

# Photovoice: A Tour Through the Camera Lens of Self-Advocates

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## Abstract

Photovoice is a creative form of Participatory Action Research (PAR) that empowers underrepresented groups from the community to become the actual researchers and instigate change. Seven individuals with intellectual and other developmental disabilities (ID/DD) were given the opportunity to document their lives through the use of photography. After creating critical dialogue within individual and group discussions, the photographers developed impactful exhibitions to share with close friends and family, as well as the broader community. The goal of this Photovoice program was to change perspectives and promote sustainable systems change toward a more socially inclusive community. While the participants collectively contributed to the six primary themes that supported the need for social inclusion, one photographer provided the reader with a tour through his camera lens as a self-advocate who was yearning to be respected as an adult. When it comes to the inclusion of individuals with disabilities, we are not the experts. Photovoice has begun to empower these experts with ID/DD and make way for their knowledgeable and relevant opinions.

*Key Terms:* Community inclusion, independent living, intellectual disability, developmental disability, Photovoice, self-advocacy

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### **Photovoice: A Tour Through the Camera Lens of Self-Advocates**

The continuous segregation of people with disabilities from their peers without disabilities is prevalent throughout history. Individuals with intellectual and other developmental disabilities (ID/DD) have been excluded from full participation in their communities. These individuals are one of the most physically and socially inactive and segregated groups in our communities (Zijlstra & Vlaskamp, 2005). Not only are individuals with ID/DD all too often inactive and segregated, they also have few opportunities to participate in decisions that affect their lives (Jurkowski, 2008). In research, they are often “worked on” as subjects rather than “worked with” as participants (Horwitz, Kerker, Owens, & Zigler, 2000; Paiewonsky, 2011).

We believe that individuals with ID/DD likely have unique and significant views toward available activities, programs, and services, which they have had limited opportunities to express. They are in need of a voice. Are there techniques that can be utilized to empower individuals with ID/DD to help create the change within the community for which they desire and strive? Through self-advocacy, people who are marginalized from society can be empowered to instigate their own systems changes in the community. Through a participatory action research method called Photovoice, we have attempted to increase advocacy and facilitate more community inclusion. By taking a glimpse through the photography lens of these self-advocates with ID/DD, we have solicited their ideas and perspectives concerning access, participation, and social inclusion in the community.

#### **Methods**

Photovoice is a creative form of participatory action research. Since this methodology is traditionally community-based, it is important to have a strong group of underrepresented individuals who are interested in community participation. This group strength often stems from a demand to hear the voices of the individuals from the underrepresented group. A research team from the Therapeutic Recreation program at the University of North Carolina at Greensboro partnered with a local chapter of The Arc with hopes to acquire a better understanding of the supports and barriers to social inclusion experienced by individuals with ID/DD. The Photovoice methodology aligned well with The Arc’s advocacy efforts. While cameras were placed in the hands of participants, this program was not only about photography. The key goal of the Photovoice program was to promote systems change toward a more socially inclusive community.

Seven individuals with ID/DD from The Arc embarked on a 2-month journey of training, photography assignments, individual and group discussions and processing, and exhibitions displaying their work. This methodology may be best described utilizing the three phases of the Photovoice program.



*Photovoice photographers from The Arc.*

## **Phase One**

The initial phase began with organizational tasks and training of student instructors from the university. Each participant with ID/DD was assigned a single instructor with whom (s)he worked throughout the program. A requirement for participation in the program was the availability of a family member or friend (described as “assistants” hereafter) who could also be enlisted to assist the participant as necessary through the program’s duration.

The program officially began with a group meeting for all participants, assistants, and instructors. This orientation included a discussion of program goals and methods, explanation of differentiating roles of the participants and assistants, demonstrations on how to use the digital cameras, explanation of photography ethics and consent, and introduction to the first photography assignment. During the explanation of differentiating roles of participants and assistants, we emphasized that photographs had to reflect the ideas of the participants. For example, participants could ask the assistant or someone else to take a photo on their behalf, so that they could appear in the photo. However, the ideas for the photos had to emanate from the participants. The assistants were trained on proper and improper ways of supporting the participants, with a focus on “assisting,” not “influencing.”

The “My Story” assignment asked participants to take photos of people, places, and activities that were important to them. The participants were given 2 weeks to complete this initial assignment, with a 30-photo maximum. When a participant completed his/her ‘My Story’ assignment, a meeting between the participant, assistant, and instructor was scheduled. During this meeting, the participant’s photographs were discussed, with a number of probing questions. The participants were encouraged to describe their photographs, with assistants helping to fill in

the details when it was necessary. Once these interviews were completed, program staff (i.e., researchers, Arc representative, instructors) held a debriefing meeting where similarities, differences, and themes across all participants were discussed.

