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The 4E Model of Empowerment through Photovoice

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“Don’t be afraid to tell your story. Your voice is important, and your story is unique.”

---Meredith Lavitt

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The Author

Carson Peters graduated from Grinnell College with a Bachelor of Arts in Biology of Global Health. Currently in her second year of the Master of Public Health Program at the University of Iowa, she is passionate about global public health and advocacy. Her participation in an international honors' program in health and community took her to Brazil, India, and South Africa to conduct infectious disease research on Tuberculosis, HIV/AIDS, and Zika. Carson's experiences abroad inspired her to conduct her senior thesis on women's cancer as a health disparity in Sub-Saharan Africa. Prior to her internship at PhotovoiceWorldwide in Summer 2020, Carson's research experiences included working at the National Institute of Health's National Institute of Allergy and Infectious Diseases, the Harvard TH Chan School of Public Health, and the Harvard Global Health Institute. In May of 2015 she interned on Capitol Hill in the House of Representatives for the Honorable Congressman John Lewis, related to her public policy and advocacy interests.

The Mentor

Laura discovered photovoice in 2000 while exploring arts-based approaches to youth programming and civic engagement for a Master of Education in Instructional Design at the University of Massachusetts Boston. Having previously worked as a photojournalist in Africa and Asia, Laura was used to taking the photos herself, but the script was flipped when she designed a photovoice civic engagement project that put cameras in the hands of teenage girls. For her doctoral dissertation in health policy/health services research at Brandeis University, Laura used photovoice to understand living with brain injury from the perspectives of individuals accessing brain injury rehabilitation services and support groups. Laura has led photovoice trainings for medical schools, professional societies, community organizations, and government agencies. She offers online photovoice professional development for clinicians, researchers, educators, students, and managers. Laura has presented and published widely on her work.

Executive Summary

During her Summer 2020 internship at Photovoice Worldwide, Carson Peters conducted a literature review on recent innovations in use of the photovoice method with people with disabilities, in particular cognitive and communication disabilities. Carson's literature review findings and her training in mathematics and epidemiology inspired her to develop an interdisciplinary model she calls the 4Es of empowerment through photovoice. By re-envisioning photovoice frameworks and theories found in the literature (Moffat & Kohler, 2008; Liebenberg, 2018; Bates, Ardrey, Mphwatiwa, Bertel Squire & Niessen, 2018; Roy, Donaldson, Baker & Kerr, 2014; Lorenz & Kolb, 2020; and Golden & Earp, 2012), Carson provides a lens for students to view the photovoice method and its use, and photovoice project findings and outcomes. Carson's literature review documents innovations in use of the method to support meaningful photovoice participation by people with cognitive and communication disabilities, an underserved yet important public health population. The 4E model is one way to conceptualize the empowerment process of photovoice. The model is intended to foster connections between quantitative and qualitative research methodologies and their student practitioners, and inspire others to envision and conduct participatory visual research that is person-centered and inclusive.

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The 4E Model of Empowerment through Photovoice

By Carson Peters

Introduction

During my internship at PhotovoiceWorldwide, I facilitated a review of the literature on recent photovoice method innovations designed for using photovoice with people with disabilities, in particular, communication and cognitive disabilities. I immersed myself in current photovoice literature and bolstered my understanding of this participatory, visual arts-based approach. I observed commonalities among the papers I reviewed and identified recurring themes, for example, using a life-based approach to photovoice when working with people with cognitive disabilities or mental illness. Several themes emerged as I was delving deeply into the literature review, including four concepts that I refer to as the 4Es: explore, enhance, encourage, and embody. I posit that when all four of these concepts are realized in a photovoice project, they additively culminate in the determinant, “empower.” Empowerment of participants is a stated purpose of photovoice (Wang & Burris, 1997).

My 4E model frames the findings from my literature review using a mathematical lens. I have a background in epidemiology both as a second-year Master of Public Health student with a concentration in epidemiology, and as a student researcher conducting epidemiological research at the National Institutes of Health. Thus, I have approached the topic of empowerment and its factors from an epidemiological perspective, which at its core is founded on mathematics and statistics.

My math lens inspired me to develop an interdisciplinary model, the 4Es of empowerment through photovoice. This model quantitatively suggests how photovoice empowers individuals while highlighting the mathematical processes involved. The model exhibits recent photovoice scholarship in the field of disability studies related to cognitive disabilities, and demonstrates how photovoice empowers communities by providing opportunities to explore perspectives, encourage action, enhance capacities and embody change.

Background/Problem

Previous literature has described the use of photovoice with individuals with physical disabilities (Dassah, Aldersey & Norman, 2017) and individuals with intellectual disabilities

(Overmars-Marx, Tomese & Moonen, 2016). Thus, my literature review focused on recent innovations with photovoice among individuals with cognitive disabilities. My purpose was to unpack innovations in bolstering meaningful photovoice participation among people with cognitive disabilities, and contribute to current photovoice method discourse. Photovoice practitioners seek to partner with people with cognitive disabilities in order to include their voices, perspectives, and experiences in policy, program, and practice decisions. Identifying innovations in the photovoice literature for people with cognitive disabilities contributes to inclusive research practice and, hopefully, policy, program, and practice improvements. Envisioning a theoretical framework that illustrates a photovoice empowerment process may encourage further innovation in the use of photovoice with this important population.

Methods

The literature review methods emulated a scoping literature review and used the frameworks of the Arksey and O’Malley (2005) and Pham, Rajic, Greig, Sargeant, Papadopoulos and McEwan (2014). These frameworks included a five-step process of identifying research questions, identifying relevant studies, determining the study selection, charting the data, and collating, summarizing and reporting the results. My research mentor, Dr. Lorenz, identified papers using the PubMed database and the reference lists of the collected papers. Search terms used included photovoice, participatory visual methods, disabilities, and published between 2010 and 2020. Papers that included a sample with physical disabilities only were excluded from the review. Papers that did not describe innovations in the use of photovoice were also excluded, as our purpose was to codify ways that researchers have been adapting the method to enhance meaningful participation by people with communication and cognitive disabilities.

