

**CANADIAN HUMAN RIGHTS TRIBUNAL**

BETWEEN:

**FIRST NATIONS CHILD AND FAMILY CARING SOCIETY and ASSEMBLY OF  
FIRST NATIONS**

Complainants

- and -

**CANADIAN HUMAN RIGHTS COMMISSION**

Commission

- and -

**ATTORNEY GENERAL OF CANADA (representing the Minister of Indigenous  
Services Canada)**

Respondent

- and -

**CHIEFS OF ONTARIO, AMNESTY INTERNATIONAL CANADA and  
NISHNAWBE ASKI NATION**

Interested Parties

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**AFFIDAVIT OF LUCYNA M. LACH  
SWORN JUNE 20, 2023**

I, Lucyna M. Lach, of the City of Montreal, in the Province of Quebec, MAKE OATH  
AND SAY:

1. I am an Associate Professor, at School of Social Work, Faculty of Arts, and Associate Member of the Departments of Paediatrics, Neurology and Neurosurgery, Faculty of Medicine at McGill University, and, as such, have knowledge of the matters contained in this Affidavit.

2. I have been retained to provide expert evidence in the Moushoom/AFN class actions, which interrelate with this matter. I have been asked by the Assembly of First Nations to provide my methodology report on the caregiving parents and caregiving grandparents of Jordan's Principle claimants under the Final Settlement Agreement signed April 19, 2023.

3. A said report is attached to this Affidavit as **Exhibit "A"**. My curriculum vitae is attached to my report.

**SWORN** by Lucyna M. Lach of the City of Montreal, in the Province of Quebec, before me at the City of Toronto, in the Province of Ontario, on June 20, 2023, in accordance with O. Reg. 431/20, Administering Oath or Declaration Remotely.



\_\_\_\_\_  
Commissioner for Taking Affidavits  
(or as may be)

\_\_\_\_\_  
**LUCYNA M. LACH**

Patricia Kim Julian Son, a Commissioner, etc.,  
Province of Ontario, for  
Sotos LLP, Barristers and Solicitors.  
Expires April 27, 2025

This is Exhibit "A" referred to in the Affidavit of Lucyna M. Lach of the City of Montreal, in the Province of Quebec, sworn before me at the City of Toronto, in the Province of Ontario on June 20, 2023 in accordance with the O. Reg. 431/20, Administering Oath or Declaration Remotely



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*Commissioner for Taking Affidavits (or as may be)*

Patricia Kim Julian Son, a Commissioner, etc.,  
Province of Ontario, for  
Sotos LLP, Barristers and Solicitors.  
Expires April 27, 2025

**Report Submitted to Moushoom Class Council Regarding  
Method for Assessment of Compensation for Caregiving Parents or Caregiving Grandparents  
Moushoom et al v Canada, Court File Nos. T-402-19/T-1141-20 and Trout et al v Canada, Court  
File No. T-1120-21**

By:  
Lucyna M. Lach, MSW, PhD  
Associate Professor, School of Social Work, Faculty of Arts  
Associate Member, Departments of Paediatrics, Neurology and Neurosurgery, Faculty of Medicine  
McGill University  
June 12, 2023

## I. Executive Summary

I was retained by Sotos LLP to assist with the caregiver components of the Jordan's Principle and Trout claims in Moushoom et al v Canada, Court File Nos. T-402-19/T-141-20 and Trout et al v Canada, Court File No. T-1120-21. I previously provided a report dated September 6, 2022 in which I addressed eligibility and evaluation for compensation of First Nations individuals who were children between 1991 and 2017 and who would qualify under the same Jordan's Principle and Trout components.

In this report, I was asked by Sotos LLP to address the following questions:

- i. Is there a way to assess the impact that delays, disruptions, or gaps in essential services and supports experienced by First Nations children had on caregiving parents and grandparents between 1991 and 2017?
- ii. Is the impact that caregiving parents and grandparents experienced the same as, or different from, what their children experienced?

There is no existing valid or reliable method or measure to assess the impact that delays, disruptions, or gaps in essential services and supports experienced by First Nations children had on caregiving parents and grandparents between 1991 and 2017. Measures of individual caregiver outcomes, as well as caregiver burden, concepts that are closely aligned with those identified in the Final Settlement Agreement (i.e., pain, suffering, or harm), could be adapted, and a new measure could be developed that is both valid and reliable. This will require an investment of time and resources for development and pilot testing, but can be done.

To answer the second question, impact that caregiving parents and grandparents experienced is related to, but not directly associated with (in a causal-linear kind of way), the impact that their children experienced. The lived experience of caregiving parents and grandparents varies based on their individual, family, and community context. Some may have been living in the context of severe deprivation, while others had access to resources that helped them to manage their child's needs. Therefore, one cannot directly align the impact of unmet needs on the child with harm that caregivers endured. Impact on caregivers requires a more nuanced and separate evaluation that takes into consideration their individual, family, and community level strengths and abilities. Not doing so would contribute to pathologizing, diminishing, and dismissing the strengths and abilities of First Nations caregiving contexts at the individual, family, and community levels.

How caregivers experienced their child and their unmet needs was not all the same. Some caregivers suffered tremendously, others suffered a lot, but not as much, and still others suffered, but the harm that they experienced, as difficult as it was, was not as grave as others. This exercise casts some as having suffered more than others, many of whom were living in the context of intergenerational trauma, precarious housing, food insecurity, and poverty. Although difficult to disentangle, the FSA does not compensate caregivers for these structural deficits. It

focuses solely on the impacts of First Nations children not having received essential services and supports through processes associated with denial, delay, or unavailability of such services and supports.

## **II. My Bio and Background**

My program of research has two main streams, the first focusses on documenting social determinants of living a life of quality among children, youth and young adults with neurodisabilities and their caregiving families, and the second focuses on the co-construction of systems of care that promote navigation of and access to supports and services needed by these individuals and families. Projects addressing social determinants have documented caregiver health, parenting, income trajectories, educational outcomes, and utilization of health services by children and their primary caregivers. Funded by Kids Brain Health Network (KBHN) and using administrative and clinical databases, this work has revealed the heightened challenges faced by this population in the Canadian context. I have collaborated with Dr. David Nicholas (University of Calgary) to increase capacity across and within government and non-government organizations to create transparent and more efficient pathways of care. Organizations that families must navigate access to have come together in Vancouver, Edmonton, Watson Lake (Yukon), and Montreal, to collaborate and innovate through program development and training. In addition, I am part of CHILDBRIGHT, and am co-leading (along with Dr. Patrick McGrath) a randomized control trial entitled Parents Empowering Neurodiverse Kids. This project is evaluating a web-based parenting program that combines group coaching and educational modules, with parent-to-parent support for parents whose children have brain-based development disorders such as Autism Spectrum Disorder or Intellectual Disability AND a mental health problem. I have also collaborated with a research team documenting the state of Jordan's Principle in the province of Manitoba. I am also a peer-reviewer for numerous journals and funding bodies.

To date, I have 75 peer reviewed publications, 13 chapters, have received just over \$5M in research funds as principal or co-principal investigator, and another \$5.2M as co-investigator. I have purposefully approached my role as a tenured academic to create a legacy by mentoring numerous graduate students. I am recognized as a social scientist in the neuroscience space, and have focussed my efforts, almost exclusively on supervising/mentoring student outputs such as theses, presentations, peer-reviewed articles and chapters. I regard this as one of the highlights of my career.

As Associate Dean in the Faculty of Arts (2012-2021), I oversaw the Student Affairs portfolio where I led a number of initiatives to improve support that students receive from their point of entry until graduation. In this role, I provided academic leadership and contributed to various faculty-specific and university-wide committees addressing student success and well-being. In the community, I am a board member on the CIUSSS Centre-Ouest Board of Directors, the Board of Governors at Centre Miriam, and the Board of Directors of Dans La Rue. Through my research and community engagement, I am committed to improving the lives of neurodivergent children, youth, and young adults and their families.

