Exploring the Lives, Communities, and Social Circles of Individuals with Intellectual/ Developmental Disabilities through Photovoice

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ABSTRACT

Historically, research on vulnerable or marginalized groups, such as persons with intellectual or developmental disabilities (IDD), has focused on studying such populations rather than meaningfully engaging them in the research process. This Indianapolis-based Photovoice study gives voice to individuals with IDD by involving them in community-engaged research and shining a light on the issues that they identified as needing attention in their communities. Nine individuals with IDD volunteered to serve as co-researchers, exploring their lives and communities through photography. Over a period of six weeks, the nine co-researchers took photos of their communities and participated in group discussions to identify common issues. Discussions about the co-researchers' photographs uncovered important themes regarding social relationships, community participation, and independence that led to action in the form of a letter writing campaign to local and national policymakers and a public art show to display and discuss their photography.

Keywords: *Intellectual and Developmental Disabilities (IDD), Photovoice, Community-Engaged Research*

STUDY BACKGROUND

Within the realm of community health and civic engagement, there is increased recognition that the concepts that inform society's philosophical and theoretical approaches to community engagement and social inclusion have been based on inadequately developed ideas and research (Bachrach & Abeles, 2004). Scholars note that it is important for research to be inclusive of vulnerable populations whose issues are not traditionally addressed within the arena of community involvement (Jurkowski & Paul-Ward, 2007). Not only should research strive to include such vulnerable populations as research subjects, but rather as equal partners in the research process. Historically, vulnerable populations, specifically individuals with intellectual or developmental disabilities (IDD), have had their voices and personal experiences represented through research that does not engage them as co-creators of knowledge, but rather as passive subjects upon which research is completed. Unfortunately, it is still somewhat rare for studies to engage individuals with IDD in research that informs and benefits their own local communities.

While there is much research that focuses on the type of community interactions and social relationships of individuals with IDD (Amado, Stancliffe, Mccarron, & Mccallion, 2013; Hill & Dunbar, 2003; McCarron et al., 2011; Taylor, 2000; Verdonschot, DeWitte, Reichraft, Buntinx, & Curfs, 2009), there is a need for research that meaningfully engages community members with IDD as co-researchers and active participants in the process. Further, there is a need for research involving individuals with IDD who themselves advocate for and take steps to bring about change in their local communities. This study employed the Photovoice methodology to do just that. After taking a deep look into their communities through guided photography and discussion, nine individuals with IDD actively engaged in a letter writing campaign and art show to start a conversation about self-identified issues in their communities and bring about change.

METHODOLOGY

Photovoice

Photovoice is a research methodology developed by Caroline Wang and Mary Ann Burris that is grounded in the fundamental principles of social justice, respect for personal autonomy, promotion of societal good, and the avoidance of harm (Wang, 2006; Wang & Burris, 1997). As described by Wang and Burris (1997), Photovoice is:

> *A process by which people can identify, represent, and enhance their community through a specific photographic technique … Photovoice has three main 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. (p. 369)*

By encouraging co-researchers to capture and discuss photos they have taken in their own environments, Photovoice enables individuals to act as catalysts for change within their own communities. This stands in stark contrast to having research participants answer formulated questions that have been developed by outside researchers. Photovoice encourages co-researchers to express their real-life experiences through photography and empowers them to express their needs and become actively involved in decisions affecting their lives (Wang, 2006). Photovoice, and this study, are fundamentally grounded in the belief that successful and effective community-engaged research is done with community members rather than on community members.

Co-Researchers

To ensure the goals of this study were aligned with the needs and desires of the disability community, nine individuals with IDD were identified to serve as co-researchers and guide the study from beginning to end. Each of the nine co-researchers live

with an IDD and were between the ages of 18 and 40 during the time of the study. Six of the co-researchers identified as female, three identified as male. Eight identified as Caucasian and one as African American. The co-researchers' names in this writing are all pseudonyms in order to protect their identities.