Using papers identified by my internship mentor, I parsed information on each paper into a table with the columns: Author, Year and Journal; Focus; Participants; Methods; Interesting or Important Considerations or Practices (see the Appendix). Each row provided information on one paper. Our main inclusion criteria were: papers whose sample had any cognitive or emotional/behavioral/psychological disability or

long-term condition that impacts same. Included conditions were: acquired brain injury (ABI), intellectual or developmental disability (IDD), mental illness, multiple sclerosis, and substance use disorder or substance abuse. Of particular interest were papers whose methods included any visual communication strategy intended to enhance the sharing of tacit knowledge (Pain, 2012); papers that demonstrated some participatory direction by participants (Rix, Carrizosa, Seale, Sheehy & Hayhoe, 2019; Lorenz & Kolb, 2020). Examples of participatory direction included helping to determine the visual method project's questions, process, data collection approach, and dissemination. In the reviewed papers, participatory direction was noted when participants were involved in helping decide on questions to answer with the camera, when to meet and how to share project findings, and whether to work one-on-one with facilitators or to meet in a group.

After conducting the literature review, I summarized the main findings and began to develop the 4E model of empowerment through photovoice (Figure 1).

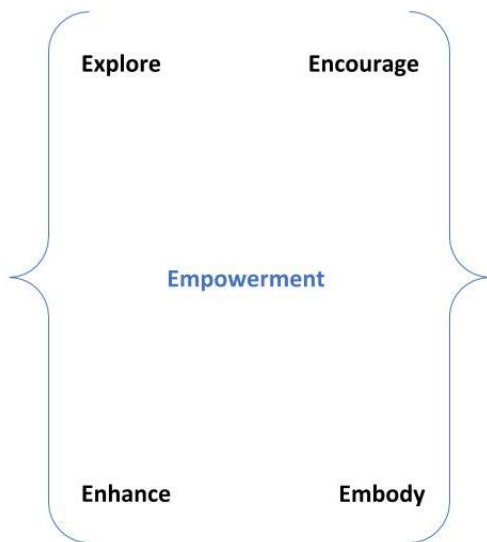


Figure 1. The 4E Model of Empowerment Matrix. The equation illustrated by the figure is {explore + encourage + enhance + embody = empowerment}. Legend: Black = Factors, Blue = Determinant

Literature Review Findings

I will briefly summarize some review findings here. The participants ranged in age from 5 years to 77 years; most were living in the community. The studies were conducted in a range of countries, from Australia to Belgium, Canada (Toronto, Vancouver and Quebec), Ireland, Puerto Rico, Sweden, Vietnam, and the United States. In the United States, studies were conducted in both urban and rural areas of Georgia, Illinois, Massachusetts, New York, and South Carolina. Study sample size ranged from two to 146

participants. Study site locations included community based centers, community spaces, community living facilities, and medical facilities (e.g., voluntary day hospital, university hospital, or psychiatric ward).

The range of cognitive or emotional/behavioral/psychological disabilities or long-term conditions included in the review were acquired brain injury (ABI), early stages Alzheimer's disease, Autism Spectrum Disorder, Addison's disease, cerebral palsy, dementia, drug addiction, intellectual and developmental disabilities (IDD), mental health-related disorders, psychiatric disabilities, and Type 1 diabetes. The consent and information-sharing process varied significantly among the studies, as did participants' relationships with the researcher and the dynamics between the participants. The study focus and methods used differed as well and included interviews, focus group discussion, photography, and video filming. For the most part, participants took the photographs; however, a researcher or caretaker was directed to take photographs for the participants in some studies. Ethical considerations were described in all the papers. One paper (St. John, Hladic, Romaniak & Ausderau, 2018) comprised a review of photovoice studies, while the remaining studies primarily used the photovoice method. My literature review findings demonstrated that, as has been argued (Wang & Burris, 1997; Liebenberg, 2018), empowerment is a major purpose and desired outcome of the photovoice method. Further, I noticed that four factors seemed to contribute to empowerment of participants and their communities, and I labeled them Explore, Encourage, Enhance, and Embody (see Figure 1). I will now discuss these four factors and how they contribute to the larger narrative of empowerment with photovoice. In Figure 2, I have depicted the literature that has informed my understanding of the four factors.

>Factor: Explore

The factor **explore** focuses on how the environment or community influences health and health outcomes. This concept is extracted from the social ecological model of community, where the environment (a social determinant of health) is shown to shape quality of life and public health trajectories (Bronfenbrenner, 1989). The environment (tangible or intangible) is observed in the built, social and physical environment, and represents barriers or facilitators to individual and community health. Moffatt and Kohler (2008) argue that "different managerial and social policies at both the macro-and the micro-level" impact the environment where there is an emerging need to "integrate history of nature with the history of human culture" (p 248). In other words, the environment for any one individual is impacted by both societal and individual actions and affected by human interactions with nature. Through the lens of community, the factor explore includes the following domains: "Education/training/skills, community leaders, Delivery of community services, Community physical environment, Community capacity, Modifications to community environments or services" (Golden & Earp, 2012). Thus, explore involves learning about the built environment (such as

homes, buildings, factories, farms, urban spaces, walkways, railroads, canals, landfills, roads, parks, or other physical/human made structures) and the community attributes (aspects of a physical space and/or community that enhance or hinder accessibility) (Perdue, Stone & Gostin, 2003). These concepts of built environment and community attributes influence public health landscapes. With photovoice, exploring public health concerns is a valuable way to begin to understand the structural and systemic issues that impact individuals and their communities, from their perspectives.

>Factor: Encourage

The factor **encourage** is an iterative process in participatory research where participants are actively involved in conducting the research. Photovoice is a participatory action research method whereby people decide on a project topic or questions, take photos, discuss their photos with the group, thematically group their photos, and advocate for change. Photovoice participation can be called having “voice” (Lorenz, 2010). A process of encouragement through photovoice rejects the traditional research model in which the researcher retains power and research subjects merely provide data, whether it be their blood, genetic material, or answers to a survey. The concept of **encourage** demonstrates the person-oriented/person-centric ideals of photovoice. Encouragement is basic to participatory action research and community-based participatory action research (CBPAR), which values the inherent knowledge, realities, needs and expertise of local communities (Liebenberg, 2018). Photovoice encourages individuals to “identify, represent and enhance their community through their lens” and “record and reflect their community’s strengths and concerns, to promote critical dialogue and knowledge about personal community issues through large and small group discussion of their photographs and to reach policy makers” (Budig, Diez, Conde, Sastre, Hernan & Franco, 2018 pp1-2). The factor **encourage** results in person-centric visual narrative findings that shift the research focus lens from researcher to participant.

