817

Agreement Statement: By signing this consent form, I agree to participate in the study:

*Exploring the Process and Potential of Photovoice with Culturally and Linguistically Diverse Adults with Intellectual and/or Developmental Disabilities*

I have read and understand the information provided to me about participating in the research project,

My signature below indicates that I agree to participate in this research project.

Printed name: ______________________________

Signature: _________________________________

Date: ______________________________

You will be given a copy of this consent form for your records.
Photovoice Fact Sheet for Participants
Photovoice enables you to describe your community through photographs.

What is the Photovoice Project?
Your will take photographs, share stories about the photographs and identifying strengths and concerns related to your community.

What is my role?
You will initially receive photography training and will take photographs of your neighborhood that reflect the issues you face. You will also be involved in group discussions and/or interviews to talk about your photographs and why you chose to take the pictures.

What is the purpose of the photographs?
The photographs are taken as part of a project to identify issues and strengths you face in your community. The photographs will be used to educate others about the issues that you feel limit as well as support people with intellectual and/or developmental disabilities.

How will my photographs be used?
Once you have taken your photographs, you will meet as a group with Amy to discuss stories related to your photographs. These discussions will be audiotaped. You will also be asked to participate in an interview for a more in-depth understanding. Group discussions and interviews and interviews will last between 30-60. Some photographs may be included in public exhibits, presentations, or publications. Your will only share photographs you consider appropriate and comfortable.

How long will the project last?
The project will last approximately 4 weeks.

What are the benefits and risks of participating in this project?
You will receive a copy of your photographs and will meet with community leaders to gain their support. You will be able to tell your stories as they relate to your photographs, express your feelings and opinions and ultimately promote community change. There is minimal risk involved. If emotional distress is experienced related to conversations, you are encouraged to visit with the Photovoice Team or counselor in your community. If needed, a mental health referral will be provided.

What if I change my mind and do not want to share photographs or participate in group discussions?
If at a later date, you do not wish to share your photographs with others or participate in discussions, you may contact the project director, Amy Bossler at bossler@hawaii.edu. Photographs and all accompanying information will immediately be removed from the project data. Participants do not have to give any reason for withdrawing. Should you wish to continue to participate but not have your photographs or stories included in the project, you may do so. There are no negative consequences for withdrawing from the project.
Photovoice Project Consent Form for People Who May Appear in Photographs

Photovoice is a process that creates space for marginalized communities to share their experiences through photography. Photovoice has three goals: (1) to enable people to record and reflect their community’s strengths and concerns, (2) to promote critical dialogue and knowledge about important issues through large and small group discussion of photographs, and (3) to reach policymakers.

If you are asked to have your photograph taken as part of the project and agree to do so, please read the following:

What is the purpose of the photographs? Your pictures may be used by the participants of the Photovoice Project to identify strengths or concerns for people with intellectual and/or developmental disabilities through photo exhibits and presentations.

What is involved? Your participation will take less than ten (10) minutes. During this time, the photographer may take pictures that contain images of you. The project is confidential. Your name or any other identifying information will not be known or listed with photographs and reports. It is good to remember that despite efforts to maintain confidentiality, there is always the chance that someone may recognize you in the photographs. Your willingness to be photographed is voluntary and you may decline.

What happens to the photographs? Photographs become the property of the Photovoice Project photographer and will be exhibited at the Easter Seals Napuakea Service Center and in a location that is yet to be determined. All photographs and information will be maintained in a confidential manner.

What if I have other questions? You may contact the Project leader, Amy Bossler at (570) 259-4379.

Agreement Statement: By signing this consent form, I agree to voluntarily have my photograph taken. I also understand and agree that unless otherwise notified in writing, Photovoice Project photographer assumes that permission is given to use my photograph(s) for these given exhibits, presentations, publications and/or other educational purposes and that no identifying information will be used.

Age: ______ Voluntary Phone #: ______________ Date: ______________

Print Name: _____________________________

Adult’s Signature: _____________________________

Photographer’s Name: _____________________________
Appendix D: Photo Release Form

University of Hawai‘i at Manoa: Photo Release Form

Exploring the Process and Potential of Photovoice with Culturally and Linguistically Diverse Adults with Developmental Disabilities

____________ Yes, you may use ANY of the photographs I took during the Photovoice project to promote the purpose of the _______ Photovoice Project

____________ Yes, you may use SOME of the photographs I took during the Photovoice project to promote the purpose of the _____ Photovoice Project

____________ No, you may not use any of the photographs I took during the Photovoice project.

Your Name: _______________________________________________________

Your Signature: ___________________________________________________

Date: __________
Appendix E: Photovoice Ethics Consent Form

Exploring the Process and Potential of Photovoice with Culturally and Linguistically Diverse Adults with Intellectual/Developmental Disabilities

Photovoice Ethics Consent Form

Participant’s Name: ________________________________________________________

In this Photovoice project, you and other participants will take pictures and share stories about the strengths and concerns of your community. This is a chance to teach others about your life as a CLD adult with I/DD.