The co-researchers in this study were identified via snowball sampling with the assistance of two initial co-researchers who worked in conjunction with the primary researcher to identify seven additional co-researchers. The primary researcher had been involved with a local non-profit organization serving individuals with IDD in a volunteer capacity for over three years and had formed friendships with many individuals within the organization. Prior to the study, the primary researcher engaged in many conversations with the two initial co-researchers who voiced frustrations about issues in their own communities (public transportation, job opportunities, etc.). After many similar, frustrated conversations, the primary researcher proposed to the two initial co-researchers the idea of using Photovoice to show others what it is like living with IDD in Indianapolis. The two co-researchers liked the idea, especially the ability to share their work with others, and agreed to participate.

To identify additional co-researchers, the two initial co-researchers and the primary researcher employed a snowball sampling technique. The two co-researchers identified other friends of theirs with IDD who they thought would like to participate. Prior to the study, the primary researcher knew six of the nine co-researchers through her involvement in the non-profit organization. The study was intentionally capped at ten total researchers, in an effort to more easily facilitate a balanced group discussion (Wang, 2006). Upon agreeing to participate, each co-researcher and their legal guardian (if required) were provided detailed information about the study and the voluntary nature of participation. Co-researchers provided their consent to participate. All were given the ability to remove themselves from the study at any time.

The co-researchers saw themselves not only as advocates for individuals with disabilities, but as advocates for their communities as a whole.

Use of the term "co-researcher" is intentional to highlight the depth of involvement of all nine individuals with IDD in research. As co-researchers, all nine individuals assisted and/or led the following aspects of the study:

- Participant recruitment
- Identification of study's primary questions to be explored through Photovoice
- Data collection
- Data/theme validation
- Presentation of findings via letter writing campaign and public art show
- Guiding Questions

Most research that employs the Photovoice methodology uses a similar process for data collection and analysis (Wang, 2006). After identifying and obtaining consent from all nine co-researchers, the primary researcher gathered the research team for their first of six face-to-face meetings. During the first meeting the primary researcher led a collaborative discussion where the team identified three primary questions around which to center the study. Acknowledging shared frustrations about various aspects of their communities, the co-researchers, in conjunction with the primary researcher constructed the following questions to guide the study and the co-researchers' photography:

1. What do you like about where you live?
2. What do you dislike about where you live?
3. What would you like to change about your community?

After identifying the guiding questions, the primary researcher led a discussion on cameras, power, and photography ethics, explaining the ethical requirements all co-researchers had to meet in order to take part in the research (obtaining permission when taking someone's photo, not sharing their photos on social media, etc.). Once all researchers were clear on the study's guiding questions and timeline, they returned to their communities to take photos.

Photo Sharing and Group Discussions

Throughout a period of six weeks, the research team met three additional times, each time following a week of taking pictures in community. In total, the co-researchers took almost 300 photographs over the six weeks. Although photography was used as the primary method by which the co-researchers identified community issues, the photos themselves are not the primary source of data within a Photovoice project. The group discussions that arise out of the sharing of photos are of principal importance and serve as the study's primary data (Wang, 2006; Wang & Burris, 1997). Thus, the three in-person group discussions held after a week of community-engaged photography by the co-researchers held significant value. The co-researchers brought to each in-person group discussion their digital photographs, sharing them on the projector for all to see. Each in-person discussion followed the same general outline: 1) co-researchers shared three to five photos with the group that they wanted to discuss, 2) each co-researcher provided context for each photo and explained its significance to the group, and 3) discussion ensued based on the selected photos shared (Wang, 2006). Each of the three group discussions lasted roughly two hours.

The three group discussions were loosely structured and were guided primarily by the co-researchers' interests, questions, and concerns. Rather than the primary researcher asking each co-researcher to respond to preconceived questions, all were encouraged to talk with one another, ask and answer each other's questions, and exchange ideas and anecdotes, acknowledging others' points of view. The primary researcher's role within each discussion was to encourage dialogue built upon the study's guiding questions and what the co-researchers would like to see in terms of social change. To allow for the most natural setting, the discussions were not recorded and were held over snacks and non-alcoholic drinks. The primary researcher took extensive notes during each group discussion which became the study's primary data. Following three rounds of photography and discussions, the research team met an additional time to debrief the prior meetings and generate plans for social action.