### III. Background Information

The Final Settlement Agreement (FSA) dated April 19, 2023 specifies, in Article 6.09, the following regarding eligibility for compensation:

Only the Caregiving Parents or the Caregiving Grandparents of **Approved Jordan's Principle Class Members** may be entitled to compensation if it is determined by the Administrator, or on appeal by the Third-Party Assessor, that such Caregiving Parents or Caregiving Grandparents themselves experienced the highest level of impact (including pain, suffering or harm of the worst kind).

Only the Caregiving Parents or Caregiving Grandparents of the **Approved Trout Child Class Members** who have established a Claim under Article 6.08(13) may be entitled to compensation if it is determined by the Administrator, or on appeal by the Third-Party Assessor, that such Caregiving Parents or Caregiving Grandparents themselves experienced the highest level of impact (including pain, suffering or harm of the worst kind).

The **impact experienced by such Caregiving Parents or Caregiving Grandparents** will be assessed through objective criteria and expert advice pursuant to a method to be developed and specified in parallel with Schedule F, Framework of Essential Services regarding Children. Such **impact (including pain, suffering or harm)** may be assessed through culturally sensitive Claims Forms designed in consultation with experts. Subject to the Court's approval, the selection of which Claimants qualify under this category will be based on objective factors (which may include the severity of pain, suffering or harm) and the number of Claimants.

#### Who is a caregiving parent?

As per the FSA:

"Caregiving Parent" and "Caregiving Parents" means the caregiving mother or caregiving father of the affected Child, living with, and assuming and exercising parental responsibilities over a Removed Child Class Member at the time of the removal of the Child, or over a Kith Child Class Member at the time of the involvement of the Child Welfare Authority and the Child's Kith Placement, or over a Jordan's Principle Class Member or Trout Child Class Member at the time of the Delay, Denial or Service Gap with respect to the Child's Confirmed Need for an Essential Service. Caregiving Parent includes the biological parents, adoptive parents

or Stepparents for each applicable Class, except as where expressly provided for otherwise in this Agreement. A foster parent is excluded as a Caregiving Parent under this Agreement. An adoption in this context means a verifiable provincial, territorial or custom adoption.

### **Who is a caregiving grandparent?**

As per the FSA:

“Caregiving Grandparent” and “Caregiving Grandparents” means a biological or adoptive caregiving grandmother or caregiving grandfather of the affected Child who lived with and assumed and exercised parental responsibilities over a Removed Child Class Member at the time of the removal of the Child, or over a Kith Child Class Member at the time of the involvement of the Child Welfare Authority and the Child’s Kith Placement, or over a Jordan’s Principle Class Member or Trout Child Class Member at the time of the Delay, Denial or Service Gap with respect to the Child’s Confirmed Need for an Essential Service. An adoption in this context means a verifiable provincial, territorial or custom adoption. Relationships of a foster parent or Stepparent to a Child are excluded from giving rise to a Caregiving Grandparent relationship under this Agreement.

Only 2 caregivers will qualify per child.

### **IV. Is there a way to assess the impact that delays, disruptions, or gaps in essential services and supports experienced by First Nations children had on caregiving parents and caregiving grandparents between 1991 and 2017?**

There is no current and existing way to retrospectively measure the impact that delays, disruptions, or gaps in essential services and supports experienced by First Nations children had on caregiving parents and/or caregiver grandparents. The FSA specifies that impact should take into consideration caregiver pain, suffering or harm, concepts that are all consistent with evaluation of caregiver outcomes in the literature. In the childhood disability/chronic illness literature, caregiver outcomes refer to physical health, mental health, social support, financial status, and caregiver burden. There are existing valid and reliable measures of each of these concepts, but none have been developed for use in the First Nations context. What this means is that the selected measure(s) would need to be adapted and piloted so that the items are culturally relevant and that the measure is both valid and reliable. Validity refers to the extent to which accurate conclusions can be drawn about the presence and degree of what is being measured (i.e., impact on caregivers); reliability refers to the extent to which the results of the measure are reproducible under different conditions (i.e., measure administered to the same person a week apart, or measure administered to the same person by different people).



Before proceeding with a review of the literature on caregiver burden, it is important to establish the conditions, the impact of which, are being evaluated (impact **of** what?). I will then proceed to an analysis of what is meant by impact (impact **on** what?).

### **Impact of what?**

The compensation to which caregivers are entitled is referred to in the FSA as compensation for the ***impact that parents and grandparents experienced***. Establishing the severity of impact is tied to the denial, delay, or gap in services and supports and so, it has to do with having had a child who had unmet needs. It does not have to do with the number of essential services/supports not provided, or with the severity of the child's impairments per se, but rather with the severity of the impact that the unmet needs of the child had on the caregiver at the time. The following elaborates on this distinction.

A reasonable assumption is that children with increasing/higher levels of impairments had higher levels of need, and that those needs may have not been met. However, neither of those concepts are the main ones being considered. It is the severity of the impact of *not being provided with what was needed* that is being evaluated for compensation. To address the issue of number of essential services/supports not provided, let us use an example. There may have been one service/support that was not provided and that would have had an enormous impact on the caregiver's well-being; alternatively, there may have been several services/supports that the child was not provided with and the degree to which those services would have had an impact on the caregiver's well-being may not come close to the one service that would have made a huge difference. Therefore, it is NOT the number of services that a child did not receive that is central to this undertaking, but rather the severity of their impact on a caregiver's well-being.

The evaluation of the severity of the impact on the caregiver is also NOT about the severity of the child's impairments. A child with multiple impairments may require a caregiver to provide daily care that involves the preparation of specialized formulas or foods, management of body hygiene, constant airway surveillance and the administration of medications (da Silveira et al., 2022). Lack of access to a service/support such as respite care may have had a negative impact on a caregiver's physical or mental health, on the caregiver's ability to work, and/or on the caregiver's ability to engage with their community, each of which are outcome indicators of impact. Similarly, a child with a single impairment (e.g., hearing impairment) who was denied access to a hearing aid and/or speech and language therapy, meant that a parent remained at home with that child, and was similarly impacted.

A method of assessing impact on caregivers must consider how a child's lack of access to services/supports such as mental health services was associated with caregiver outcomes such as not being able to work or being incessantly worried about whether their child will live or die. The assessment of severity of impact would therefore need to take into consideration aspects of the caregiver's experience of hardship (e.g., had to quit work or was not able to work, or experienced physical or mental health problems) that was connected to their child's denial,

delay in, or lack of access to adequate mental health services. It does not have to do with the nature, frequency or severity of the child's mental health condition per se.

### **Impact on what?**

The FSA specifies that impact should take into consideration impact on caregiver pain, suffering or harm. The literature provides some guidance regarding how to conceptualize and measure impact of having a child with impairments or health challenges. However, the literature does not differentiate impact of having a child with impairments/health challenges from the impact of having a child with impairments/health challenges and unmet needs. We therefore have to turn to the former to provide some direction regarding the answer to the question, 'impact on what?'

Individual caregiver outcomes reflected in the caregiver literature cover employment/income, hours of direct care, physical and emotional health, social isolation, and strained family relations. It is important to note that caregiver outcomes such as experienced racism, stigma, or discrimination, or housing and food precarity, are not typically considered.

Employment- or income-related consider the extent to which caregivers experience absenteeism or loss of productivity that result in unpaid leaves of absence (Arora et al., 2020), forfeiting of advancement opportunities, inability to work, job loss, and financial instability. (Dantas et al., 2019). Caregiving parents are at risk to all of these possibilities due to the direct care responsibilities that are considered extraordinary. They spend numerous hours per week providing care related to child's needs (Arora et al., 2020; Matsuzawa et al., 2020), provide extra feedings, attend to personal hygiene, dressing, and toileting (McCann et al., 2012), and are very involved in attending to their child's health care needs such as attending appointments, hospitalizations, medication administration, provision of specialized education, therapy/intervention procedures and health care management (McCann et al., 2012). These obligations have consequences as parents have fewer hours of sleep per day (Lee, 2013; Matsuzawa et al., 2020), experience injury related to provision of care (Black et al., 2022), higher levels of stress (Dantas et al., 2019), and exhaustion (Nicholas et al., 2016). Studies have documented that their physical health is worse than those whose children do not have special health care needs (Lach et al., 2009). Living with constant sense of uncertainty (Nicholas et al., 2016) and hopelessness, they are more likely to have symptoms of mental distress (Gull & Kaur, 2023; Scherer et al., 2019). These obligations also mean that they are less available to engage in other social activities (Dantas et al., 2019), and feel isolated (Nicholas et al., 2016). Finally, family routines, relationships, and activities are altered (Dantas et al., 2019; Lach et al., 2009; McCann et al., 2012), as the family system (Jellett et al., 2015) struggles to adapt to the child's unmet needs.

