

PLEX Engagement in Research Community of Practice

Jun 2025: Lessons Learned from the Co-Design Process of an Educational Toolkit to Support Younger Women's Parental Role, Responsibilities, and Goals Post-Stroke

This document provides a summary of engaging people with lived experience (PLEX) in the co-development of an educational toolkit.

Key Presentation Points

- As most existing stroke recovery resources did not address gendered or age-specific needs, actively involving PLEX helped create a context-specific toolkit for young women
- Forming relationships with PLEX over time created space for honest feedback
- Co-design can be therapeutic, validating, and transformative when done right

What did we discuss?

- **How did PLEX shape the Toolkit?:** PLEX helped reframe the content into more accessible and empathetic language, alongside adding specific modules guided by their experiences (e.g., parenting-specific guidance)
- Creating a safe space is vital for meaningful co-design: Prioritize clear, inclusive language and permission to use "pause or pass" when sharing experiences. Foster emotional safety through frequent check-ins.
- **Involve PLEX across the whole spectrum of the project:** PLEX were involved in the planning, doing, and sharing of the educational Toolkit.
- **Provide flexibility for engagement:** Flexible formats such as online meetings and an asynchronous running Google document provided opportunities for PLEX to engage when they were able.
- There is power in connection: Meeting and sharing experiences with others can be transformative.

Relevant Resources on PLEX Engagement in Research:

- 1. <u>Jay and Sari Sonshine Centre</u>: A link to the Jay and Sari Sonshine Centre website which provides information about stroke prevention and cerebrovascular brain health care at Toronto Western Hospital.
- 2. Jay and Sari Sonshine Centre LinkedIn: A link to the Jay and Sari Sonshine Centre LinkedIn page.



