

The Everyday Experience of Living with and Managing a Neurological Condition (The LINC Study)

Project Summary

What are the goals of the LINC study?

We are doing this study to better understand how you and others living with neurological conditions do things like

- work
- go to school
- raise families
- take part in community activities

We want to know what supports and resources you and your children need to make everyday life possible and meaningful. Specifically, we want to do three things:

- create detailed stories about families like yours using your own words and voices
- describe to what extent your neurological condition changes
 - your overall health
 - the resources you use
 - your ability to do things that you need to do, that you want to do, and that you are expected to do
- look at how your everyday activities are affected by
 - your health
 - your belief (confidence) in your own abilities
 - the support you receive because of your condition
 - your ability to manage your life and activities

How will the LINC study be done?

This study has four parts—a review of the literature and three other studies:

Study 1: A Snapshot in Time: An in-depth survey of 3500 people living in Canada

We are surveying 3,500 people in Canada—adults with neurological conditions and parents of children with neurological conditions. In this survey we will ask about three things:

- participation in everyday life
- health
- use of resources such as family, healthcare, and social and community services

Study 2: A Year in the Life of 350 Canadians: A series of monthly conversations

For this study, we will choose

- 300 adults, aged 17 to 65
- 50 parents of children, aged 5 to 16

If you are an adult who is chosen to take part in this study, we will ask you to have 18 monthly telephone conversations with us during which we will discuss you and/or your child's

- health
- participation in everyday activities
- health or social resources used to manage the health condition

If you are the parent of a 13 to 16-year-old child who has a neurological condition AND you have been chosen to participate in this study, we would like to ask your child to participate as well. With your permission, we will ask your child to complete three surveys over one year.

Study 3: Eighteen Individual Stories

For this study, we want to build 18 case studies—12 adults and six parents who agree to be interviewed about living with and managing a neurological condition. If you agree to be part of this study, we will ask you to name five people that you think support you as you live and manage your or your child's health condition. We would like to interview the five people you name as well.

What will this study mean for me?

The LINC study, with its literature review and three other studies, will help us to learn more about how having a neurological condition affects your everyday life. We are particularly interested in how you manage your condition. The results of this study may help those who create policies and services for you to better understand your needs.

Who is doing the study?

Our team includes researchers and practitioners from St. John's Newfoundland; Charlottetown, PEI; Winnipeg, Manitoba; Kingston, Ontario; and Halifax, Nova Scotia. In Halifax, the main researchers are

- Dr. Tanya L. Packer, Professor and Director of the School of Occupational Therapy at Dalhousie University
- Dr. Joan Versnel, Assistant Professor and Occupational Therapist in Dalhousie's Faculty of Health Professions