In addition to these individual outcomes, there are studies that examine caregiver burden, a concept that comes close to what is referred to in the FSA as pain, suffering, and harm. Caregiver burden refers to the multifaceted strain perceived by the caregiver from caring for family members and/or loved one over time (Liu et al., 2020). Measures of caregiver burden

vary from ones that are unidimensional (i.e., greater and lesser caregiver burden), to ones that are multidimensional and that tap into different aspects of caregiver burden. The caregiver burden literature is relatively well established for caregivers of aging adults with dementia, first appearing around the early to mid 1980's (Montgomery et al., 1985; Zarit et al., 1980). Measures used in those studies are now appearing in the disability literature (Boluarte-Carbajal et al., 2022; Boyer et al., 2006; Domínguez-Vergara et al., 2023) and in the caregivers of children with chronic health conditions (Javalkar et al., 2017) and/or disabilities (Calderón et al., 2011) literature. However, none have been developed for use with First Nations. Nonetheless, this represents a good starting point for considering what is possible. The following describe a few of these measures.

One of the versions of the Zarit Caregiver Burden Interview (Zarit et al., 1980) is comprised of 22 items that are answered on a five-point Likert-type scale (Never = 0; Rarely = 1; Sometimes = 2; Quite often = 3; and Almost always = 4). The ZBI items assess the perceived impact of caregiving on the caregiver's physical health, emotional health, social activities, and financial situation. Overall ZBI scores range from 0 to 88 points, where a high score implies a greater perceived caregiver burden. (Domínguez-Vergara et al., 2023).

Family Burden Assessment Scale developed by (Yildirim & Sari, 2008) evaluates the following: economic burden (6 items), social burden (6 items), physical burden (5 items), emotional burden (11 items), perception of inadequacy (8 items), and time requirement (7 items). It uses a 5-point Likert type scale and items are scored as "Never (1), Rarely (2), Sometimes (3), Often (4), and Always (5)". The lowest score that can be obtained from the scale is 43, the highest score is 215. Those who get 97 points or more are considered burdened. This scale was developed to be used in the Turkish population.

A third measure to consider is the Burden Scale for Family Caregivers (BSFC; Graessel et al., 2003). There is a 28-item version and a 10 item version, both of which have been validated for family caregivers of individuals with and without dementia. The measure generates a score between 0 and 84 which can be classified as mild, moderate or severe caregiver burden (see <https://www.psychiatrie.uk-erlangen.de/med-psychologie-soziologie/forschung/psychometrische-versorgungsforschung/burden-scale-for-family-caregivers-bsfc>). The measure is currently being used in a study of caregivers of adolescents with various health care needs who are transitioning into adulthood (personal communication, Professor Laura Brunton, Western University). Similarly, the 10-item version (Graessel et al., 2014) generates a score between 0 and 30, but does not lend itself to the same classification as mild/moderate/severe.

The key message here is that it is possible to adapt an existing measure and establishing validity and reliability for use in the First Nations context.

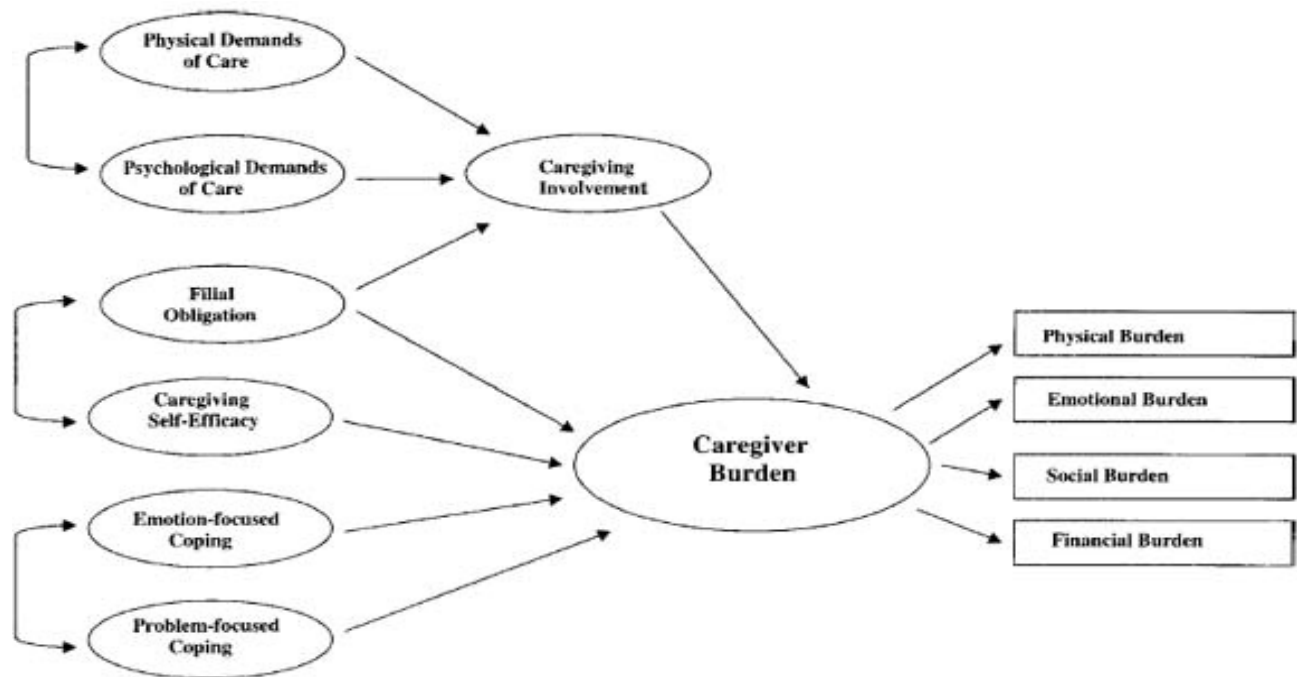
**V. Is the impact that caregiving parents and grandparents experienced the same as, or different from, what their children experienced?**

**The relationship between harm that a child suffered and harm that caregivers suffered is not a causal linear one.** At first glance, one may come to the conclusion that a child's level of pain and suffering related to unmet needs invokes an equal level of caregiver pain and suffering. Of course, no caregiver is emotionally immune from the impact of their child's pain and suffering. However, not all caregivers will experience the impact of their child's unmet needs in the same manner. We must also take into account the context and therefore variability within which the caregiver's experience of their child and their unmet needs occurred. For example, some caregivers may have had access to a supportive family or community, or were able to draw on internal coping resources that mitigated the experience of what their child was going through. Other caregivers may have had a child with similar unmet needs, but were extremely isolated had little support, and had more limited coping resources. This is not meant to blame caregivers as many were doing the best they could in a context of intergenerational trauma and suffering, poor housing conditions, and extreme poverty. What this does highlight is that a proportion of caregivers were raising their children in the context of tremendous hardship and suffering, while others did not experience that same level of hardship or suffering due to the context within which they were living.