>Factor: Enhance

The factor **enhance** captures a range of stakeholders in photovoice and utilizes multiple research methods, including participatory visual methods, to develop comprehensive, multidisciplinary, and holistic narratives of individual and community health. **Enhance** relies on patient participation, focuses on photovoice method adaptations and innovations relevant to different participant groups and purposes, and uses a participant-centered intrinsic or self-motivated approach (Bates, 2018). By capitalizing on networks and relationships with stakeholders, the factor **enhance** leads to findings that identify the “impact of social enterprise activity on health outcomes and their social determinants” (Roy, Donaldson, Baker & Kerr, 2014, p 1). In so doing, the factor **enhance** illuminates a multi-pronged participatory research approach that *enhances* an interdisciplinary research, policy, programming and practice discourse that includes participants, researchers, and decision-makers.

>Factor: Embody

The factor **embody** comprises the intersectionality of biology and sociology in shaping disease, disability, and illness experiences, by illuminating the meaning of illness in a social context. The concept of embodiment has been used in the contexts of health movements and aesthetics-based visual methods such as photovoice. Embodied health movements illuminate “challenges to existing medical/scientific knowledge and practice and often involve activists collaborating with scientists and health professionals” (Brown, Zavestoski, McCormick, Mayer, Morello-Frosch & Gasior Altman, 2004, p 50). Embodied aesthetics include art perception (impression side) and active art making (expression side) (Koch, 2017). The factor **embody** focuses on the ways that individuals experience, manifest, and channel health and illness experiences and meanings. **Embody** illustrates that social health narratives need to be flexible, holistic, and interdisciplinary in order to be effective in supporting the health of individuals and communities.

>Determinant: Empowerment

The concept of **empowerment** is the model’s major determinant and serves as its culminating factor or the “big picture”. According to Wang and Burris (1997), photovoice seeks to empower individuals and communities, and the goals of photovoice are to: “enable people to record and reflect their community’s strengths and concerns; promote critical dialogue and knowledge about important issues through small group discussions of photographs, and; reach policy makers” (p 1). **Empowerment** is a central element of the “original conceptual underpinnings” of photovoice and “its implementation” (Budig et al., 2018, p 3).

Empowerment focuses on the power and self-perception of individuals involved in photovoice projects. Ideally, participating in photovoice enables individuals to become empowered in their identity and as change agents in their community. The determinant **empowerment** means creating opportunities for mobilization and the amplification of voice through sharing lived experiences with peers and outside audiences. **Empowerment** also reflects the photovoice literature on empowerment, which is considered both a process and an outcome. **Empowerment** exists in an interwoven, interactional, and complex system to which many actors and stakeholders contribute. For an individual participant, **empowerment** relates to knowledge, capacity to act, and perceived competence; to critical awareness of environmental factors impacting life and health, and to having skills to act on that awareness and cope with adverse circumstances (Budig et al., 2018; Hennink, Kiiti, Pillinger & Jauakaran, 2012; Kolb and Lorenz, 2021).

With photovoice, exploring public health concerns are a valuable way to begin to understand the structural and systematic issues that impact individuals and their communities, from their perspectives. **Empowerment** is an outcome of participatory visual research practices and the determinant of the four contributing factors described above.

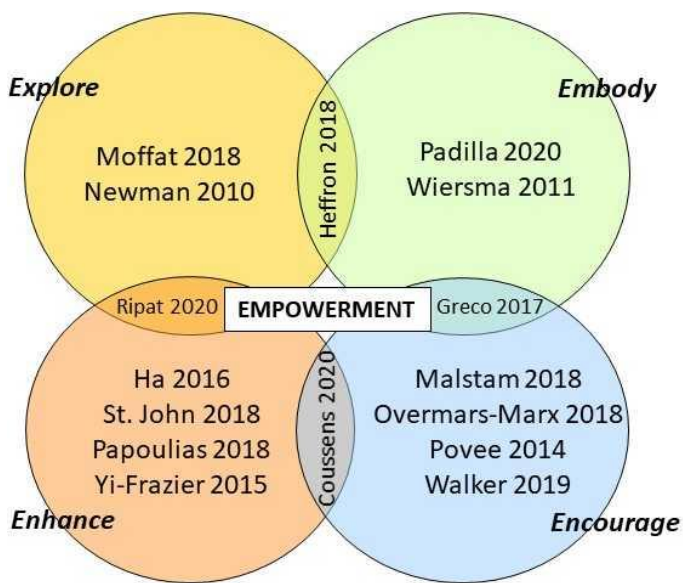


Figure 2. 4E Model of Empowerment with Photovoice. A Venn Diagram depicting the intersectionality of factors culminating in the determinant. Papers are listed by first author and year. For full author list and citation, see references.

Discussion

The 4E model illustrates how photovoice can lead to empowerment among individuals with communication and cognitive disabilities. These concepts are intertwined and interactional and contribute to empowerment, a concept central to photovoice and an outcome of this interactional process. By assembling and altering past frameworks and theories of Moffat et al. (2008), Liebenberg (2018), Bates et al. (2018), Roy et al. (2014), Lorenz and Kolb (2020), and Golden and Earp (2012), I seek to contribute to prior scholarship and provide a lens for other students to view the photovoice method and photovoice project findings and outcomes.

I have organized the 4E framework in the following way: we start with **explore** to contextualize the issue; before turning to **encourage** to actively engage individuals, **enhance** to actively collaborate with stakeholders, and **embody** to engage both heart and mind in illustrating health and illness experiences. Together, the four factors lead to opportunities to **empower** communities and influence interdisciplinary policy, program, and practice discourse. The four factors are both interrelated and correlative, and empowerment is the culminating outcome.

This model has developed additively from the foundations of photovoice and its practice over the past 30 years. I suggest that the model contributes to a holistic understanding of

photovoice methodology and how it works. I hope that this model energizes emerging researchers to empower participants through holistic research practices to create positive health outcomes for themselves and their communities.

Conclusion

My literature review on photovoice with people with cognitive disabilities demonstrates that photovoice is holistic, person-oriented, and sustainable. Innovations in the photovoice method support meaningful participation and communication by people with cognitive disabilities. I posit that the 4E model is a call to action for researchers to facilitate photovoice with individuals who may be marginalized by cognitive disabilities and to focus on their lived experiences, expand discourse and their knowledge basis through participatory visual research, and encourage practical, life-enhancing skill-building among participants. The theoretical framework developed further re-frames photovoice research by illustrating the empowerment process, while also serving as a bridge to connect the disciplines of quantitative and qualitative research and innovative methodologies.

What is Photovoice?

Photovoice is a participatory visual research method that puts cameras in the hands of people with valuable lived experience so they can explore and share their perspectives on health, family, community, and their futures.

For 25 years, photovoice projects have been carried out around the world, with youth, persons living with chronic health conditions, persons who have physical, emotional, developmental, or cognitive disabilities, homeless, pregnant teens, veterans, and many others.