Identifying Themes across the Data

The primary data collected and analyzed in this study is the extensive notes taken during the research team's three group discussions. Analysis of the group discussions is outlined below in detail. However, as the co-researchers' photography is what initiated all discussions, a summary of the co-researchers' photos is described in Appendix A.

While all co-researchers actively participated in formulating the study's guiding questions, photography, and group discussion, the primary researcher led the analysis of the data, identifying themes across the group discussions and presenting them to the research team for feedback, corrections, and ultimately validation. The primary researcher's analysis of the data occurred in these steps: 1) Data exploration, review, and memoing; 2) Open coding; 3) Axial coding; and 4) Selective coding, data reduction, and development of overall themes.

The data exploration, review, and memoing phase included a review of all notes from a holistic perspective with the goal of understanding the breadth and scope of the data. This general, more explorative review helped to identify patterns within the data (Glaser & Strauss, 1967; Schatzman & Strauss, 1973). Open coding, or the development of initial themes occurred after the data exploration and memoing phase (Creswell, 2007; Strauss & Corbin, 1990). In this phase, emerging themes and patterns were identified, illustrating the major categories of the data. After initial codes were identified through open coding, axial coding was employed to build out and clarify original ideas and categories. Focused axial coding involved the creation of additional codes and sub-codes focused around specific ideas and concepts, allowing for more in-depth understanding (Strauss & Corbin, 1990). Selective coding followed the processes of open and axial coding with the goal of reducing superfluous data and clarifying themes from the connected categories of codes (Stake, 2010; Strauss & Corbin, 1990).

Co-researchers were involved in the validation of themes throughout the process of analysis. Following the primary researcher's initial analysis of the data, the research team convened and the primary researcher shared the emerging themes identified. The co-researchers provided feedback, suggesting edits and additions to the initially identified themes. Within a two-hour work session, the research team finalized the analysis, agreeing to the themes detailed in the next section.

EMERGING THEMES OF FOCUS GROUP DISCUSSIONS

During the group discussions the co-researchers enjoyed sharing their photos and stories about when they felt empowered. The co-researchers found it important to discuss issues facing their communities that they believed needed to be addressed to improve the lives of all Indianapolis residents, not just those with disabilities. While many discussions centered on the fact that life is oftentimes more difficult for those with IDD, the co-researchers saw themselves not only as advocates for individuals with disabilities, but as advocates for their communities as a whole.

Findings are divided into four distinct themes that were most discussed during the group meetings: 1) social circles and friendship, 2) integrated and meaningful environments, 3) social identity, and 4) community change. Discussion of these topics arose from the photography shared by the co-researchers in response to the three aforementioned questions constructed to guide the study and the co-researchers' photography.

Social Circles and Friendship

"DSI Conference is National Down Syndrome Congress and you meet a lot of people with Down syndrome, they have talent show. I have hundreds of friends there." ***– Belle***

The issues of friendship, social circles, and community were all discussed in great detail among the co-researchers. Three major factors contributing to the size of one's social circle were identified: having the time to spend with friends, having access to quality transportation, and the ability to live independently. Conversely, the increasingly busy lives of friends, not being able to use public transportation, and/or living at home with one's parents limited the social interactions of the co-researchers, which they saw as problematic.

The co-researchers' social circles were primarily comprised of family members, staff, friends (with and without IDD) and co-workers. The majority of the co-researchers did not have a preference when it came to being friends with people with or without IDD. However, one third of the co-researchers preferred to have friends with IDD. Aladdin explained, "I have more fun with [people with disabilities]. They understand," (Focus Group, June 30, 2015). Though most of the co-researchers did not distinguish friends as having or

not having a disability, most of their social circles were comprised of other friends with disabilities, begging the question of choice or necessity.

