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### **Title**

Making Visible the Invisible: Using Photovoice to Understand Living with Brain Injury

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### **Learning Objectives**

After viewing this poster, participants will be able to:

1. Articulate the potential value of gaining an insider perspective on living with brain injury.
2. List the steps involved in carrying out a participatory action research project using photovoice.
3. Describe some of the challenges faced by the participating brain injury survivors, the strategies they have employed to face those challenges, and some facilitators and barriers to rehabilitation from their perspective.

### **References**

1. Adelman, C. (1993). Kurt Lewin and the origins of action research. *Educational Action Research*, 1(1), 7-24
2. Balcazar, F. E., Keys, C. B, Kaplan, D. L., & Suarez-Balcazar, Y. (1998). Participatory action research and people with disabilities: Principles and challenges. *Canadian Journal of Rehabilitation*, 12(2), 105-112
3. Wang, C., Burris, M. A., & Ping, X. Y. (1996). Chinese village women as visual anthropologists: A participatory approach to reaching policymakers. *Social Science & Medicine*, 42(10), 1391-1400

### **Abstract**

Rehabilitation professionals have advocated for gaining an insider or patient perspective on living with disability, including brain injury, and facilitators and barriers to rehabilitation.<sup>i,ii</sup> Involving people with a disability in research about their lived experience may increase the relevancy of research to real-life situations and provide an opportunity for those with a chronic condition to play a participant-expert role in the research process.<sup>iii, iv, v, vi</sup> Action research in the tradition of Kurt Lewin involves integrating science and practice in a dynamic group setting and emphasizes the combining of science and social practice.<sup>vii</sup> For this study, carried out from September-November 2006, members of 'Mild' Brain Injury Survivor Support Group in Framingham, MA participated in a 10-week photovoice project,<sup>viii</sup> supported by SHIP and BIA-MA. The participating survivors took photographs of living with their brain injury, discussed them in a group, wrote narratives to accompany selected images, and prepared an exhibit to inform and educate policymakers, providers, and peers. Grouped under nine categories, including Chaos, Strategies, and Hope for the Future, the images and narratives convey these survivors' challenges and sense of mutual support as they

work to accept their different abilities and move on with their lives.

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<sup>i</sup> Prigatano, G. P. (2000). Neuropsychology, the patient's experience, and the political forces within our field. *Archives of Clinical Neuropsychology*, 15(1), 71-82.

<sup>ii</sup> Rich, M., Lamola, S., Gordon, J., & R. Chalfen. (2000). Video intervention/prevention assessment: A patient-centered methodology for understanding the adolescent illness experience. *Journal of Adolescent Health*, 27, 155-165.

<sup>iii</sup> Booth, T., & Booth, W. (2003). In the frame: Photovoice and mothers with learning disabilities. *Disability & Society*, 18(4), 431-442.

<sup>iv</sup> Bruyere, S. M. (1993). Participatory action research: Overview and implications for family members of persons with disabilities. *Journal of Vocational Rehabilitation*, 3(2), 62-68.

<sup>v</sup> *ibid.*

<sup>vi</sup> Balcazar, F. E., Keys, C. B, Kaplan, D. L., & Suarez-Balcazar, Y. (1998). Participatory action research and people with disabilities: Principles and challenges. *Canadian Journal of Rehabilitation*, 12(2), 105-112.

<sup>vii</sup> Adelman, C. (1993). Kurt Lewin and the origins of action research. *Educational Action Research*, 1(1), 7-24.

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