The variability in caregiver outcomes is consistent with both theoretical and empirical literature. Theoretical literature is very critical of the 'tragedy narrative' of those who have impairments (Oliver, 2013) as it obscures alternative narratives that reveal both structural issues that contribute to the complexity and resilience in the lives of these children, families, and communities (Hemingway, 2011). To be clear, these theoretical perspectives do not address narratives about the experience of having a child with unmet needs. However, as stated earlier, unmet needs are related to impairments or health challenges. This alternative narrative is also consistent with a First Nations perspective that emphasizes how children are regarded as an honour and as a gift (Greenwood, 2006) and how the culturally diverse communities to which they belong can support their holistic development (Ineese-Nash, 2020). Taking this perspective further, the impact of having a child with impairments or health challenges and unmet needs is therefore not an exclusively tragic story, but rather one that is far more nuanced and complex. It is also a story about love, commitment, doing the best one can in the face of structural adversity, and about drawing on resources to do what is needed. The resources that First Nation children needed were not adequately provided; the CHRT proceedings and this class action are ways in which theirs and their caregiver's suffering and harm is acknowledged.

Theoretical models explaining variability in caregiver outcomes identify how child, parent, family, school and community and societal factors that all play some kind of role (Graessel et al., 2003)

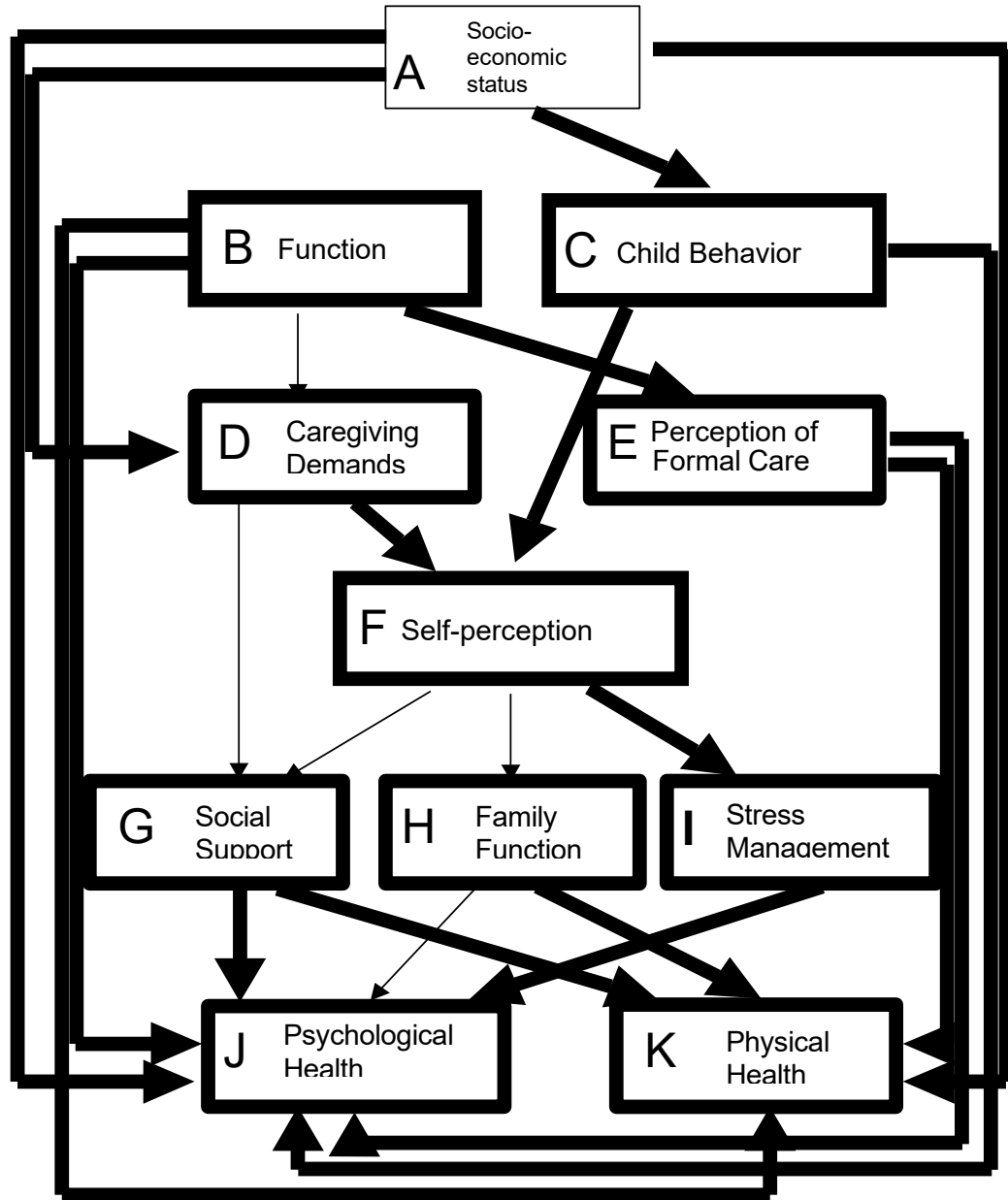
Figure 1.



Structural model of the caregiver burden model - See (Chou, 2000)

Chou's (2000) model focuses on the demands of care as well as different aspects of the individual caregiver that explain variability in caregiver burden.

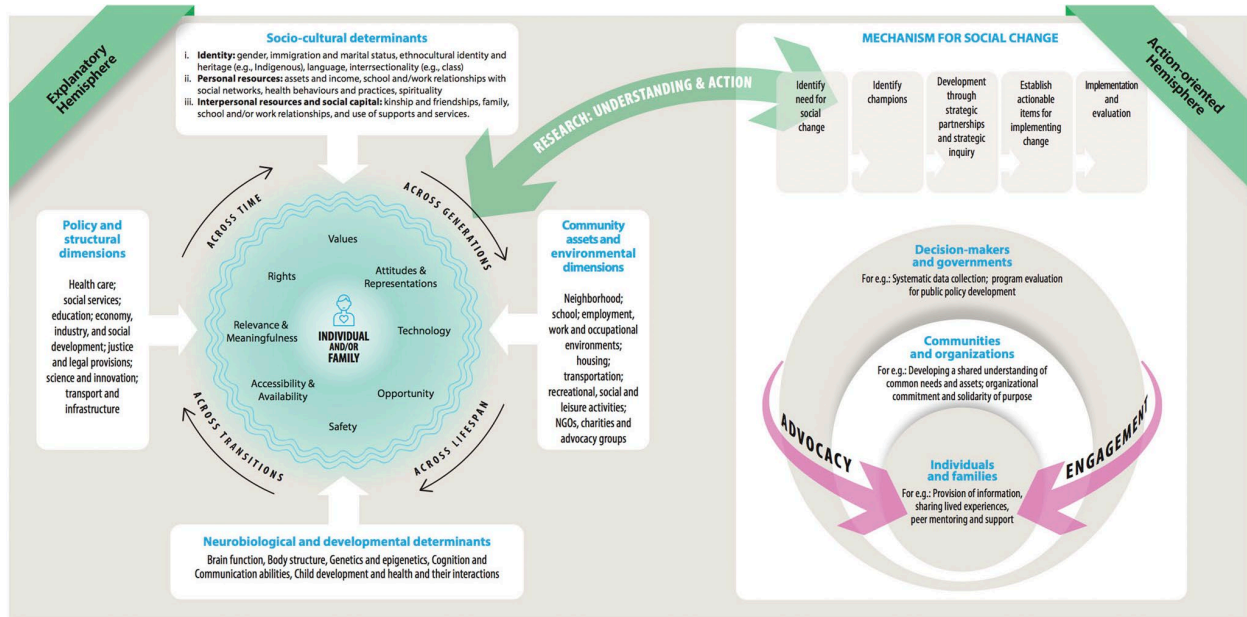
Figure 2.



Conceptual Model of Caregiving Process and Caregiver Burden Among Pediatric Population – see (Raina et al., 2004)

Raina et al., 2004 depict caregiver outcomes of psychological and physical health as being a function of socioeconomic conditions, child, caregiver, family, and social support factors.