In a 2011 study, McCarron et al. found that 67 percent of individuals with IDD did not believe it was difficult to make friends with new people. The co-researchers' sentiments echoed McCarron et al.'s findings, noting that most did not believe making friends is particularly difficult. Joseph, discussing a holiday party his apartment complex recently held, explained that he was able to invite guests, but, "We couldn't invite many people because they were too busy. So, it was just us [residents with IDD]". (Focus Group, July 7, 2015). Aladdin added, "[My friend] she just have baby and her too busy to hang out. I don't see her no more," (Focus Group, June 23, 2015). As the lives of their adult friends without IDD progress with marriage and children, those with IDD are often relegated to the back burner of friendship and are awarded social time when it is convenient for others.

In addition to the busy lives and schedules of friends without IDD, the lack of sufficient or reliable public transportation compounded the issue of not being able to freely spend time with others. The co-researchers found the lack of accessible, public transportation within Indianapolis very disappointing. As not all of the co-researchers had driver's licenses, the need for reliable public transportation was of utmost importance. Without the ability to effectively move about the city, they had to rely on others to get them to and from work, social activities, and errands. Robert stated, "Tuesdays are the only days I have staff, so that's the only days I have rides. I have to ask family and friends or try to use the [local public transportation system]," (Focus Group, June 16, 2015). Joseph agreed with Robert's frustrations and added, "The [public transportation system] equipment is sometimes faulty and doesn't allow people with wheelchairs to get on it," (Focus Group, June 16, 2015). The inability to utilize public transportation put a great strain on their independence and negatively affected how they are able to navigate their communities.

Integrated and Meaningful Environments

"When I'm working I feel included. I feel included because I've been there two years and they know me and they know I work hard and I do a good job." ***– Sunshine***

The co-researchers discussed their community and inclusive environments – places where they feel safe, valued, and empowered – at great length. The co-researchers' noted that many of the environments where they felt the safest were those where social inclusion and the integration of individuals with IDD was an explicit goal. Aladdin spoke at length about his love of Special Olympics and how he is so proud to be an athlete, "I go to Indiana Special Olympics State Games. I want people to know I go there and I an athlete. I have fun there." (Focus Group, June 16, 2015). Robert, a long-time participant in Best Buddies has been paired in many friendships with individuals without IDD and recently attended a friend's Fourth of July party, exclaiming, "It was really nice of [my friend] to invite me to her Fourth of July party this year," (Focus Group, July 7, 2015).

In addition to environments where the social integration of individuals with IDD is a priority, many co-researchers noted they felt most valued at work, interacting with co-workers or customers. Many of the employed co-researchers enjoyed not only feeling valued at work, but included and integrated into a professional community. Jerry explained, "I feel great when I go to work because people know me by name. When I see newcomers, I welcome them. I feel valued and plus I get paid there every two weeks. I help with the household expenses," (Focus Group, June 16, 2015). In a similar vein, the ability to volunteer and utilize their talents to give back to others increased their sense of self-worth. Angelina, who volunteered with the National Down Syndrome Society, recently won an award for her many contributions to the organization. She proudly stated, "I'm so happy I got this award. I was the first top volunteer at the National Down Syndrome Society. I am proud!" (Angelina, Focus Group, June

23, 2015). Being seen beyond their disability, as productive members of society who contribute to the greater good, provided the co-researchers with the tools to live productive, happy, meaningful lives.

In addition to environments where they felt valued, the ability to make their own choices was an issue the co-researchers believed impacted how secure and integrated they felt in the community. Being able to make choices for one's self provided them not only with a sense of independence, but also self-worth. They noted that for many with disabilities, choice is often limited by someone else – a parent, staff, etc. For the co-researchers, the concept of personal choice was most associated with one's living situation. Those who lived independently felt they had the most freedom to make choices for themselves – how they spend their free time, who they associate with, etc. Angelina said:

I like to live at my apartment. They have a lot of community events like a cookout, Bible study every Sunday, especially the garden I like to do. Especially I like be independent and be on my own and with my boyfriend and my friends. If you want to be in a group to watch movies or play pool and some card games, you can (Focus Group, June 16, 2015).

Adding to Angelina's sentiments, Sunshine agreed:

My apartment is my own place. There is no noise, I can watch whatever I want to watch [on the TV]. My brother doesn't come in and change the station. I grew up in a loud house and I like the quiet (Focus Group, June 16, 2015).