PhotovoiceWorldwide's mission is to help individuals and organizations worldwide use photovoice safely, ethically, and successfully, and to create a global community for photovoice peer-to-peer support and continuing education.



For more information, visit our website at www.photovoiceworldwide.com

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Appendix: Recent Innovations in the Photovoice Method with People with Cognitive and Communication Disabilities, 2010-2020

This review focuses in particular on photovoice with people with cognitive disabilities and chronic conditions affecting health, self-perception, and communication abilities.

Author/yr/jrnl	Focus/why	Participants	What did they do	Considerations/interesting/ surprising
Coussens/2020/ PloS ONE	To capture subjective experiences of participation among young children with Developmental Disabilities	16 children, 5–9 years old, who had Developmental Disabilities in Belgium	Protocol and phases: recruitment, informed consent from parent, informed assent from child and interview 1, in depth interview 2 based on photographs, member check and interview 3, data analysis. Photos were taken by the children when doing meaningful activities: “take photos or make movies of activities they did at home, in school and in their community during a week” (2). Children had 2 strategies to refuse—walk away or mother-assisted (1).	Photo elicitation, Participation Action Research Safely worked with children: explored level of participation of young children with Developmental Disabilities. Ex: Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed 47 total photos among participants. Adapted informed consent based on a comic strip to receive children’s assent. “Easy to understand book format” (4). Themes: playing, learning and family and friend gatherings. Included sub themes. Text interviews included. Thematic map (Figure 2). Interviews: used “props for non-verbal demonstration of their thoughts and events during the interview” (2). Used a robust digital camera that is child friendly to provide to participants. Child centered approach: “describe their pictures and were prompted to reveal the thoughts and feelings the pictures evoked” (2). Six phases: Figure 1 NVivo10 Qualitative Data Analysis Software
Greco/2017/ Scandinavian Journal of Occupational Therapy	To examine if and how photovoice, a participatory research method used to empower and highlight the unique experiences of vulnerable groups, could be used as a recovery-oriented self-report measure for children with a mental health disorder.	Four children with mental health related disorders. Study occurred at voluntary day hospital program’s psychiatric treatment center for severe behavioral disorders. Children attended the program 4 days per week, with admission lasting from 3 to 10 months.	Children created life books from photographs and images of what mattered to them. Nine sessions. Ethnographic methods used (child interviews, participant observation) in classes and at recess before, during and after the weekly sessions. Ethical approval was obtained from Research Ethics Committee Lifebook: children each created a life book from photos taken and images selected about their personal experiences; had full control of their books; focused on activities in and outside of school (Table 2).	Participatory research: children were co-researchers; a narrative-phenomenological theoretical framework of what mattered most to the them was assessed; the project empowered the children to articulate what mattered in their everyday lives. Used hermeneutic circle of data analysis (Figure 1). Group Sessions and Interviews: occupational therapist facilitated group sessions and ethnographic narrative interviews. In Session 9: children determined “whether and with whom to share the content of their completed life books, including (a) to not present their book, (b) separate in-class presentations; (c) a cumulative presentation for all the students and staff; and/or (d) an exhibit at a family event.” (224) One participant showed book to her family at home and the other three participants presented their life book at in-class presentations that they arranged with their teacher. Had individual interviews and group sessions. Safely worked with children with severe behavioral disorders using in photovoice in psychiatric setting.

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Gustafsson/2018/ Scandinavian Journal of Occupational Therapy	To describe Life filming as a participatory approach with older community-dwelling adults regarding the design of their local environment.	Included 7 community-dwelling older adults (65 years and older) at Cultural center for seniors, in Gothenburg, Sweden. Participants lived in the urban district where the community center was located. The community center recruited a group of older persons interested in collaborating with the Age-friendly Gothenburg project. They were Assumed to be healthy older people with “good” SES conditions.	Used a descriptive single case study. Data was generated through field notes and memos, and analyzed utilizing thematic analysis. Group activity occurred. Participants validated the findings and the five themes that emerged. Participants used life film as a group activity and produced at least one film each. Participation was voluntary; written consent was obtained regarding public dissemination of the produced films.	Used life filming that supported participation, both as a process and an outcome. Participation was a process and an outcome. Used a single case study to show a complex process of intervention in a real life context. No formal ethical approval for study- rather had continuous ethics discussions in the research group and with participants during implementation in order to maintain an ethical stance Structure of Life filming as a group activity (table 1). For a list of produced films and vimeo links see (table 2). Films had various time (1.03 to 5.38 mins); each participant produced at least one film; the moving images, music and other aspects of the film boosted participation and illuminated their voice. Life film outcomes: facilitated personal engagement, practical skills, and feelings of mastering technology; community-dwelling older persons experienced real possibilities to influence their local environment. Policy impact: municipality received information and opinions about the age friendliness and gained insights for improvement in the city; the municipality received confirmation that Life filming can serve as an operative means to support participation in Citizen dialog. Important for strategic city planning for age-friendly improvements to existing environment.
Ha /2016/ Global Public Health	To provide a means of meaningful participation in research about their lives, experiences, and needs. To share experiences, health, and well-being of children and families with ASD.	9 children with Autism Spectrum Disorder (ASD) in Hanoi, Vietnam. Many had limited verbal communication skills.	Over 1 year period. Included participant observation, in-depth interviews with parents, caregivers, and health professionals, an online survey and a public exhibition. Recruited through a community organization, The Hanoi Club of Parents of Children with Autism and a parent-run school for children with ASD.	Modified photovoice and used as part of an ethnography study. Safely working with children. Methods in working with children: “simplified questions and asking children to choose photographs and develop albums in order to engage them” (559); used caregivers in process to discuss photos. Networks: Hanoi Club and the parent-led school were selected for recruitment; used these communities to access a network of families of children with ASD. Included parents in research. Demonstrated need for triangulation with “observations and interviews with parents and others in the interpretation of the photographs” to holistically understand photos (559). More than 2100 photos were taken by children. Product: public exhibition; reduction of social stigma. Potential usage regarding ASD in education, public health, and social policy.

