

Looking Back, Looking Forward: Understanding the Impact of Using an Assistive Technology Device (ATD) - Participatory Visual Methods

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The following article is the eighth of a multi-part series on traumatic brain injury. The article is a continuation from part A of “Looking Back, Looking Forward,” published in Exceptional Parent’s February issue. TBI has received limited national attention and support. TBI is also the signature of the military conflicts in both Iraq and Afghanistan. This series is published by the Traumatic Brain Injury -Resource Optimization Center (TBI-ROC) and its Advisory Group, facilitated by JBS International, Inc. The TBI-ROC is a recognized source and leader for advancing national attention to the myriad of policy, research, practice and service needs supporting of civilian and military individuals who incur a TBI as well as their families.

Managing the cost of rehabilitation for a child, teenager or young adult who has incurred a TBI can be supported through the use of an ATD. Theresa Rankin, a nationally recognized TBI advocate who incurred a brain injury 41 years ago, was able to use ATDs only through her dedicated advocacy and that of her family, friends and providers. Gaining access to ATDs was a challenge. However, ATDs were effective in helping Theresa complete her education, pursue competitive employment and improve her quality of life. Her struggle to gain access to an ATD lasted more than 30 years. Theresa was able to gain access to an ATD through funding from the Virginia Department of Rehabilitation Services.

The following describes the benefits a particular ATD—Participatory Visual Methods. It can be a cost-effective tool that all families can use to help their child re-integrate into the community.

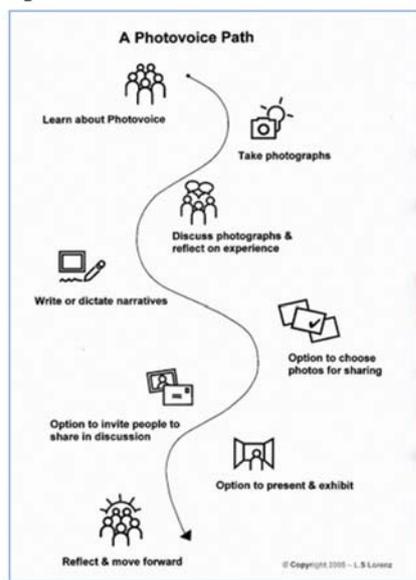
Childhood and adolescence are powerful times for shaping the development of identity. All young people struggle to be seen as resources in their families and communities. Brain injury can make the struggle that much harder. Providing opportunities for

young people with brain injury to advocate for their perspectives on living with brain injury and achieve positive change can have lasting effects by planting seeds of self-worth, confidence, and success. One example of such an opportunity is photovoice, a process that puts cameras in the hands of young people with a brain injury. They can take photographs of their lives, discuss them with others, write captions, and develop outreach products, from personal binders to websites, exhibits, and presentations that raise awareness and advocacy for perspectives with policymakers, providers, educators, communities, and peers. Photovoice engages young people in reflecting on and advocating for their perspectives, an increasing way to “give voice” to people whose perspectives are often ignored.

An advantage of photovoice and other “participatory visual methods” that use visuals (drawings, photographs, collage, murals, or video) is their flexibility. They can be used by a young person working alone, in collaboration with a parent, sibling, or friend. Photovoice can be used to explore a range of topics, from personal experience to community resources and problems related to disability, health care, and/or education; from the sim-

ple - to reflect and advocate within a family or small group of friends, providers, or community members, to the ambitious - to reach policymakers worldwide through a website or video on the Internet. Photovoice topics and purposes may grow over time. Young people in many countries with TBI who have participated in photovoice often sign up to support their personal journey of healing. As they realize the positive impact their pictures and captions are having on each other, they become motivated to raise awareness about TBI with people who make decisions.

FIGURE 1
A Photovoice Path



As a parent, in considering the steps involved in doing photovoice, as seen in Figure 1. First, discuss photovoice with the child and determine a topic to explore using a camera. A good way to start is by answering the question: “What is it like to live with a TBI?” Seek to investigate both positive and negative aspects of the selected topic. For example, identify the positive things about living with TBI (family, friends, medical team, and the courage to get out of bed every day).