Social Identity

"I don't like to fight. I like to talk things through. I'm a lover, not a fighter. I like sports, cars, and motorcycles. I like attractive women. I don't like drama." – ***Joseph***

In a 2011 study analyzing the social identities of individuals with IDD, Cameron found that the socially-generated identities of individuals are primarily dependent upon one's social organizations, the people who surround them, and the language used to define their social groups. The co-researchers echoed Cameron's sentiments and noted their disability is not generally how they define themselves, but rather what they like to do, with whom they associate, and the groups to which they belong. The majority of the co-researchers were actively involved in various community programs and supports specifically designed for individuals with IDD. However, when asked, none of the co-researchers identified first as an individual with a disability. Having a disability is but one characteristic that comes secondary to other personal traits such as a love of animals, a profession, or a family role. When asked to describe themselves, the co-researchers gave a plethora of answers. Sunshine noted, "I love horses and I'm a hard worker," (Focus Group, June 16, 2015). Robert explained that she identifies as a hard worker, strong volunteer, and a student who went to college for two years at a local university (Focus Group, June 16, 2015). All of the co-researchers understand that they have a disability, but it is not what ultimately defines them. Rather, it is other members of society that identify them first and foremost as someone with IDD.

This is particularly important for individuals with IDD, as they have traditionally been left out of such decisions and treated as subjects rather than co-investigators, partners, and collaborators in research.

Through their discussions regarding disability and social identity, the co-researchers discussed their belief that a physical or mental impairment is not automatically internalized as a negative trait by those who have IDD. Rather, various societal structures and barriers that restrict the individual choice, independence, and adulthood of individuals with IDD appear to be the largest factors contributing to the

negative social identities of individuals with IDD. Disability identity, in social terms, is then defined as a socially constructed phenomenon by individuals without disabilities which is then imposed onto individuals with IDD. As such, individuals with IDD are disabled by the physical and attitudinal barriers society constructs for them. The societal barriers most frequently discussed among the co-researchers were childlike language and lack of adequate transportation, resulting in them being seen not as adults, but rather as dependent childlike individuals.

Community Change: An Agenda for Action

When the co-researchers discussed what they saw as the most pressing issues in their communities they identified the following two issues as most needing attention:

Public safety. Collectively, the co-researchers identified public safety as one of the primary issues needing to be addressed in their communities to improve life for not only themselves, but for other citizens with and without IDD. This included issues such as homelessness, gun violence, and accessible streets and sidewalks. The fact that a great deal of the group's conversations centered on how to improve the safety and inclusivity of their communities for all citizens illustrated their collective sense of pride, empowerment, and self-worth. When given the opportunity to voice their concerns and improve their communities, the co-researchers acted with a sense of agency which is unfortunately not always attributed to people with IDD.

Empowerment and autonomy for individuals with IDD. In addition to identifying areas of improvement in regard to public safety, the co-researchers recognized two issues which could be improved to increase the freedom and autonomy specifically for individuals with IDD: more opportunities for employment and additional facilities to assist with independent living. They noted that positive changes in these areas would improve the lives of individuals with disabilities by increasing their autonomy, empower them to be more independent, and in turn, increase their happiness and self-worth.

One of the most discussed issues was the need they saw for meaningful and integrated employment opportunities for individuals with IDD. Employment, they agreed, is one of the most significant factors aiding the construction of one's positive social identity. The majority of the co-researchers wanted to be given the opportunity to receive a pay check and contribute to society. The ability to purchase things for themselves and pay rent were deeply satisfying for those who held jobs. Angelina proudly stated, "I like my job. I make people happy by cleaning locker rooms … I have my own name badge and business cards," (Focus Group, July 7, 2015). Unfortunately, not all of the co-researchers were employed. Maraj was desperately seeking work: "It's difficult to find a job. I have ten years' experience at McDonalds, but no job. We need more jobs for people to make money!" (Focus Group, June 16, 2015).