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Heffron/2018/ Scandinavian Journal of Occupational Therapy	To evaluate photovoice as a participatory research method, examine environmental barriers and supports to community participation, and develop strategies to support self-determination and community participation for and with people with I/DD. To identify action plan strategies for improving participation choice, control, and goal attainment.	146 community dwelling adults (30+ years) who were diagnosed with I/DD and were receiving community living supports and services Majority had an income of less than \$12,000 per year and were receiving public income assistance. Participant demographics (age, gender, and race/ethnicity) in Table 1. Located in cities across the USA: New York, Chicago.	Utilized participatory action research and photovoice: Conducted interviews and audits of participation environments to identify high interest participation activities and documents. Participants teamed up to select, contextualize, and codify the data. Thematic analyses involved both inductive and realist approaches (382) .	Conceptual model of nine themes at microsystem, mesosystem, exosystem, macrosystem, and chronosystem environmental levels (figure 6). Study was reviewed and approved by the Institutional Review Board of the University of Illinois at Chicago. Themes included physical environment, social environment, economic environment, and community participation (Table 3). Recruitment method: Recruitment occurred at collaborating community sites in Illinois, Washington, and New York. Diverse participants. Provided practice and policy implications: for health care providers/practitioners, and policy makers regarding advocacy, built environment, financial factors. Large group size (146). Worked with researchers. Life approach and analysis.
Kruger/2019/ International Journal of Qualitative Methods	To explore how imagination is a useful method to expand upon stories. To illustrate how artistic and interview data from Beyond the Present: Risk and Body Stigma in Public Health project is used for qualitative health research.	13 participants who shared self identify in “whichever ways were important to them” (2, Table 1). Age range: 24-60. Gender identity, sexual orientation, race, occupation, SES, and characteristics/ other identities included. Toronto, Canada	Participants sculpted “someone who will die of non-communicable disease.” Then participants used lifeline (tactic) where they were asked to “represent time (a past, present, and future) on the board, give their sculpture a name or title, situate their sculpture on or around their lifeline, and populate the lifeline with what is important to their sculpture’s life.” (2) Then, semi structured interviews occurred regarding participant’s art, stigma, risk and health, and method. Sculpting and life lining occurred in 3 weeks, 2-hour session at local art café. 2-hour interview sessions occurred.	Used malleable methods of sculpting, life lining. Focus on embodied health research. Methodological frameworks: “(1) embodied or tactile, (2) creative, (3) imaginative, and (4) absurd. Inspired by Gastaldo, Magalhaes, Carrasco, and Davy’s (2012) body mapping, Bagnoli’s (2009) timelines, and Longhurst’s (2000) life map” (2). Inclusive: recruitment process and individuals self-identified with identities that resonated with them. Participants interacted with art during interview “(adding finishing touches, touching the art, pointing to it, and moving it around to see it from various angles)” (2). Themes of: Concrete and Reflective: Relating Objects and Subjects; Uncertainty, Unknowledge, Perfection, and Half-Formed Ideas; Imagination, Ontological Universalism, and Shadow Live Flexibility: no categorical answer, open ideas and thinking to produce art forms.

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Lorenz/2010/Visual Studies	To explore photovoice as a method to give people with brain injury a voice in society; both in their personal lives and with policymakers.	8 support group member volunteers. All in 40s and 50s with “recognized disability from brain injury” who were already support group members. 2 were brain tumor survivors, 6 had TBI. All considered high functioning. 3 worked part time or did volunteer work. All lived in 7 communities in Massachusetts. 5 participants continued through the outreach phase.	Implementation occurred between Sept and Nov 2006 with 10 meetings. Participants were given questions to consider about how brain injury affected their lives as they took photos. Each participant was given 2-3 disposable cameras and 3-5 weeks to take pictures. Participants spoke about at least one photo each meeting. 5 participants continued to meet to work on presentation for BIA-MA conference, library exhibits, website displays, et cetera.	Had a trial exhibit in a comfortable environment. Raised idea of people doing individual photovoice projects. Strong focus on abstract/metaphor due to invisible nature of brain injury.
Malstam/2018/ Scandinavian Journal of Occupational Therapy	To explore challenges and possibilities situated in everyday life	5 participants (2 women and 3 men) with auto-immune Addison’s disease. Participants were invited and recruitment occurred through purposive sampling at University Hospital. Between 40 and 77 years old, and had lived with AAD for 1–57 years. 3 of them worked (50%, 75%, and 100% time, respectively), and 2 had retired. All from Sweden. All but one had families including partners and children of different ages.	6 group discussions were facilitated over 7 weeks. Participants in the photovoice group reconsidered their role in the research project, to be an active group member versus being a participant. Data generated from group sessions were visually analyzed or transcribed and analyzed with thematic analysis. 5 themes emerged. Used Swedish language, while the synthesis of the quotes was translated into English.	Questions asked: “what makes me feel good, bad in everyday life, and planning and adaptations in everyday life.” (360) Used the term “member” to refer to participants. Members decided how many sessions, if the goals were accomplished , and the content , the format and duration. This also included ground rules for sessions, consensus in session time, number of photos taken, and logistics. Color photos shared in figures. Product: booklet including photographs and stories; intended for others with AAD, relatives, healthcare professionals, and other stakeholders. Language transcription. Small sample size (5).

Author/yr/jrnl	Focus/why	Participants	What did they do	Considerations/interesting/ surprising
Martin /2013/ International Journal of Environmental Research and Public Health	To “describe the lived experience of those with dementia and their carers” and see if the technology-based NOCTURNAL system could address challenges that this population faces during nighttime hours by providing “pervasive ambient assisted living” in their homes and “move beyond this to offer therapeutic interventions.” A “secondary aim...was achieving commercialization readiness for the final service.”	8 people with dementia had final prototype system installed for a three-month evaluation at home. They needed to have early stage dementia with a “confirmed diagnosis” and be “in receipt of a care package and living in his or her own home, or holding tenure in support living.” Several more participants began but dropped out, often due to the progressive nature of dementia. All lived in Ireland.	Researcher conducted interviews to “establish the main issues/risks and care needs that arise during the hours of darkness.” Themes were identified from these interviews that influenced prototypes of NOCTURNAL. The system was installed in participants’ homes (as a PC tablet). Evaluated three stages of the prototype over three months, with participants giving feedback on how it worked, and also looking at data such as sleep-wake patterns with the system in place. Researcher also conducted focus group with “fit healthy older people” to get thoughts on prototype.	Continued to recruit people throughout entire project, which was very unique. They had a difficult time retaining participants because of the progressive nature of dementia. During interviews, two people went to participant’s home to “safeguard both the vulnerable participant and the researcher.”
Newman/2010/ Rehabilitation Nursing	To use photovoice to create an evidence base of environmental barriers and facilitators to community participation through analysis of data based on the World Health Organization's International Classification of Functioning, Disability and Health taxonomy of environmental factors	10 individuals with spinal cord injury (SCI) located in/ around Charleston, South Carolina, USA. Patients 18-65 years, had chronic paralysis due to SCI, level and severity of paralysis requiring locomotion with a wheelchair, and duration of disability longer than 1 year. 40% were female, 60% male; 50% African American, 50% White; age range: 24-61, with a mean age of 42.1; and an average 13.9 years of education; average time since last injury was 17 years	Recruitment was a collaborative effort between project facilitator and peer counselor at the dRC. Partnership with community: collaborated with the disability Resource Center (dRC) in Northern Charleston, SC. Photovoice documented actual community experiences of people with SCI. Three assignments and interviews occurred. Some participants only completed one assignment and interview (ex: couldn’t think of anything else to photograph); one participant wanted a fourth interview (to discuss more). Themes focused on accessibility, whether related to healthcare services (medical appts, or community access for leisure activities). Included facilitators	Usage of WHO’s International Classification of Functioning, Disability and Health taxonomy. Focus on environmental factors using taxonomy. Analytical framework: Figure 1. Community Participatory: Advocacy to work with stakeholders; staff at dRC were participants in the photovoice project. Discussion themes included questions such as “how do you define community?”, “what helps you go where you want to go and what you want to do?” and “what prevents you from going where you want to go and doing what you want to do?” Participants also brainstormed on issues relevant to their lives for an iterative process. Power was placed in the hands of the participants and gave them control over the issues that were photographed and discussed. The prioritization of issues by the participants and advocacy, fostered shared power between the “traditional academic researcher” and the community. Ex: researcher categorized themes and consulted with participants to acquire feedback. Participants were allowed to keep digital cameras (that were provided initially) for compensation. Patients with tetraplegia were provided adaptive photo equipment (ex: small tripods, support arms, cable releases).

