

Fifth Biennial Conference of the International Society of Critical Health Psychology,
Beverly, MA, July 18-21, 2007

Title: MAKING VISIBLE THE INVISIBLE: USING PHOTOVOICE TO ELICIT THE
PERSPECTIVE OF BRAIN INJURY SURVIVORS

Author: Laura S. Lorenz, A.B.D., M.A., M.Ed.

Affiliation: Doctoral Candidate, Heller School for Social Policy and Management,
Brandeis University, Waltham, MA, USA

Contact Information: 56 Chase Road, Marlborough, MA 01752; Home phone: 508-624-
0555; Cell phone: 774-285-1371

Presentation preference: Poster

Abstract: Rehabilitation professionals have long advocated for gaining an insider perspective on living with chronic conditions, including brain injury.^{1,2} Involving people with a disability in research about their lived experience provides an opportunity to play a participant-expert role in the research process.^{3,4,5} Yet efforts to understand the perspective of brain injury survivors need to be sensitive to fair process, which views knowledge as “a resource locked in the human mind.”⁶ Brain injury survivors may face challenges in reflecting on their situation, developing their ideas, and communicating them. These challenges require a creative approach to eliciting the survivor’s perspective on his or her experience. For this study, eight members of a brain injury survivor support group participated in a 10-week photovoice project,⁷ for which they took photographs of living with their brain injury, discussed them in a group, wrote captions to accompany selected images, and prepared an exhibit to inform and educate policymakers, providers, and peers. Grouped under eight categories, the images and texts convey their challenges and sense of mutual support as these survivors work to accept their different abilities and move on with their lives. The group is continuing its work in an ongoing outreach phase.

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

² 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.

³ Booth, T., & Booth, W. (2003). In the frame: Photovoice and mothers with learning disabilities. *Disability & Society*, 18(4), 431-442.

⁴ 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.

⁵ 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.

⁶ Kim, W. C., & Mauborgne, R. (1997). Fair process: Managing in the knowledge economy. *Harvard Business Review*, 75(4), 65-75, p 71.

⁷ 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.