Figure 3:

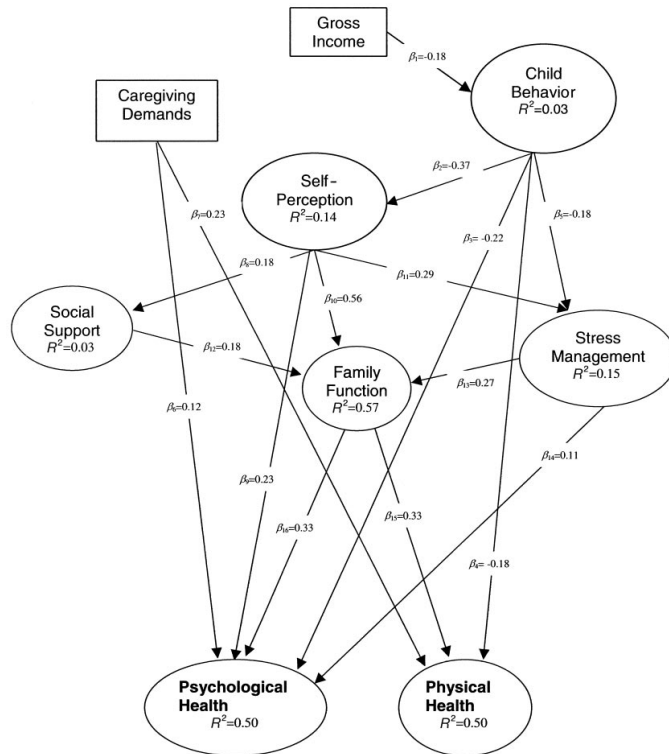


Canadian Framework for Social Determinants of Health Among Children with Neurodisabilities and their Families - see (Filipe et al., 2021)

In this framework, caregiver is situated at the centre of green circle (on the left side). In addition to socio-cultural determinants, community assets and environmental dimensions, as well as policy and structural dimensions play a role in processes that impact caregiver outcomes such as caregiver burden.

At an empirical level, the impact of having a child with impairments or health challenges that require services and supports and that are met to different degrees, on caregiver outcomes, requires testing relationships in these models. This means that risk and protective factors, other than the unmet need, that reflect the context within which the child and caregiver were living, are considered. For example, the model depicted in Figure 2 was tested by Raina et al., 2005. Using structural equation modeling, they found the following:

Figure 4.



In Figure 4, we see that there are multiple pathways for explaining indicators of caregiver burden that involve income, child factors, caregiving demands, and other aspects of the caregiver, family, and support system. Studies have repeatedly shown that caregiver well-being is a function of the complexity of the child’s level of function and demands of care (Chou, 2000; McCann et al., 2012; Miller et al., 2016), behaviour problems (Lach et al., 2009; Morris, 2014) as well as caregiver factors such as coping style (Chou, 2000; Raina et al., 2005) support from family and friends and community (Zaidman-Zait et al., 2017). What this means is that two caregivers whose children had similar impairments/health challenges and unmet needs will experience the impact of those unmet needs differently.

### Piloting the Forms, Questionnaires and Application Process

All forms, questionnaires, and processes for application will be piloted in 2 stages. In the first stage, up to 15 claimants, 15 caregiving claimants, 10 professionals and 10 navigators will be interviewed in order to arrive at a version of the questionnaires and forms that will be submitted to a larger pilot phase. The larger pilot phase will not start until this is completed. The number of claimant participants needed for the pilot will be determined in consultation with statisticians and a steering committee comprised of First Nations and non-First Nations partners.



The following depicts a proposed timeline:

Year	2023							2024		
Month	6	7	8	9	10	11	12	1	2	3
<b>Stage 1: Governance and Administration</b>										
Identify working group members	█									
Establish governance structure and procedures	█									
Hire Project Coordinator	█	█								
Finalize draft plan	█	█								
Steering group meetings	█	█	█	█	█	█	█	█	█	█
<b>Stage 2 - Finalizing Forms, Questionnaires and Processes - Claimant and Caregiver Claimant Forms</b>										
Identify community for pilot		█								
Interview 15 claimants			█	█						
Interview 15 caregiver claimants			█	█						
Interview 10 professionals			█	█						
Interview 10 navigators			█	█						
Analysis of data				█	█					
Adaptation of instructions, forms, and questionnaires					█					
<b>Stage 3 - Piloting the Forms, Questionnaires and Processes</b>										
Identify communities for pilot	█	█	█	█	█					
Obtain consents	█	█	█	█	█					
Recruitment of participants						█				
Administration of questionnaires							█	█	█	
Data entry								█	█	█
Data analysis										█
Final report										█

Best practices pertaining to First Nations information governance are driven by OCAP principles. Ownership, control, access, and possession of any information collected at any stage of the pilot will need to be articulated. I consulted with Albert Armieri and Aaron Franks from the First

Nations Information Governance Centre (FNIGC) on March 20, 2023. They have expertise in questionnaire design, and broker relationships with regional partners. I highly recommend that they be engaged in this process.

### **Conclusion**

Guidance for the evaluation of the impact of unmet First Nations children's needs on caregiving parents and grandparents is provided, almost exclusively, through literature that lies outside of the First Nations context. What this theoretical and empirical literature indicates is that hardship and suffering can be assessed, but that it will be require an adaptation of existing measures, piloting of that measure, and establishing culturally appropriate methods for its administration.

The FSA explicitly identifies that compensation to caregiving parents and grandparents is related to impact and that the impact includes pain, suffering, and harm. This pain, suffering, and harm must be linked to the denials, delays, or gaps in services and supports. The method of evaluation will seek a way to distinguish greater from lesser negative impact. *This should not minimize the possibility that First Nations sons and daughters who had unmet needs that were not addressed due to delays, disruptions, or gaps in services, also brought light, growth, and positive meaning to the lives of their caregiving parents and grandparents. That is consistent with how children in the First Nations context are, in fact, viewed.*

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**LUCYNA M. LACH**  
**Curriculum Vitae**

**CONTACT INFORMATION**

McGill University, Faculty of Arts  
550 Sherbrooke St. Ouest,  
Suite #100, Tour Est  
Montreal, Quebec, H43A 1B9  
(514) 398 7050  
[lucy.lach@mcgill.ca](mailto:lucy.lach@mcgill.ca)

**ACADEMIC APPOINTMENTS**

June 2009 -

Present                      McGill University, Faculty of Arts, School of Social Work, Associate  
Professor, Tenured

May 2004 –

Present                      McGill University, Faculty of Medicine, Department of Paediatrics (Child  
Development Program) and Department of Neurology and Neurosurgery  
(Division of Neurology), Associate Member

November 2003 –

May 2009                      McGill University, Faculty of Arts, School of Social Work, Assistant Professor,  
Tenure Track

September 2001 –

October 2003                      McGill University, Faculty of Arts, School of Social Work, Assistant Professor,  
Special Status

January 1999 –

Dec. 2000                      University of Toronto, Faculty of Social Work, Sessional Lecturer

**EDUCATION**

Doctor of Philosophy, 2004

University of Toronto, Faculty of Social Work

Thesis: Social Experiences of Children and Adolescents Diagnosed With Intractable  
Epilepsy; Supervisor: Elsa Marziali

Master of Social Work, 1986

University of Toronto, Faculty of Social Work

Bachelor of Arts (Honours in Sociology), 1984  
University of Toronto, University College