Author/yr/jrnl	Focus/why	Participants	What did they do	Considerations/interesting/ surprising
		with a range of 2-36 years.	for potential interventions and determining barriers .	Impact: evidence of issues affecting citizens with disabilities with the public and policy makers has been shared. The bill to strengthen accessible parking laws in South Carolina was passed by the South Carolina House and Senate and subsequently signed into law in June 2009. The SC Department of Motor Vehicles began issuing new parking placards and license plates for people with disabilities.
Overmars-Marx/2016/ Journal of Applied Research in Intellectual Disabilities	To evaluate the guided photovoice approach to analyze the effectiveness of using photovoice among people with intellectual disabilities. To obtain more knowledge about the perspectives of people with intellectual disabilities on their social inclusion in the neighborhood.	14 participants with mild to moderate intellectual disabilities in U.S.	Participants and present authors walked around neighborhood together. Participants photographed places and people in neighborhood with the researcher. Then, photographs were discussed during an individual interview. Alternative approach of guided photovoice. Stage 1: Staff members invite all residents in criteria. Stage 2: Taking the photographs with the researcher. Stage 3: Discuss photos during individual interview to reduce bias or external influences. Use of these questions: "Could you tell me more?" and "Can you give an (other) example?" Stage 4: post interview. Do not analyze the photos outside the interview context.	Encompasses extra involvement of the researcher ex: photo walks. Evaluated photos not taken and followed up regarding specific questions ex: what "photographs not taken" and the "example" questions. Used "active listening" to encourage participant to share Person centered approach rather than group sessions ex: Use an individualized approach regarding informing and training participants. Staff members are designated as neutral party.
Padilla/2020/Arts Health	"To identify local interpretations of complex social and structural factors that are most salient to the well-being of local Dominican populations affected by drug addiction" (1). To describe the political and institutional structure of drug	7 activist-artists we originally recruited in 2014 were living on the street or in "shooting galleries. 4 men and 3 women. Volunteers at FUNDOREDA and public health prevention services. Site Study: broader metropolitan area of	Used photovoice methods. Participants had regular meetings and co-learning discussions over a 1 year period. In co-learning discussions, activist artists "learned about photographic techniques, ethical procedures, captioning, policy mapping, the selection of images to create a story, and the logistics of developing an exhibit" (5). Interviewed policy experts.	Community-based participatory research methodology and applied theoretical orientation of critical medical anthropology. Adapted Photovoice with at risk population/active drug using populations. Framework of sydemic theory. Situated in prior photovoice project, Lens Project. (Proyecto Lentes); functioned as an ethnography. Group decided to select images and create interpretations for photos collectively. Fostered cohesion and support among the cohort. Ex: Referred to the group as "la familia FotoVoz." Themes: effects of medical abandonment, humanize the suffering

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	policies and programs in the Dominican Republic.	Santo Domingo, Puerto Rico.	Included “informant interviews and participant observation at 15 public and private substance use service organizations in Santo Domingo and Boca Chica” (5).	<p>addict, challenging police abuse and corruption.</p> <p>Approx. 800 pictures were taken to be used at the final exhibit. Exhibit was shared in various locations in the DR and FL. This includes the National Council for Drug Control in the DR, School of Public Health at the Universidad Autónoma de Santo Domingo, several local high schools, in the lobby of the Sixth Latin American Conference on Drug Policy, and various community organizations</p> <p>Reciprocity: “established a donation-based food and clothing bank for street-based drug users that operated out of FUNDOREDADA” (5).</p> <p>Growth opportunities: coordinated professional opportunities for where artists could present research- at the Universidad Autónoma de Santo Domingo and at public health conferences. Some participants have sought drug rehab and others are pursuing educational training.</p> <p>Grassroots community organizing model to improve policy related to drug addiction.</p> <p>Policy focus: exhibition is a part of an educational curriculum on drug policy and harm reduction; policy reform.</p> <p>Language: captions and titles originally written in Spanish. Translator into English for captions, but titles are in both languages.</p>
Papoulias/2018/Health Care Analysis	<p>To highlight the strengths and potential contributions of participatory visual methods for healthcare quality improvement research.</p> <p>To explore how the patient experience can generate knowledge in health systems.</p> <p>Design in Mind: “to elicit mental health service user perspectives of the design and physical environment” (181).</p>	<p>Equal number of men and women.</p> <p>Number of participants unknown.</p> <p>Located in acute psychiatric wards in an inner-city environment; in-patients.</p>	<p>Mixed methods.</p> <p>Participants were recruitment from two of the inner city acute wards.</p> <p>“Researcher accompanied them across the ward and recorded the reasons they gave for their choices” (183).</p> <p>Participants were instructed to take photos “one of something they liked and one of something they did not like about the ward.” (183).</p> <p>Participants were subsequently interviewed individually.</p>	<p>Facilitated the Design in Mind using a participatory model via photo-elicitation</p> <p>Emphasis for reflexive approach.</p> <p>Limitations: time and budgeting constraints as well as ethical and clinical considerations.</p> <p>Functioned within the mental health ward, needed to navigate ethical considerations, and ensure confidentiality.</p> <p>70 photos were produced: majority positive photos.</p> <p>Provided insight about improvements for ward and quality of life in mental health unit.</p> <p>Quant analysis: gender analysis of frequency of themes extracted and photos accessed (ex: men were 3X more likely to take photos of their bedrooms) (183).</p>