### **Phase Two**

Phase Two commenced with the second photography assignment. Participants were asked to take photos that represented the people, places, and activities that made them feel important, along with highlighting their skills and talents. The participants were given an additional 2 weeks to complete this assignment, with a 20-photo maximum.

Similar to Phase One, there was an individual meeting that followed this assignment, where participants explained each photo to the instructor. The participant and instructor then identified three primary ideas based on topics that were discussed frequently. The participant selected one photograph representing each of the three ideas. The three photos were further discussed with a series of probing questions (i.e., “Why did you take this photo?” “How does this activity, person, or place make you feel?” “Is there anything that would make this activity, person, or place even better or more enjoyable?”).

Following these individual meetings, program staff conducted their second debriefing meeting. The photos and ideas selected during the individual meetings were reviewed with six primary themes being identified by program staff based on reoccurrence and consistency across all participants for both Phase One and Two assignments. While being careful to ensure that each photographer was represented, one photo was chosen to represent each of the identified primary themes.

As a final step in Phase Two, program staff led a group discussion where each participant explained his or her thematic photo to the entire group. The conversation was directed toward the group, and all participants were encouraged to explain their feelings and opinions regarding the particular theme that each photo represented. Program staff conducted a third and final debriefing meeting where they reviewed the information gathered from the group meeting and identified quotes that best illustrated the participants’ perspectives.

### **Phase Three**

The final phase of the Photovoice program consisted of preparations for two community exhibitions: a pilot exhibition at the local Arc for family and friends, and a primary exhibition at a community location for the broader community. Each participant produced an individual display with a 5-photo collage, “My Story” photo book, and props that represented each participant (e.g., a small painting that represented an artist’s interest in art). Individual collages were accompanied by narratives using quotes from the participants’ interviews. Participants stood by their individual displays during the exhibitions and answered questions that attendees asked about their photographs and experiences in the Photovoice program. Seven enlarged photos representing the primary themes that embodied the group were also on display. Each of the primary photos was accompanied by a narrative describing the particular theme. Quotes from the group discussion and individual meetings to reflect the voice of the group accompanied each

primary theme photo. Participants stood by their individual displays and answered questions and shared their ideas throughout the exhibitions.

The goal of the primary exhibition was to create community impact and promote community inclusion. It was both beneficial and necessary to invite key members of the community who represented various positions in society. Marketing efforts centered around targeting those individuals in positions to create change. The primary exhibition was held at the city's Chamber of Commerce located in the downtown area. The attendees of the primary exhibition included friends and family members of the photographers, local policymakers, recreation providers, teachers and other service providers, government representatives, and general citizens.

### A Peek Through the Lens of One Photographer

A total of six primary themes represented the entire Photovoice cohort, including: hidden talents, community membership and sense of belonging, consumerism and making choices, desired independence, limited connections to the community, and desire to be treated as adults (for greater detail, we refer the reader to Schleien, Brake, Miller, & Walton, in press). One of the participants, Paul, a 33-year-old self-advocate, allowed his voice to be heard through a powerful depiction of his desire to be treated as an adult.

**Saving and spending his own money.** Similar to most adults within our society, there is no "free ride" for Paul. This Photovoice participant not only works hard for his money, but puts all of his hard-earned cash to work. He saves and spends his money on the various expenses that life entails, including rent at his parent's house.



*Paul with his employer.*

Paul stated:

"This is what my dad loves to hear. I like to pay room and board. I buy gifts for birthdays and Christmas for siblings, like my brothers and sisters, and I love doing that. My cell phone and movies. And one thing that really takes my heart, I get to treat my dad to coffee and my parents out to eat... To be independent, to have money in my pocket, which is awesome, buy all of those things I like to do."

**Household responsibilities.** While Paul works hard on the job, he does not return home and simply relax. Paul prepares for the independence he desires by going above and beyond paying room and board. He has taken daily housework at his parent's house into his own hands. Two of Paul's favorite household chores are taking care of the laundry and dishes. Returning home from a full day's work, and then completing household chores, should sound familiar to most adults.

Paul explained:

“I would like to one day own a house. Where I can do the dishes, the laundry, the cooking and the cleaning, all of that. I just love to do it... It makes me who I am. A person who is more independent.”



*Paul doing his dishes and laundry.*

**Becoming a guardian.** As individuals mature into adulthood, work and household chores are not the only responsibilities they acquire. Many adults have a natural desire to take care of or to protect a person or thing within their lifetime. This may be in the form of a parent who wants a child, a young adult who desires a pet, an individual who is searching for a home, or a college graduate pursuing a career in the helping professions. Much like other adults, Paul longs to care for and protect others. Paul explained these desires through the use of a photograph of a statue of dolphins displayed in his living room. He connected this attachment to dolphins with his wishes to be a guardian:

“I love dolphins so much. I always felt touched by dolphins. They are known as the gentle giants, the guardians, the protectors of the ocean, which I really love. To help in different ways that I can, like, one day be a lifeguard. Try to help other people... I feel like I’m one of the guardians, protecting... just maybe one day I could be able to save lives... I need to be somebody’s hero.”



