



STUDY:

THE PSYCHOLOGICAL AND PHYSICAL HEALTH, STRESS AND NEEDS OF CAREGIVERS OF CHILDREN WITH DISABILITIES ENROLLED IN FAMILY-CENTERED SUPPORT PROGRAMS

You are invited to participate in a study entitled “The Psychological and Physical Health, Stress and Needs of Caregivers of Children with Disabilities Enrolled in Family-Centered Support Programs” that is being conducted by Kyla Roberts who is a graduate student in the Faculty of Education at the University of Lethbridge. You may contact the student researcher at kyla.roberts@uleth.ca if you have questions about this study or if you are interested in receiving a summary of the findings upon completion (available after September 2018).

As a graduate student, Kyla is required to conduct research as part of the requirements for a degree in Master of Education Counselling Psychology with a focus on addiction and mental health. It is being conducted under the supervision of Dr. Em Pijl. You may contact Dr. Pijl at 403-332-5232. Two other researchers, Dr. Kellett and Dr. Piquette, will be active consultants and committee members throughout the study. If you have any questions about their involvement, you may contact Dr. Peter Kellett at 403-329-2643 and Dr. Noella Piquette at 403-394-3954.

The purpose of this research project is to expand on previous findings and to investigate the psychological and physical health, stress and needs of caregivers of children with disabilities who are enrolled in family-centered support programs in Alberta, Canada.

Research of this type is important because the literature in this field, although limited, has strongly demonstrated that caregivers of children with disabilities, in comparison to caregivers of children without disabilities, experience an exorbitant amount of stress, which can have detrimental effects on their physical and psychological health. To the knowledge of the author, this study will be the first of its kind to explore the mental and physical health, stress and needs of caregivers of children with disabilities enrolled in a family-centered wrap-around services program in Alberta, Canada.

You are being asked to participate in this study because you have identified as a caregiver of a child (or children) with disabilities enrolled in a Specialized Services program or a caregiver of a child (or children) without disabilities. The present study will be comparing the experiences of caregivers of children with disabilities to caregivers of children without disabilities to better understand how caring for a child with disabilities may deviate from the typical caregiving experience.

If you agree to voluntarily participate in this research, your participation will include an online survey that will take approximately 15 minutes to complete.

Participation in this study may result in emotional discomfort or distress. To prevent or deal with these risks, a list of mental health specialists within the Lethbridge and Calgary is included in

this consent form to support you emotionally and psychologically. Moreover, the results of this study may reach policy makers and service providers. Thus, it is important to note that your participation in this study has the potential to influence future program development and policy reform.

While there are no known direct benefits to you for participating in this research, your participation may improve our understanding of the psychological and physical health, stress and needs of caregivers of children with disabilities.

Your participation in this research is completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or explanation by exiting the online survey. It will not be possible to remove the data submitted up to the point of withdrawal because there is no personal identifying information in the survey that could be used to identify your specific responses. If you do not complete the survey, your data will be included in the study at the discretion of the student researcher and supervisor. Qualtrics Research Suite®, the online survey tool used in this study, will automatically save the data from partially completed surveys, even if the window on the computer screen has been closed.

In terms of protecting your anonymity, you will be assigned a numerical code and will have the contact information of my research supervisor, my own contact information, and the contact information for the University of Lethbridge Office of Research Ethics. Your identity will also be kept confidential from any other members of the research team including the supervisory committee.

Participation is voluntary and your responses will not be identified with you personally as the survey collects no identifying information; however, as with any online survey, neither anonymity nor confidentiality can be completely guaranteed.

The survey is being hosted on Qualtrics Research Suite® and their privacy policy can be accessed at <https://www.qualtrics.com/security-statement/>. Canadian data in Qualtrics is stored in Canada. The Suite is password protected and encrypted. SPSS Statistics® software will be used to analyze the data on a password-protected computer. Raw data organized in Excel® and SPSS will be kept on a password protected or encrypted USB key that will only be stored in a locked cabinet in Dr. Pijl's locked office or will be in the hands of the student researcher and/or the supervisor. Your confidentiality and the confidentiality of the data will be further protected by consent.

At the beginning of the online survey, consent will be obtained by the participants checking a box stating that they agree to the conditions of participating in the study. Participants completing online surveys will not be asked to provide a name or signature, thus all survey responses will remain confidential, aside from the IP addresses associated with participant data.

Upon concluding the research, all data from this study and copies of the consent forms will be destroyed within five years.

Other planned uses of this data and results of this study include being disseminated in journals (hard copies and online), within a written thesis (hard copies and online), at professional conferences and potentially at community events. Upon concluding the research, all data from this study and copies of the consent forms will be destroyed within five years.

In addition to being able to contact the researcher Kyla Roberts and, if applicable, the supervisor Dr. Pijl at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Office of Research Ethics at the University of Lethbridge at research.services@uleth.ca or 403-329-2747.

This study will solely reflect the interests of the researchers involved and is not representative of the opinions of Family Support for Children with Disabilities (FSCD), Pacekids or the various organizations which provide Specialized Services to the community.

You must be between the ages of 18 and 65 to participate in this survey.

If you wish to participate in the survey, submission of your responses will be accepted as implied consent to participate. Thank you in advance for your participation.

If you require support, please contact the appropriate agency below:

Lethbridge Referral Phone Numbers

- 1) Lethbridge Counselling Services: 403-942-0452
- 2) Associates' Counselling Services Inc: 403-381-6000
- 3) Crossroads Counselling Centre: 403-327-7080
- 4) YWCA Lethbridge & District: 403-329-0088
- 5) Distress Line of South Western Alberta: 403-327-7905 OR 1-888-787-2880
- 6) Lethbridge Family Services: 403-327-5724
- 7) University of Lethbridge Counselling Services: 403-317-2845
- 8) Family Centre: 403-320-4232

Calgary Referral Phone Numbers

- 1) Calgary Counselling Centre: 403-265-4980
- 2) Canadian Mental Health Association: 403-297-1700
- 3) Distress Centre (24/7 crisis line): 403-266-1601
- 4) Distress Centre (online chat):
<http://m2.icarol.com/ConsumerRegistration.aspx?org=2181&pid=1&cc=en-US>
- 5) Distress Centre (counselling): 403-266-4357
- 6) Wood's Homes (Eastside Family Centre): 403-299-9696
- 7) Wood's Homes (24/7 crisis line): 403-299-9699 or 1-800-563-6106
- 8) Wood's Homes (texting crisis services): 587-315-5000