## **ADMINISTRATIVE APPOINTMENTS**

- 2022-present MSW Program Director, School of Social Work, McGill University
- 2012-2021 Associate Dean (Student Affairs), Faculty of Arts, McGill University
- 2020-2021 CO-CHAIR, Committee on Student Services (Subcommittee of Senate), McGill University
- 2018-2019 CHAIR, Committee for Implementation of the Policy Against Sexual Violence, McGill University
- 2012-2021 CHAIR, Committee on Student Affairs, Faculty of Arts, McGill University  
CHAIR, Scholarship Committee  
CO-CHAIR, Curriculum Committee, Faculty of Arts  
MEMBER, Senate  
MEMBER, Faculty Council, Faculty of Arts  
MEMBER, Subcommittee on Student Affairs Policy  
MEMBER, Subcommittee on Student Services  
MEMBER, Enrolment and Student Affairs Advisory Committee  
MEMBER, Exchange and Study Away Steering Committee
- 2011-2012 GRADUATE PROGRAM DIRECTOR, MSW Program, School of Social Work, Faculty of Arts, McGill University
- 2010-2016 MEMBER, Staff Selection, Promotion, and Tenure Review Committee, School of Social Work, Faculty of Arts, McGill University
- 2011-2012 MEMBER, Scholarship Committee, Faculty of Arts
- 2010-2011 MEMBER, Governance Task Force, Canadian Association for Social Work Education
- 2006-2010 UNDERGRADUATE PROGRAM DIRECTOR, BSW Program, School of Social Work, Faculty of Arts, McGill University
- 2006-2007 SUPERVISOR, MSW Student, Child Development Program, Montreal Children's Hospital
- 2004-2005 DIRECTOR, Centre for Applied Family Studies, Faculty of Arts, McGill University

- 2004-2006 MEMBER, BSW Committee, School of Social Work, Faculty of Arts, McGill University
- 2004-2008 MEMBER, Board of Accreditation, Canadian Association of Schools of Social Work
- 2003-2007 MEMBER, Curriculum Committee, Faculty of Arts, McGill University
- 2002-2003 ASSOCIATE DIRECTOR, MSW Program, School of Social Work, Faculty of Arts, McGill University
- 2001-2003 MEMBER, Staff Search Promotion and Tenure Committee (SSPT), School of Social Work, Faculty of Arts, McGill University
- 2001-2003 MEMBER, MSW Committee, School of Social Work, Faculty of Arts, McGill University
- 1999-2001 PROJECT DIRECTOR, Hospital For Sick Children, Research Institute. Population Health and Brain and Behaviour Divisions.
- 1997-1999 CONSULTANT, EARLY INTERVENTION SERVICES OF YORK REGION
- 1996-1997 MEMBER, STRATEGIC TRANSFORMATION AND REDESIGN TEAM, HSC
- 1991-1997 SUPERVISOR, MASTER OF SOCIAL WORK GRADUATE STUDENTS, HSC
  - Faculty of Social Work, University of Toronto
  - Faculty of Social Work, Sir Wilfred Laurier University
  - Faculty of Social Work, Washington University

## RESEARCH

- 2020-2022 LES EXPÉRIENCES D'EXCLUSION ET D'INCLUSION SOCIALES CHEZ LES PERSONNES VIEILLISSANT EN SITUATION DE NEURODIVERSITÉ ET LEURS PROCHES.** Shari Brotman (PI), Tamara Sussman (McGill), Émilie Raymond (Laval), Marie-Hélène Deshaies (Laval), **Lucyna Lach (McGill)**, Daniel Dickson (Concordia), Laura Pacheco (CIUSSS de l'Ouest-del'île-de-Montréal); Zelda Freitas (CREGES-CIUSSS du Centre-Ouest-de-l'île-de-Montréal), Julien Simard (McGill) (collaborators);
  - \$149,705 awarded by Société et culture (FRQSC) Action concertée – Programme de recherche sur les personnes âgées vivant des dynamiques de marginalisation et d'exclusion sociale
  - My role is to provide substantive support regarding the neurodisability literature and lived experience of families raising children/young/young adults with neurodisabilities; I will also provide input into the implementation of the project methods.

- 2020-2022    NOTHING WITHOUT US: TOWARDS INCLUSIVE, EQUITABLE COVID-19 POLICY RESPONSES FOR YOUTH WITH DISABILITIES AND THEIR FAMILIES.** Jennifer Zwicker (PI), David Nicholas (Co-PI), Denise Keiko Shikako-Thomas (Co-PI), Chantal Camden, Mayada Elsabbagh, Anne Hudo, Matthew Hunt, Sebastian Jodoin, **Lucyna Lach**, Raphael Lencucha (Co-applicants), Neil Belander, Krista Carr, Robert Lattanzio, Nicky Lewis, Michael Prince (collaborators).
- \$199,965 awarded by Canadian Institutes of Health Research (CIHR) COVID-19 Mental Health and Substance Use Service Needs and Delivery Program
  - Using a mixed methods design, this research maps COVID-19 policies implemented in each province and their alignment with disability-inclusive design that promotes resilience and mental health, describes acute mental health needs of youth with disabilities and their caregivers and co-designs recommendations using evidence to better match COVID-19 policy responses
  - My role is to support implementation of the qualitative component of the project.
- 2018-2020    WHO BENEFITS FROM GOVERNMENT DISABILITY FINANCIAL SUPPORT? AN ASSESSMENT OF HOW DISABILITY BENEFITS SUPPORT CAREGIVERS OF CHILDREN WITH SEVERE DISABILITIES IN CANADA AT DIFFERENT INCOMES.** Jennifer Zwicker (PI), Daniel Dutton, **Lucyna Lach**, David Nicholas (Co-applicants), Rubab Arim, Dafna Kohen, Kathleen O’Grady (collaborators).
- \$74,675 awarded by Social Sciences and Humanities Research Council (SSHRC) Insight Development Program
  - This research uses a mixed methods approach to determine the take-up of federal disability benefits and supports among families of children/youth with DD in each province and across income levels.
  - My role is involves oversight of qualitative component of the project.
- 2017-2022    INTEGRATED NAVIGATIONAL SUPPORT FOR FAMILIES OF CHILDREN WITH NEURODEVELOPMENTAL DISABILITIES: A PILOT IN ALBERTA, BRITISH COLUMBIA, AND THE YUKON.** David Nicholas and **Lucyna Lach (Co-PIs)**, Jenn Zwicker and Community Partners
- \$199,992 awarded by Kids Brain Health Network
  - This is a community-based participatory project that involves the development of partnerships between managers/directors in the health, social services, and education sectors, non-government organizations, advocates, and family members. A collective community impact approach is being used to develop a shared understanding of the challenges that families of children with neurodisabilities face accessing services, mapping assets, and developing joint initiatives to improve families’ experience of navigating services.
  - \$750,000 (2018-2022) awarded by Azrieli Foundation
  - \$660,000 (2018-2022) awarded by Anonymous Donor

- 2016-2022 PARENTING PROGRAM FOR CHALLENGING BEHAVIOUR IN CHILDREN WITH NEURODISABILITIES: STRONGEST FAMILIES NEURODEVELOPMENTAL.** Patrick McGrath and **Lucyna Lach (Co-PIs)**, Megan Aston, Christine Ellsworth, Anna Huguet, Patricia Lingley-Pottie, Jennifer McLean, Patricia Monaghan, Mike Sangster, Krista Sweet, Lori Wozney and Donna Thomson
- \$1,395,046 awarded by CIHR Strategic Patient Oriented Research (SPOR) entitled **CHILD-BRIGHT: Child Health Initiatives Limiting Disability – Brain Research Improving Growth and Health Trajectories.** Annette Majnemer, Steve Miller, Dan Goldowitz (Co-PI's) et al. I am co-principal investigator on one of 13 projects; value of the SPOR \$25 Million.
  - 3-arm RCT testing an online and telephone-based parent coaching intervention
  - Providing co-leadership for all aspects of the project
- 2016-2018 MECHANISMS OF INTERGENERATIONAL FAMILY VIOLENCE PERPETRATION TRANSMISSION: THE PHENOMENOLOGY OF ADOLESCENT AFFECT REGULATION.** Katherine Maurer (PI), Robert Buckley, **Lucyna Lach**, Delphine Collin-Vezina, Heather MacIntosh (Co-Applicants).
- \$68,389 awarded by Social Sciences and Humanities Research Council (SSHRC) Insight Development Grant Program
  - Phenomenological study examining adolescent experience of managing difficult emotions
  - Contributing to recruitment, analysis and interpretation of data
- 2016-2019 THE FAMILY NAVIGATOR: A GLOBAL PARTNERSHIP TO EXPAND ACCESS TO CARE FOR AUTISM AND RELATED CONDITIONS.** Mayada Elsabbagh , Brigitte Auger, Mimi Israel (Co-PIs), Marie-Josée Fleury, Ridha Joober, Keiko Shikako-Thomas, Peter Szatmari, Wendy Ungar (co-applicants), Jonathon Green, Sebastien Jacquemont, **Lucyna Lach**, Annette Majnemer, Laurent Mottron, Illina Singh (collaborators). CIUSS Montreal-West, ACCESS Canada, Montreal Children's Hospital, MUHC Technology Assessment Unit, World Health Organization, Autism Speaks (decision makers).
- \$377,778 awarded by CIHR Patient and Health Systems Improvement (PHSI) Grant
  - Collaborator
  - RCT to evaluate the efficacy of a family navigator intervention for families of children with autism and other neurodisabilities
- 2015-2018 HEALTH ECONOMICS AND SOCIAL DETERMINANTS OF HEALTH (HE-SDOH): A FRAMEWORK FOR UNDERSTANDING SOCIOECONOMIC AND QUALITY OF LIFE OUTCOMES AMONG CHILDREN WITH NEURODISABILITIES AND THEIR CAREGIVERS.** **Lucyna Lach**, David Nicholas, Herb Emery, Jennifer Zwicker (CoPI's),