Photovoice also provides opportunities to reflect on problems related to living with a TBI such as feelings of isolation, limitations on mobility or independence, or limited rehabilitation opportunities nearby. The photographs can be explicit—showing school books that may be harder to read than before; or they can be symbolic—metaphors for feelings that may be difficult to express in a constructive way than with words alone. Exploring both positive and negative answers to photovoice questions is vital. Over time the answers can lead to ideas of action that might strengthen positive things identified and improve negative ones.

Photovoice involves doing action research. The child may consider the implications of taking pictures for research. For

example, asking permission before taking any photos of someone or their property; explaining what the pictures are to be used for. Use of role-play scenarios can be a helpful way to prepare the child. Although potentially scary, explaining photovoice to others and asking permission to take their photo or to include it in a binder or exhibit can lead to positive engagement and conversations.

The possibilities for types of cameras are flexible. Use a film, disposable, or digital camera. If holding the camera steady is an issue, investigate options for using a tripod or placing the camera on a sturdy surface. If physical limitations pose challenges, giving the camera to someone else to take photographs is a common strategy. Some children will want to be spontaneous, without thinking ahead what photos to take; others may prefer to plan out each photo out carefully. Using a combination of these strategies can be helpful.

Once the child has a few pictures—perhaps as few as one or two, provide opportunities for him or her to reflect on them alone, with someone else, or with a group of people participating in the photovoice activity. Consider using a structured approach to talking about the photovoice photos. Table 1 provides a list of questions that were developed for discussing photographs taken for community development projects.

TABLE 1
Sample Photo Discussion Questions

SHOWED
What do you <u>SEE</u> here?
What's really <u>HAPPENING</u> here?
How does this relate to <u>OUR</u> lives?
<u>WHY</u> does this problem/situation/strength exist?
How could this image <u>EDUCATE</u> the community/policy makers/ etc.?
What can we <u>DO</u> about it (the problem/situation/strength)?

A common next step with photovoice is to write captions for selected photos. A caption can be short or long - a few words, a paragraph, a poem, or even the lyrics to a song. If writing is a challenge, let the child dictate their captions to someone else. Encourage the child to write as if speaking to someone else. Let the child develop his own voice and keep editing to a minimum.

Once the child has several photos and captions, think about the photos as a group. The possibilities are limitless. Developing themes can be challenging and is also an excellent way to use the brain. Themes can help audiences quickly grasp what the child wants to say with photovoice. Think about possible audiences with whom the child can reach out to with photos, captions, and themes: other students, family members, or the healthcare team, the community, the school system, or elected officials. Consider different audiences, what they need

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to know about TBI, and the actions the child would like them to take to support sensitivity, and enhance perspective. Now consider ways to reach the audiences identified—with a binder or booklet, with framed photos and caption, poster, Facebook page, an exhibit, PowerPoint presentation, or a video. Creating more than one outreach product may be useful. Consider what would be fun to work on alone and what could be done in collaboration with others, and assess doing some of both. Outreach can be an excellent way to engage the child in advocacy efforts to improve the lives of others with TBI, from friends to student-athletes, soldiers injured in the Wars in Iraq and Afghanistan, and many more.

Photovoice is one way to engage a child with TBI in efforts to reflect on and improve their situation and potentially have a positive impact. The photovoice guidelines provided here are just that—guidelines. Table 2 contains some suggestions of photovoice resources. Included is a link to a simple guide to undertaking a photovoice project. •

Table 2 Photovoice Resources

- “Brain Injury X-Posed: The Survivors View,” a photovoice project by adult brain injury survivors. See the exhibit on www.brainline.org and at www.biama.org. (Search for “photovoice.”)
- A simple guide to undertaking a photovoice project, available for free download at http://www.brainline.org/multimedia/presentations/photovoice/Photovoice_Facilitators_Guide.pdf.
- o Brain Injury Survivors: Narratives of Rehabilitation and Healing, a book illustrating the use of photovoice with adult brain injury survivors. Find out more at: https://www.rienner.com/title/Brain_Injury_Survivors_Narratives_of_Rehabilitation_and_Healing
- A video paper describing the use of photovoice to improve clinical care: Lorenz, L. S., & Chilingirian, J. A. (2010). Using visual and narrative methods to achieve fair process in clinical care. *Journal of Visualized Experiments*. <http://www.jove.com/index/Details.stp?ID=2342> doi: 10.3791/2342