Author/yr/jrnl	Focus/why	Participants	What did they do	Considerations/interesting/ surprising
Povee/2014/Disability and Society	To explore the process, opportunities and challenges associated with the use of photovoice with people with intellectual disabilities, illustrated through a research project entitled 'This Is Me'.	18 individuals (11 male and 7 female), aged 20–45 years. Included Members of an Advocacy Agency that supports people with an intellectual disability living in the SW region of Western Australia. 13 chose to be interviewed in pairs or small groups; 5 requested for parent or guardian to be present).	Used photovoice Questions: "Who am I?", "What makes me me?" and "What is important to me?" Members were given no direction as to what to photograph, as per the photovoice philosophy. Photograph period was 3 months: the number of photographs taken by each member ranged from 2 to 83 photographs, with an average of 37 photographs taken by each member. Contextualized photos via the following questions: "What made you take this photograph; and What is happening in this photograph?" The interviews were flexible and akin to a conversation" (899). Interviewed: 10 members interviewed once, 3 members interviewed twice and 3 interviewed three times and 1 member interviewed four times.	Project creation: "This is Me" to explore social roles and identities of people with intellectual disabilities living in the community Adhered to the six stages of photovoice identified by Booth and Booth (2003). Community engagement: researcher was well known to the Members of the Agency and was involved with the community before research started. Consent: information sheet and consent form that utilized simple language, pictures, bullet points and the repetition of information. Participants were identified as co-researchers. Interview Discussion: "Members that were not verbal... pointed at photographs and used facial expressions and gestures to convey their story" (899). Impact: photograph exhibition. Members selected their own photographs for display. Public photograph exhibition was held at a local shopping center, with Members involved in setting up and manning the display. Local stakeholders such as community development officer and representatives of disability agencies attended the photograph exhibition. Research ownership: "research topic must be owned by people with intellectual disabilities (Walmsley and Johnson 2003)" (897). Challenge: addressed the uncertainty and for having researchers share control in the research process.
Ripat/2019/Disability and Rehabilitation: Assistive Technology	"To explore how the attitudinal environment influences the participation experiences of young adults with disabilities who use assistive technology" (314).	22 adults using assistive technology. Young adults ages 17–35 years) who had used AT (e.g., wheelchair, communication device or prosthetic device) since childhood or young adolescence. Participant demographics (Table 1)	"Completed individual interviews before and after engaging in a photovoice process. 10 of the participants then took part in a focus group. Data were analyzed inductively using a thematic analysis approach" (314).	Used social constructionism as described by Burr. 3 themes emerged from analysis and 1 theme emerged from focus group discussions. -3: (a) seen and treated as different; (b) assumptions made and (c) impatience. - 1: photos as a means of consciousness-raising. Project promoted consciousness-raising. "Custom adaptations were made to each camera as needed in consultation with the participant, to ensure participants were able to independently take photos, for e.g., with switch adaptations or providing mounting devices for the participant's wheelchair and participants were allowed to keep their adapted camera at the study conclusion" (315).

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Routhier/2019/JMIR Research Protocol	"To understand the places people using MAT go and the things they do, to identify perceived barriers and facilitators as well as users' desired environmental modifications, and to understand subjective and objective issues related to environmental accessibility." (1)	"36 participants per site who represented six types of MAT users (ie, cane, walker, crutches, manual wheelchair, power wheelchair, and scooter)." (1). These participants completed the Photovoice procedure. 24 participants were recruited to each study site for SWAN data collection (1). Conducted in Vancouver and Quebec City, Canada.	Mixed methods: Research questions and methods (Table 1) + outcome measures (3). Photovoice and GPS methods were concurrent. Diary occurred simultaneously. Participants had option of GPS tracking. Then 20 min qualitative semi-structured interviews were conducted about main MAT and other MATs used. Photovoice addressed objectives 2 and 3. Participants completed training session, on how to operate camera feature of app, ethical photo etiquette, video release form. Given consent form to obtain consent from individuals in photos. Then, for the next 2 weeks (may have been concurrent with GPS data collection) photos or videos were taken. Participants used Apple iPad mini. Then, there was an individual photovoice interview. Participants selected a max of 10 images. Focus groups were held. Varied at each site. Questions asked in Table 1 such as themes, improvements, suggestions collected (4-5).	Activity diaries method: Used iPad (supplied) for activity diary app. Participants described places visited, activities and mode of transportation used, and if they were accompanied by others. Support: participants were given troubleshooting document for devices and contact information of research assistant to help with technology and app. Research assistants answered any questions regarding equipment and process, conducted interviews, analyzed data, contacted participants to check in after 1 week, served as point of contact Caption either written by participants or researchers- if consent provided and participants prefer. Researchers identified potential images of interest. Photo consent form given to participants to share with individual in their photos. Partnership with municipalities and community members. Quantitative methods about outcome measures and recruitment stats (Table 2). Measures: Measure of Environmental Accessibility (MEA) "Stakeholders' Walkability/Wheelability Audit in Neighbourhood (SWAN). Outcome: 19 locations have been identified by the participants and evaluated in the Quebec City by MEA; 20 locations have been identified participants in the Vancouver region. Policy outcome: "improvements to MAT design; provision and training in MAT use; or the development of policies, regulations, actions, or services to improve the mobility of individuals with disabilities" (2). Product: photo exhibition – increase public awareness. Stakeholders attended and listened to stories regarding photos. This exhibition will be at local, community centers, or other public venue. Participants assisted with photo exhibition planning process.
Schleien /2013/ Annals of Leisure Research	To give individuals with intellectual and developmental disabilities (ID/DD) a voice to speak about community inclusion and to "instigate change...by sharing these voices." Also to	Seven individuals with ID/DD were chosen from a local south-eastern chapter of the Arc, an organization meant to promote inclusion of those with ID/DD. Participants all had good verbal	All participants needed assistants to help with photo taking; the roles between photographers and assistants were clearly delineated. There was training on photography ethics. Participants were assigned to take 2 weeks and no more than 30 photos to show what was important to	Interesting point that often communities for people with disabilities are limited to family, paid staff, and others with disability. Funded by Office of Special Education Programs, Office of Special Education and Rehabilitative Services, US Department of Education. Provided with "pocket-sized photo-release booklet" with "brief written explanation of the project...and a space to obtain signatures from individuals" photographed.