By signing this ethics consent form you also agree to follow the ethics of Photovoice. Please read the following statements and sign your initials next to each statement, to confirm that you have read and understand each ethic of Photovoice.

1. ______ I will not intrude into an individual’s personal space both publicly and privately.

2. ______ I will not disclose embarrassing facts about the individuals I photograph.

3. ______ I will not place individuals in false light with my photographs.

4. ______ I will respect the confidentiality of the stories that were discussed during the Photovoice reflection sessions.

5. ______ I will obtain the signature of all individuals represented in my photographs.

By signing this ethics consent form means that you have read, understand and respect the ethics and privacy concerns involved in a Photovoice project. If you fail to follow these principles you may be asked to leave the project.

______________________                    ____________
Print Your Name Here                           Date of Birth

______________________                    ____________
Sign Your Name Here                            Today’s Date
Photography 101

Photograph 101: Light

*Pay careful attention to the light conditions in your photographs*

- Try to shoot photos of people in shade so the light is even across your subject(s).
- Try to place the sun at your back when you are shooting your photos. This will help you avoid shadowy faces.
- Always use your flash!

Photography 101: Shooting

When shooting a photograph, hold the camera steady and release the shutter carefully

- Hold the iPad with both hands, with elbows against your body and feet spread apart. This helps to avoid camera shake or vibrations which leads to blurry pictures.

Photography 101: Composition

Composition is the placement of elements (people, objects, environment) in a photograph within the frame of the photograph

- Pay attention to how you arrange the people, objects, and environment in your photograph.
- Use your grids.
- Centered is not always best.
• Think about viewpoint and consider taking a photo from varying levels.

iPad Camera 101

iPad Diagrams
Using iPad Camera

Camera at a glance

Quick! Get the camera! From the Lock screen, just swipe 📸 up. Or swipe up from the bottom edge of the screen to open Control Center, then tap 📸.

Note: When you open Camera from the Lock screen, you can view and edit photos and videos you take while the device is locked by tapping the thumbnail at the lower-left corner of the screen. To share photos and videos, first unlock iPad.

With iPad, you can take both still photos and videos using the front FaceTime camera or the back camera.
**Zoom in or out**
Spread a photo, webpage, or map for a close-up—then pinch to zoom back out. In Photos, keep pinching to see the collection or album the photo’s in.

Or double-tap a photo or webpage to zoom in, then double-tap again to zoom out. In Maps, double-tap to zoom in, then tap once with two fingers to zoom out.
Appendix G: Photovoice Project Photo Log

**Photovoice Project Photo Log**

**Photographer’s Name:** ___________________

**Directions:** Please log each photo you take in the table below. You will need to write down the photo number (from the iPad), describe what’s happening in the photo and tell me why you chose to use it.

<table>
<thead>
<tr>
<th>Photo #</th>
<th>Description</th>
<th>Reflection of the Photograph</th>
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</tbody>
</table>
Appendix H: Photovoice Data Analysis (SHOWED) Form

Photovoice Data Analysis (SHOWED) Form

Photographer’s Name: ______________________________________________________

iPad Number: _______________ Date: ____________________

Photo Number: ________________ Photo Title: ____________________________

1. What do you SEE?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

2. What is really HAPPENING?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

3. How does this relate to OUR life?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

4. WHY does this situation, concern, or strength exist?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

5. What can we do to EDUCATE others about this situation, concern, or strength?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

6. What can or needs to be DONE?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
Appendix I: Community Member Survey

Community Member Survey

1) What is your name?

2) Where are you from?

3) What agency are you apart of?

4) Circle all that apply:  I have a disability  I am a parent  I am a guardian  I am a service provider

5) What did you like about the Photovoice presentation?

6) What did you not like about the Photovoice presentation?

7) What did you learn from the presentation?

8) Would you like to be interviewed about your participation in today’s presentation?