*Paul's dolphin statues and figurines.*

**Leisure activities for adults.** In addition to work, household duties, and protective responsibilities that go along with adulthood, there are the necessary leisure and recreational interests and choices that are part of one's quality of life. When individuals reach the age of 21 in the United States, they gain adult privileges that differ from those who have not yet reached young adulthood. Paul referred to one of his leisure activities when he discussed his strong desire to be treated like other adults:

“This is my element, my little pizza, in the background is one of my favorite teams, Duke. Since my brother went to Duke. It's beer. I will admit that. When my mom and dad, if they go out on Saturday, I stay in and have pizza and a beer and watch basketball.”



*Paul enjoying a Duke basketball game.*

A peek through Paul's camera lens reveals a variety of supporting evidence of his advocacy to be respected as an adult. When Paul introduced his theme to the other Photovoice participants during group discussion, he eloquently explained his idea this way, "You should treat us the way we are. We are adults. We are not kids."

The entire Photovoice group was unanimous in their affirmation of Paul's proclamation. Being treated as children was evidently something they all had experienced as young adults, and felt embarrassed by it. One individual opined, "Sometimes you feel sheltered from the public," when not being treated like an adult. Others added, "It hurts your feelings," "being picked on is one of my biggest things," and "you don't feel comfortable." One participant summed up the frustration expressed by many when he affirmed, "I can do stuff on my own." The participants were fully aware of the responsibility that comes with being an adult. As one participant remarked, "Being a grown-up is really hard. You have to be independent. Sometimes you have to do the things you have to do when you're grown up." And as for the responsibility that comes with drinking alcohol, "You have to understand your own limitations."

### **Concluding Remarks**

Photovoice has the power to impose a number of benefits on the individual photographer, as well as at the interpersonal, organizational, and community levels. After receiving a "tour" through Paul's lens, it is plainly visible that empowerment and self-advocacy skills were among the benefits experienced by the participants. However, the importance of Photovoice methodology could expand and move beyond these individual benefits. The importance of this research is also

encompassed in the impact on the community's understanding of, and actions to make our communities more inclusive. This component of Photovoice is typically absent from the outcomes as programs end prematurely. Many authors argue that Photovoice can have an impact on policy, but they do not discuss or evaluate the impacts (Baker & Wang, 2006; Fournier, Kipp, Mill, & Walusimbi, 2007; Nowell, Berkowitz, Deacon, & Foster-Fisherman, 2006). Two researchers completed a comprehensive review of Photovoice methodology and summarized:

Although photovoice is often conceived of as a community intervention, its impact at the community level has not been well described or assessed. None of the studies reviewed used community- or neighborhood-level analysis. Throughout the literature, there was little attempt to evaluate the long-term impact of photovoice on individuals or communities, although it was often assumed that intention to act, increasing the understanding of community concerns, and individual empowerment would have important long-term impacts on community health (Catalani & Minkler, 2010, p. 447).

Like many other efforts in the area of systems change, the end result can lie at the end of a long road of struggle and determination. With Photovoice, photographers are given a tool that does not expire or fade. Their voices are captured in photographic displays that not only depict their honest opinions toward society, but also have the ability to travel, show in a variety of settings, and communicate to myriad audiences. We must keep these exhibitions on the move, continue to impact exhibition attendees, and offer action steps that will empower the community to become more welcoming and accommodating of those who live at the margins of society.

As communities attempt to address areas of accessibility, broader participation by underserved populations, and sustainable systems changes supporting inclusive service delivery, it is necessary for approaches to be taken by numerous stakeholders. Communities everywhere must recognize that people with disabilities are a substantial and growing part of society, and perhaps, the largest minority group in the U.S. Like other community members, they should be provided with opportunities to make choices concerning the activities in which they wish to take part. Communities can only be receptive and responsive to societal needs when the voices of community members are heard and clearly understood, including those with ID/DD who have traditionally been ignored. When it comes to the inclusion of individuals with disabilities, we are not the experts. People with disabilities, as self-advocates, are the true experts within their own lives. With a voice and willing audiences, individuals can help communities discover solutions to overcome the myriad barriers that exist. These obstacles, although appearing difficult to address in the eyes of some community leaders, policymakers, practitioners, teachers, businesses, programs, and ordinary citizens, can be ameliorated. As the Photovoice participants ended their journey of photography, discussion and processing, growth, expression, and empowerment, Paul left us with powerful and memorable words with which we leave you, the reader, to reflect upon, "We all have a voice. What we say with that voice, we show through our pictures."

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