Just as having gainful employment helps create a positive social identity, so too does the ability to live life on one's own terms. For many of the co-researchers that meant being able to live independently, without the constant supervision or interaction with one's parents. Joseph proudly exclaimed, "I've lived alone since I was eighteen and I love it. My parents don't tell me anything!" (Focus Group, June 16, 2015). Sunshine, who also lives independently, highlighted the importance of being able to do things for yourself, "It's important to have a clean house. It means you take care of your things and can do it by yourself," (Focus Group, June 16, 2015). Being able to support yourself and live independently, they believed, should be an option for all adults, with or without a disability.

TAKING SOCIAL ACTION

Arguably, the most important component to any Photovoice study is taking action on the issues brought to light during the research team's discussions as explored through their photography. After

completing the three rounds of photography and group discussions, the research team convened to plan actionable steps toward making their voice heard to various community members and policymakers. With any Photovoice study, the outlets and methods of sharing identified themes and photography vary depending on the team, the local context, and the ultimate goals of the project (Farley, Brooks, K., & Pope, 2017). In this study, after much discussion, the research team identified two ways to showcase their work and make their voices heard: a letter writing campaign targeted to individual stakeholders at the local, state, and national levels; and hosting a public art show featuring their photographs to ignite community conversations.

The research team believed mailing letters to community organizations, policymakers, and stakeholders on the local, state, and national levels coupled with a public display of their photography would initiate discussion about the topics and issues they found most pressing in their communities. To most effectively share their sentiments within the letter, the co-researchers agreed to highlight specific topics of interest which fell under the larger umbrellas of public safety and empowerment and autonomy specifically for individuals with IDD. The letter, which was drafted and signed by the entire research team and sent to various stakeholders, is shared in full in Appendix B.

In addition to the letter, the research team wanted to share their photography with the local Indianapolis community in hopes of initiating conversations similar to those they had within the group discussions. To do so, the primary researcher secured an exhibit space in the downtown area of Indianapolis to display a selection of the co-researchers' photographs. The exhibit space was provided for free, as the co-researchers' display was held in conjunction with a fundraiser for a local nonprofit organization that provides services for individuals with IDD. The exhibit was held during "First Friday," a designated monthly event where local artists and musicians publicly share their work. Each co-researcher identified three or four photos to display and discuss with attendees. During the photo exhibit and within the letter to local and national policy makers, the research team discussed the need for safer communities where all citizens can feel comfortable, secure, and empowered.

LIMITATIONS

Qualitative research, specifically that which embraces participation from a small percentage of the population being studied, lends itself to various issues limiting the scope and generalizability of such research. In this study the research team was small, including only nine co-researchers. While this small group included individuals of different genders, races, ages, socio-economic status, and disabilities, it is not an all-encompassing account of what it means to live with a disability in Indianapolis. Although discussions were often driven by what life is like living with IDD, the type or severity of one's disability was not the focal point. Disabilities vary in terms of the severity, causes, and levels of support needed, and the input of the co-researchers was unique to their individual lives, disabilities, and social supports.

IMPLICATIONS FOR RESEARCH AND PRACTICE

Although this study among Indianapolis community members with IDD is limited in its generalizability, it suggests that Photovoice can be successfully utilized to actively involve individuals with IDD to shape the decisions that influence their lives and communities. Furthermore, this study exemplifies the need for including individuals with IDD in social programming, planning, and research. This is particularly important for individuals with IDD, as they have traditionally been left out of such decisions and treated as subjects rather than co-investigators, partners, and collaborators in research.

This study had two distinct purposes: to involve individuals with IDD in community-engaged research and to shine a spotlight on the issues facing Indianapolis, specifically issues of concern within the disability community. Photographs taken by

the co-researchers, in combination with the discussions that stemmed from said photographs, illustrated what issues were of most importance to them: the need for more integrated and meaningful employment for individuals with IDD, additional opportunities for individuals with disabilities to live independently, the necessity of a reliable and functional public transportation system, etc. Photographs and discussions also showed how the co-researchers are involved in their communities, the extensiveness of their social circles, or lack thereof, and how they are physically and socially integrated into larger society. Future research should continue to include the perspectives of individuals with IDD to ensure the authentic representation of the disability community within research. Many of the themes which emerged from the co-researchers' photographs, or lack of photographs, are worth exploring in further detail to better understand the connections contributing to the various issues the co-researchers saw as most prominent in their lives.