David Rothwell, Dafna Kohen, Rubab Arim, Gabriel Ronen, Nora Fayed, & Rachel Birnbaum.

- \$700,000 awarded by NeuroDevNet (NDN), National Centre of Excellence (funded by Industry Canada)
- Co-principal investigator role
- Multiple projects using existing population-based, administrative, and clinical datasets to document various social determinants of health (income trajectory, ethnocultural status, social support, access to care) of children with neurodisabilities and their caregivers; findings support capacity building for health economic evaluations of NDN projects
- Focus groups and individual interviews with parents of children with neurodisabilities at different stages of transition (dx, entry into school, high school, and leaving high school) regarding their experience of and need for support

**2014-2017 SOINS EN COLLABORATION EN SANTE MENTALE JEUNESSE: CARACTERISTIQUES DES INTERVENTIONS THERAPEUTIQUE ET QUALITE DES SERVICES.** Lucie Nadeau, Andre Delorme (Co-PIs), Sara Fraser, Vania Jiminez-Siguoin, **Lucyna Lach**, Nicholas Moreau, Lourdes Rodriguez Del Barrio, & Cecile Rousseau

- \$477,734 operating grant awarded by CIHR (Partnerships in Health System Improvement)
- role purpose of the project is to document outcomes and process indicators associated with 3 different models of delivery of mental health services
- co-investigator; providing input into design of study and interpretation of findings

**2014-2016 CP2: ENGAGING COMMUNITY PARTNERS FOR CHILDREN'S PARTICIPATION.** Keiko Shikako-Thomas, Michael Shevell, Maryam Oskoui, Chantal Camdem, **Lucyna Lach**, Isabelle Émond, Nathalie Trudelle, Walter Wittich

- Doug Maynard, Marie-Claire Major, Margaret Guest (Collaborators)
- Nadine Bergeron (Knowledge User)
- \$12,500 planning grant awarded by CIHR Institute Community Support; OPHQ \$17,500 and REPAR \$17,500
- co-investigator role; contribute to planning and execution of a KT event with community partners invested in facilitating participation of children with CP

**2012-2015 POVERTY AND ETHNOCULTURAL DIVERSITY AS THE CONTEXT FOR PARENTING AND SERVICE ACCESS FOR CHILDREN WITH NEURODEVELOPMENTAL DISORDERS IN MONTREAL, QUEBEC.** **Lucyna M. Lach**, David Rothwell, Cecile Rousseau, Sebastien Breau, Monica Ruiz-Casares, Dana Anaby, Daniel Amar, Peter Rosenbaum, Dafna Kohen, David Nicholas.

- \$20,000 awarded by McGill University; McGill University Collaborative Grant Competition; Additional \$15,000 from SSHRC to CIHR internal grant; McGill University
- primary investigator

- conduct a review of literature, focus groups, and planning grant meeting to prepare submission to CIHR or provincial funding body

**2010-2014 THE HEALTH OF CANADIAN CAREGIVERS: USING ADMINISTRATIVE HEALTH SERVICES DATA TO UNDERSTAND DETERMINANTS OF HEALTH.** Jamie Brehaut, Dafna Kohen, Peter Rosenbaum, Anton Miller, **Lucyna M. Lach**, Marni Brownell, Kimberley McGrail, Rochelle Garner, Rubab Arim & Anne Guevremont (Collaborator)

- \$349,699 awarded by the Canadian Institutes of Health Research; Operating Grant
- co-investigator
- provide input into design, implementation, analysis, and interpretation of findings

**2010-2014 DETERMINANTS OF ACTIVE INVOLVEMENT IN LEISURE FOR YOUTH: DAILY LIVING WITH DISABILITY.** Annette Majnemer, **Lucyna M. Lach**, D. Maltais, Barbara Mazer, Line Nadeau, P. Riley, C. Rohlicek, Norbert Schmitz.

- \$388,272 awarded by the Canadian Institutes of Health Research; Operating Grant
- co-investigator
- provide input into design, implementation and analysis of findings

**2010 A DIALOGUE ON THE HEALTH OF CAREGIVERS OF CHILDREN WITH DISABILITIES.** Jamie C. Brehaut, Dafna E. Kohen, and Rubab G. Arim, **Lucyna M. Lach**, Peter Rosenbaum, Anton Miller, & Rochelle Garner.

- \$40,000 awarded by the Canadian Institutes of Health Research; Meetings, Planning, and Dissemination Grant.
- co-investigator
- presented results related to health of caregivers of children with chronic health conditions and neurodevelopmental disorders to policy makers, institutional and clinical leaders, advocates and parents

**2009-2015 CIHR TEAM IN PARENTING MATTERS! THE BIOPSYCHOSOCIAL CONTEXT OF PARENTING CHILDREN WITH NEURODEVELOPMENTAL DISORDERS IN CANADA.** Peter Rosenbaum (Nominated Principal Investigator), **Lucyna M. Lach (Co-Principal Investigator)**; Dafna Kohen (Co-Principal Investigator); Michael Saini, Rochelle Garner, Rachel Birnbaum, David Nicholas, Jamie Brehaut, Delphine Collin-Vezina, Ted McNeill, Alison Niccols, & Michael McKenzie and collaborators

- \$780,114 awarded by the Canadian Institutes of Health Research; Emerging Team Grant: Children with Disabilities (Bright Futures For Kids With Disabilities) Competition
- co-principal investigator – rated as 1<sup>st</sup> of 8 studies reviewed in this competition
- responsible for conceptualizing the grant, managing the research teams, implementation of 4 projects, training and supervision of RAs, interpretation of findings, and dissemination

