



## SLI Brain Injury Research Council - Research Brief

### *Residential transitions: Perspectives of brain injury survivors*

**This study summarized residential transition experiences of a group of chronic brain injury survivors. Participants addressed themes of investment in the transition process, transition to more/less restrictive environments, the search for a balance between support and independence, the desire to pursue interests, and the ongoing search for fulfillment and a sense of accomplishment. Their suggestions have guided utilization of results.**

#### Background

Following acquired brain injury, individuals typically experience multiple transitions in roles, participation, and living situations over time. Some post-injury transitions serve as signs of improvement or recovery and some as signs of decline or loss. In all cases, the priority is that transitions are experienced in the most supportive and integrative ways possible. Successful transitions to community (re-)integration post-brain injury often necessitate long-term supports to the individuals transitioning and are priorities of life-long rehabilitation.

#### Methods

A qualitative design was used that consisted of semi-structured interviews with 21 chronic brain injury survivors living in group homes. Interview data were analyzed by two researchers using a structured analysis process (coding) with an inter-judge reliability of 92%.

#### Findings

- People spoke most often about ‘Finding a balance between support and independence’, followed by ‘Defining a new purpose in life’, and ‘Transition to more or less structure’.
- The majority of participants expressed a belief that they had moved from a more structured environment to a less structured one and liked being in a less restrictive environment (*I liked being able to go out every day*). Some felt that there was not enough structure while others described too much structure.

**Table 1. Survivor-suggested transition practices and strategies, by study theme**

Transition Theme	Suggestion
Feeling invested in the transition process	Be told about the possibility of moving as a first step. Discuss the pros and cons of moving. Tour the new place before a commitment is made. Have an interview at the new place to ask questions and learn about the place. Have a say in the decision to move or not.
Transitioning to more/less structure	Staff should sit down and explain the rules and why things are what they are.
Finding a balance between support and independence	Staff name tags would make it easier to know who to ask for help. Staff should not call residents ‘patients.’ Have times for staff to get to know residents and vice versa.
Defining a new purpose in life	Counselors should meet with residents to talk and to give help. All brain injured people should be in exercise class to use different muscles and build them up. To help people get back to work, go over job interviews and filling out applications.
Engaging in hobbies and interests	Do more in the community (e.g., choral singing; museums). Have more things to do (e.g., computer lessons; cooking classes).
Experiencing faith, fulfillment, acceptance	It takes a while to adjust, and everyone needs to be patient. Don’t lose hope or give up.

- Participants said moving to their current residence facilitated their acceptance of their injury and gave them solace. (*everyone else that got a place here was going through the same thing that I was . . . it just made me feel like I wasn't the only one*).
- Participants indicated they were not actively involved or invested in the transition process. Most participants said their families and the residence staff made decisions and arrangements for their moves without resident input (*They didn't tell me that I was leaving, that...they wanted me to live here*). Once established in their new residences, participants expressed being invested in their residential communities (*I make suggestions and offer my 10%*).
- Some participants indicated having a new purpose in life now and some didn't.
- Throughout their interviews, survivors spontaneously expressed ideas regarding practices and strategies that would have made their transition easier, faster and/or more positive (see Table 1).

## Utilization

- **Food preparation:** Nutrition and healthy cooking are now training topics for staff members and offered in a 2-hour cooking class once or twice a month at Advocates, Inc. main offices. Residents have opportunities to participate in food preparation/cooking classes once a week.
- **Admissions process:** Inappropriate candidates have been removed from the applicant waiting list, making it easier for staff to use. Staff are being more deliberate about getting applicant input during the review process. Potential candidates and family members are now required to visit the program. Applicants are now encouraged to have a meal at the house, to become acquainted with residents, staff, and house protocols before they move in.
- **Quality of life:** To track application of study results and potential impact over time, the SLI Brain Injury Wellness Center is incorporating a quality of life scale into ongoing programmatic monitoring and evaluation and research studies.

## References

O'Neil-Pirozzi, TM, Lorenz, LS, Demore-Taber, M, and Samayoa, S. (2015). There will be some changes made: A survivor perspective on post-acquired brain injury residential transition. *Brain Injury*, Published online September 23. <http://dx.doi.org/10.3109/02699052.2015.1075147>.

Lorenz, LS, O'Neil-Pirozzi, TM, Demore-Taber, M, and Samayoa, S. (2013). Transitional life experiences of the long term brain injury survivor: A qualitative study to understand survivors' perspectives. Poster. American Congress of Rehabilitation Medicine 90<sup>th</sup> Annual Conference, Progress in Rehabilitation Research, Orlando, FL, November 12-16.

**The SLI Brain Injury Research Council** is an inter-disciplinary group of researchers and clinicians doing collaborative research to support the physical, cognitive, and social fitness of people with chronic ABI living in the community.

**Supportive Living Inc**, a non-profit charity, strives to raise the quality of life for survivors of brain injury. To achieve this mission, SLI develops appropriate and affordable supportive housing; provides life-long physical, cognitive, and social fitness through wellness programs; and fosters research aimed at improving the lives of those affected by brain injury.

**For more information about this study and SLI's Brain Injury Research and Education Program**, contact Laura Lorenz, SLI Director of Research and Education, at [llorenz@brandeis.edu](mailto:llorenz@brandeis.edu).

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