    Yes. My phone number is:______________________
    
    No. Please do not contact me.
Appendix J: Community Member Interview Consent Form

Community Member Interview Consent Form

Exploring the Process and Potential of Photovoice with Culturally and Linguistically Diverse Adults with Intellectual and/or Developmental Disabilities

My name is Amy Bossler. I am a PhD candidate at the University of Hawai’i at Manoa (UH) in the College of Education. I am leading a research project on Photovoice. The purpose of my study is to explore the process and potential of Photovoice with culturally and linguistically diverse adults identified as having an intellectual and/or a developmental disability.

Activities and Time Commitment: If you decide to participate in this project you will be asked to participate in a short (between :10:-:20) recorded interview to uncover the perceptions of local community leaders about Photovoice for communicating the issues and needs of culturally and linguistically diverse adults with intellectual and/or developmental disabilities.

Benefits and Risks: You will be able to share your perceptions of the Photovoice research project, express your feelings and opinions on the process, and promote community change. I believe there is little risk for you in participating in this research project. However, if you become stressed or uncomfortable answering any of the interview questions, we can skip the question, take a break, stop the interview, or withdraw from the project.

Privacy and Confidentiality: During this research project, I will keep all of the interview transcriptions in a safe place. Only my University of Hawai’i advisor and I will have access to the data. After I transcribe the interviews, I will erase/destroy the audio-recordings. When I type and report the results of my research project, I will not use your name or any other personally identifying information. Rather I will use pseudonyms (fake names) and report my findings in a way that protects your privacy and confidentiality to the extent allowed by law.
Voluntary Participation: Your participation in this project is completely voluntary. You may stop participating at any time without any penalty or loss. There are no negative consequences for withdrawing from the project.

If you have any questions about this research project, please call me at (570) 259-4379 or email me at bosslr@hawaii.edu. If you have any questions regarding your rights as a research participant, please contact the UH Committee on Human Studies at (808) 956-5007, or uhirb@hawaii.edu.

If you agree to participate in this project, please sign and date this signature page and return it to:

Amy Bossler  
2355 Makanani Drive  
Honolulu, HI 96817

Agreement Statement: By signing this consent form, I agree to participate in the study:

Exploring the Process and Potential of Photovoice with Culturally and Linguistically Diverse Adults with Intellectual and/or Developmental Disabilities

I have read and understand the information provided to me about participating in the research project, my signature below indicates that I agree to the conditions to participate in this research project.

Printed name: ________________________________

Signature: _________________________________

Date: _______________________________

You will be given a copy of this consent form for your records.
Appendix K: Focus Group Interview Guide

Focus Group Questions

1. When you first started the Photovoice training what did you like or dislike about the project?

2. Now that the project is complete, what did you like best about the Photovoice project?

3. What would you change?

4. Could you tell me about a time when you faced a challenge while completing the Photovoice project?
   
   What occurred? Who was involved?

   How did you handle the challenge?

   What was the outcome?

5. Think about the times when you had to take pictures on your own, what challenges did you face?

   How did you solve them?

6. How did you feel taking pictures on the theme of bullying?

7. Think about the photo discussions, what did you learn through these discussions?

8. How did you feel about being presenters during the SAAC meeting?

9. In what way is your life different because of your participation in the Photovoice project?

10. How will you use Photovoice in the future?
Appendix L: Interview Guide

Interview Questions

1. Tell me about what happened during the Photovoice project.
   
   What was it like?
   
   Why did you sign up?
   
   Who influenced your actions?

2. Could you describe the most important lessons you learned through the Photovoice project?

3. How have your feelings about Photovoice changed since you started the project?

4. As you look back on the Photovoice project, are there any experiences or events that stand out in your mind?
   
   Could you please describe it?
   
   How did the event affect what happened in the project?

5. How would you describe Photovoice?

   Would you describe what you think the best Photovoice training program would be like?

6. Who has been the most helpful to you during the Photovoice project? How has he/she been helpful?

7. When you went home to take pictures, who helped you take your photos?

8. After completing your Photovoice project, what advise would you give to someone interested in starting his or her own Photovoice project?

9. Is there anything else you think I should know to better understand your feelings about the Photovoice project?
Appendix M: Community Member Interview Guide

1.) What did you like about the Photovoice presentation?

2.) What did you learn?

3.) What would you change to make the Photovoice process support CLD individuals with I/DD to communicate their strengths, issues, and needs?

4.) How did the Photovoice process make you feel?

5.) How did the Photovoice process support your needs?

6.) How do you think the Photovoice process helped people with disabilities share their stories, thoughts, and needs?
References