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	<p>“narrow the gap between how others see [these individuals] and how they see themselves.”</p>	<p>communication and understood the consent process, with mild to moderate ID. The participants were ages 48, 34, 35, 21, 38, 32, and 26. Five had ID, two had Down syndrome. Five had jobs, one was a student, and one was unknown. Six lived with their parents and one lived in a college dormitory.</p>	<p>them. Following assignments asked about what made them feel important and what their skills were. All assignments had supplemental worksheets. The researcher reviewed photos with each participant and formed primary themes, which participants later confirmed or corrected. Photos were displayed in two exhibitions; a pilot one at the Arc, and one in the Chamber of Commerce.</p>	<p>In addition to main display, also had individual’s boards with more photos and a “My Story” photo-book. Participants stood by displays so attendees could ask questions. Provided exit survey from exhibition.</p>
<p>St. John /2018/ Scandinavian Journal of Occupational Therapy</p>	<p>To describe the process of using a photovoice method with individuals with ID and present results from two participants to understand their meaning of health.</p>	<p>2 participants were recruited as a part of a larger Photovoice study in U.S. Anne: 36- year-old white female, college graduate, employed part time. Jack: 32- year-old male, did not disclose his race or ethnicity. He had completed some college courses. Was employed part time at a grocery store Both Anne and Jack lived in supported living apartments and received services from paid caregivers.</p>	<p>Consisted of camera orientation and training session; 2-4 photo collection sessions; an individual interview and photo captioning session; and, collective photo sharing and focus group with at least 1 fellow participant. Participants completed a total of 5-7 sessions across the 4 stages of photovoice data collection. Used photos, personal narratives and focus group data to identify themes of Personal Identity of Health, Nutrition, and Meaningful Occupation.</p>	<p>Participants were recruited through the distribution of flyers contacting community agencies and service providers. Small and focused sample size. Photovoice adaptations: Used Jurowski model as framework. Data collection for this study was adapted from the Photovoice structure outlined by Plunkett, Leipter, and Ray Guiding questions (Table 1). Visual Representation of participant narrative data (Figure 1) Did not include caregivers in this study. Research partner (graduate student) was required to be present for all sessions and for all stages of data collection, affirming consent, and managing photo equipment. Research partners needed to build trust. Additional assistance provided as needed ex: tech assistance, probed question when needed during session – case by case.</p>

Author/yr/jrnl	Focus/why	Participants	What did they do	Considerations/interesting/ surprising
Wiersma/2011/ Dementia	To understand how photovoice could be used as a methodology with this group, and to examine the benefits and challenges of using photovoice with people with Alzheimer's.	Four participants (3 men and 1 woman) in the early stages of Alzheimer's disease, in the U.S.	Questions around the image were posed, such as 'What is this picture about?' 'Tell me about the significance of this picture.' 'Why did you include this picture?' Background information about lived experience with diagnosis/disease. Participants choose 8-10 pictures that were important to them. Questions asked: around the image were posed, such as 'What is this picture about?' 'Tell me about the significance of this picture.' 'Why did you include this picture?' Focus group with all participants for feedback and discussion was not held due to ethical issues.	Pilot project Terminology: changed nomenclature based upon facilitators of the group recommendations Ethical brochure for recruitment based upon Wang and Redwood-Jones (2001) Involve the caretakers in all stages of the research ex: taking photos, obtaining consent and matching the consent forms with photos Explored challenges such as validating qualitative research in discourse. Focused on the importance of creative analytic practices Issues with data collection: ethics, consent and capacity Used dyadic approach. Had thank-you session instead of a focus group related to issues of consent because of issue with inclusion of caregivers. Thank-you session, including participants seeing photos taken with caregivers. Outcome: participants given a copy of photos to keep after; had a thank-you session instead of a focus group related to issues of consent. Product: TBD, visual and textual form with purpose to "humanizing face to Alzheimer's disease and to present the human face (and life)" (214).
Walker/2019/Disability and Rehabilitation	"To use a qualitative, community-based participatory action research method – photovoice – to identify perceived facilitators and barriers to physical activity among adolescents with cerebral palsy (CP) in a rural community" (2).	15 participants including adolescents with CP (n= 7) and parents (n = 8) *one family chose only to have a parent participate. All parent participants were female. All children communicated verbally or with an assisted device. Located in rural, southeast Georgia.	Used 9 step methods for photovoice (Table 1). Completed versions of the Barriers to Physical Activity. Questionnaire for People with Mobility Impairments (focus on barriers and facilitators). Had training session. Provided 2 weeks to take photos; after in-depth and focus group interviews with participants. Research questions (pg 3). Tablets with digital camera provided.	Used the SHOWed method. Clearly described photovoice methods using Table 1, per Wang and Burris, 1997 (reference 44). Quant analysis: questionnaire (Table 2 and 3). Used textual evidence from interview in thematic analysis. Included color photos- Figure 1-6). Safely worked with children. Tablets with camera were provided for photo taking to enhance functionality for children. Parents and children were participants and interviewed separately. Researchers provided minimum number of photos to take (8 photos). Collectively took 81 photos. Proposed action items: accessibility, opportunities for involvement and engaging the community. Targeted plan and stakeholders needed (Table 4). Facilitated a community forum – present photos and recommended actions to 13 influential stakeholders; held on campus at the researchers' home institution. Forum focused on themes of accessibility and awareness.

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Yi-Frazier /2017/ Qualitative Health Research	To explore the feasibility of using a photo-sharing mobile phone app Instagram to accomplish the principles of photovoice. To assess the rates of recruitment and retention and satisfaction for using Instagram related to diabetes topics	20 adolescents (14 to 18 years old) in the US with type 1 diabetes for 6 months or longer, English-speaking, with personal access to Instagram on an Android. Patients with upcoming clinic appointments at a large tertiary care hospital.	Participants used Instagram to post any diabetes-related photo for 3 weeks. Individual interviews and a focus group were also offered, and recruitment and retention statistics were tracked. Researchers examined and categorized the type of diabetes-related photos shared.	Use of hashtags: using #diabetesteenproject developed. Demonstrated the impact evaluation related to sharing content on public platform for Instagram (ex: number of quantitative impact and value of interest). Collection of public photos resulting from this project to be maintained; the number of hashtags and amount searched/tracked was recorded. Shared photos and thematic approaches (that were categorized by staff) included humor, diabetes care, food, exercise/sports, life with diabetes, type 1 vs type 2, talking with others who don't have diabetes.