This study inviting the perspectives of individuals with IDD in research suggests that Photovoice is not only an effective participatory research tool to aid in the advancement of disability rights, but one that is much needed. The use of photography and the primacy of the visual image coupled with the opportunity for individuals to express their real-life experiences through group discussion provides individuals who are often not asked to share their opinions a platform to be heard. Community members also are able to collect data through photographs in places where other, outside researchers might not have access. This study demonstrated that Photovoice can foster the active participation of individuals with IDD in research while giving value and weight to their contributions as co-researchers, not research subjects.

APPENDIX A

Summary of the Co-Researchers' Photographs

The significance of place. 94 of all the photographs (32%) highlighted safe places the co-researchers identified as important to their lives. The most prominent locations included their homes, serene spots within nature, religious places of worship, or unique locations they visited when travelling.

The primacy of friends, with and without IDD. 59 photos (20%) featured individuals who the co-researchers identified as friends. The majority of co-researchers who took pictures of friends were those who either lived independently or were involved in various community organizations that provide opportunities for people with IDD (Special Olympics, Best Buddies, etc.)

The importance of social activities and community participation. 53 photographs (18%) were taken when co-researchers were active in their communities. Photos ranged from enjoyable social activities such as attending professional sporting events, conferences, and summer camps, or while they were at their place of employment or volunteering in their community.

Pride in the ability to live independently. 44 of all photographs (15%) highlighted many of the co-researchers' apartments where they live independently without parents or siblings. All of the co-researchers who lived independently expressed great pride in having the ability to do so. The co-researchers who lived with parents and/or siblings articulated their desire to live more independently and move out of their childhood homes.

The low profile of staff and family members. Less than 1% of all photographs taken were of the co-researchers' family members or siblings. Staff and relatives, particularly parents, are typically known to provide great assistance to individuals with IDD throughout life. However, very few of the co-researchers included photographs of these supports.

The absence of romantic partners. Less than .5% of all photographs included romantic partners. Only two of the co-researchers took pictures of individuals to whom they were romantically attracted.

APPENDIX B

Letter Written by Research Team to Various Local, State, and National Stakeholders

Dear _____,

We are residents of Indianapolis and we are trying to make the world a better place for people with intellectual and developmental disabilities (IDD). We are a group of adults with disabilities who for the past six weeks have been meeting as a group to talk about how to make Indianapolis better. We have some things we want to discuss with you. We have identified the following issues within Indianapolis that we want to bring to your attention:

Crime: We have noticed a lot of violent crimes in Indianapolis recently. This is scary. We think policemen should be more available to help with these crimes. Using a crime-stopper number is helpful and should made more well-known to residents of Indianapolis.

Homelessness: We have seen an increase of people on the streets asking for money. We think homeless shelters should be more available to these people to help them get back on their feet and get a job. They need to know how to find homeless shelters.

Guns: We think there is too much gun violence in the city. This is scary when people get shot in the stores and in their homes. We would like to increase safety laws when people want to buy guns. Only police should be able to have guns. Please try to keep guns away from kids.

Employment: We have talked a lot about how employment is the way to best support yourself and make money. Having a job makes us feel respected, like good members of society. We want more employers to hire people with disabilities in Indianapolis.

Living Independently: Most of us live independently and we love it. It makes us responsible for our actions and we don't have to depend on our parents as much. It makes us feel good about ourselves. We think there should be more places for people with disabilities to live independently in Indianapolis.

Indy Go: It would be really nice to have a more structured schedule with the Indy Go Open Door bus system. Sometimes when we call the dispatch, they hang up on us and it is rude. It sometimes makes us late to our jobs. Sometimes the bus doesn't show up at all and we miss work.

These are the biggest concerns we think our city faces. We would like to make sure Indianapolis is as safe and inclusive of all people, as possible. We would appreciate your support with these issues.

Sincerely,

(Names of co-researchers omitted)

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