- 2009-2011 A SYNTHESIS REVIEW OF INTERVENTIONAL OUTCOMES IN PAEDIATRIC AUTISM.** David Nicholas, Lonnie Zwaigenbaum, Sheila Roberts, Joyce Magill-Stevens, **Lucyna M. Lach**, Margaret Clarke, and Decision Makers Margaret Whelan, Laura Cavanagh, Margaret Spoelstra,
- \$99,960 awarded by the Canadian Institutes of Health Research Synthesis Grant: Knowledge Translation
  - co-investigator – rated as 1<sup>st</sup> of 68 studies submitted to the competition
  - responsible for developing methods, recruitment, training and supervision of RAs, interpretation of findings.
- 2009-2014 OUTCOME TRAJECTORIES IN CHILDREN WITH EPILEPSY: WHAT FACTORS ARE IMPORTANT? QUEBEC SUBSAMPLE OF THE CANADIAN STUDY OF PAEDIATRIC EPILEPSY HEALTH OUTCOMES.** **Lucyna M. Lach (Principal Investigator)**, Michael Shevell, Lionel Carmant, Gabriel Ronen, David Streiner, Peter Rosenbaum, Charles Cunningham, & Michael Boyle.
- \$255,820 awarded by the Ministère de la Santé et des Service Sociaux
  - principal investigator – funding received to collect data in Quebec (Montreal Children’s Hospital and Ste. Justine) and to contribute to the pan-Canadian study on HRQL in epilepsy (see below)
  - responsible for all aspects of implementing this research
  - additional funding received from CRIR (\$15,000), McGill University Faculty of Arts (\$7,500), Faculty of Medicine (\$5,000), MUHC Research Institute (\$2,500), VP Research (\$7,500), and CIHR McMaster Team (\$50,000)
- 2008 PARENTING IN A BIOPSYCHOSOCIAL CONTEXT: CHALLENGES, SUCCESSES, AND THE IMPACT OF PARENTING ON THE WELL-BEING OF CHILDREN WITH NEURODEVELOPMENTAL DISORDERS IN CANADA.** Peter Rosenbaum (Nominated Principal Investigator), **Lucyna M. Lach (Co-Principal Investigator)**; Jamie Brehaut, Delphine Collin-Vezina, Rochelle Garner, Dafna Kohen, Ted McNeill, David Nicholas, & Michael Saini.
- \$9,927 awarded by the Canadian Institutes of Health Research Emerging Team Grant Competition: Children with Disabilities (Bright Futures for Kids with Disabilities); Letter of Intent
  - co-principal investigator – one of 9 studies (out of an original 16) funded to develop a full proposal for funding to be submitted in September 2008.
  - responsible for team meeting in Ottawa on the 12 and 13<sup>th</sup> of June, coordinating development of the grant proposal and final submission of the grant proposal.
- 2008-2009 PARENTING CHILDREN AND ADOLESCENTS WITH CHRONIC HEALTH CONDITIONS AND DISABILITIES: A SYNTHESIS OF THE RESEARCH.** **Lucyna M. Lach (Principal Investigator)**, David, Nicholas, Ted McNeill (Michael Saini and Peter Rosenbaum as collaborators)



- \$36,983 awarded by the Social Sciences and Humanities Research Council – Research Development Initiative (SSHRC-RDI)
- primary applicant – study funded to conduct a systematic review of parenting literature and to develop a theoretical model for use in future studies
- responsible for project management, develop of algorithm, supervision of students and research assistants, writing up final report.

**2008-2013 OUTCOME TRAJECTORIES IN CHILDREN WITH EPILEPSY: WHAT FACTORS ARE IMPORTANT?** Gabriel M. Ronen, David L. Streiner, Peter L. Rosenbaum, **Lucyna M. Lach**, Michael H. Boyle, & Charles E. Cunningham.

- \$767,485 awarded by the Canadian Institutes for Health Research (CIHR)
- co-applicant – study funded to test a theoretical model of determinants of health related quality of life in children and adolescents with epilepsy
- responsible for development of theoretical model tested, analysis and interpretation of pilot data, choosing measures, project management.

**2007-2011 DETERMINANTS OF PARTICIPATION AND QUALITY OF LIFE AMONG ADOLESCENTS WITH CEREBRAL PALSY.** Annette Majnemer, Denise Keiko Thomas, Michael Shevell, **Lucyna M. Lach**, Mary Law, Norbert Schmitz, (and Allan Colver, Kathleen Montpetit, France Martineau, Michele Gardiner, Louise Koclas as collaborators).

- \$300,834 awarded by the Canadian Institutes for Health Research (CIHR)
- co-applicant – study funded to test a theoretical model of determinants of participation and quality of life
- responsible for choosing measures, interpretation of data, publications.

**2007-2008 DETERMINANTS OF PARTICIPATION IN LEISURE ACTIVITIES AMONG ADOLESCENTS WITH CEREBRAL PALSY.** Annette Majnemer, Denise Keiko Thomas, Michael Shevell, **Lucyna M. Lach**, Mary Law, Norbert Schmitz, Allan Colver, Kathleen Montpetit, France Martineau, Michele Gardiner, Louise Koclas.

- \$40,000 awarded by the Réseau provinciale de recherche en adaptation-réadaptation (REPAR)
- co-applicant – study funded to test a theoretical model of determinants of participation

**2007-2009 REHABILITATION SERVICES FOR PRESCHOOL CHILDREN WITH PRIMARY LANGUAGE IMPAIRMENT: INDIVIDUAL VS DYAD INTERVENTION.** Barbara Samuel (Mazer), Annette Majnemer, **Lucyna M. Lach**, Elin Thordardottir, & Michael Shevell.

- \$258,632 awarded by the Fonds de Recherche en Santé du Québec (FRSQ- Subventions de Recherches Cliniques ou en Santé des Populations)
- co-applicant – study funded to examine effectiveness of dyadic versus traditional approaches to providing rehabilitation services for preschool children with language impairment.

**2006-2008 PANDEMIC PLANNING FOR PAEDIATRIC CARE.** David Nicholas, Beverley Antle, Donna Koller, Cynthia Bruce-Barrett, Anne Matlow, Randi Shaul Zlotnik, & **Lucyna M. Lach.**

- \$159,632 awarded by the Canadian Institutes for Health Research
- co-applicant – study funded to review existing institutional, provincial and federal policies and build a consensus for best practices to guide paediatric-based pandemic planning.
- responsible for liaison with Quebec-based paediatric hospitals and rehabilitation centres.

**2006-2007 CHILDHOOD-DISABILITY – LINK: A WEBSITE LINKING INFORMATION AND NEW KNOWLEDGE TO SERVICE PROVIDERS AND FAMILIES.** Annette Majnemer, Jeffrey D Atkinson, Kim Cornish, D Feldman; Eric Jean Fombonne, S Ghosh; Eva Kehayia, Nicole Korner-Bitensky, **Lucyna M. Lach**, Mindy Levin, Catherine Limperopoulos, F Malouin, Barbara Mazer, Line Nadeau; Michael Shevell; Laurie Snider.

- \$20,048 awarded by the Réseau Provincial de Recherche en Adaptation-Réadaptation, Fonds de Recherche en Santé du Québec.
- co-applicant – study funded to develop plans for a website that will provide a forum for exchange of evidence regarding childhood disability
- regular written contribution to web-site regarding research progress, publications

**2006-2007 DETERMINANTS OF QUALITY OF LIFE IN ADOLESCENTS WITH CEREBRAL PALSY: A QUALITATIVE STUDY,** Annette Majnemer, **Lucyna M. Lach**, Michael Shevell, Denise Keiko Thomas.

- \$7,500 awarded by the Montreal Children's Hospital Research Institute
- co-applicant – study funded to build a theoretical model of factors that influence quality of life in adolescents with cerebral palsy
- project management, training of interviewers and supervision of data analysis

**2005-2007 THE HEALTH OF CANADIAN CAREGIVERS: CAN A NATIONAL LONGITUDINAL DATASET BE USED TO MODEL THE HEALTH OF CAREGIVERS OF CHILDREN WITH DISABILITIES?** Jamie Brehaut, Dafna Kohen, Anne F. Klassen, **Lucyna M. Lach**, Anton Miller, Peter Rosenbaum.

- \$274,464 grant awarded by the Canadian Institutes for Health Research. Operating Grant – Population Health.
- co-applicant – study funded to examine the health of caregivers of Canadian children with chronic health conditions and disabilities using the National Longitudinal Study of Children and Youth (NLSCY) in Canada
- team leader for analysis and interpretation of data pertaining to caregivers of children and youth with neurodevelopmental disabilities; contribute to interpretation of SEM pertaining to health of caregivers of children with chronic health conditions and disabilities

- 2005-2006 LATENCY AGE CHILDREN WITH EPILEPSY AND THEIR PEERS : PERCEPTIONS OF PEER RELATIONSHIPS AND SOCIAL SUPPORT.** Lucyna M. Lach, Beverley Antle, Janice Hansen, Catherine Frazee and Karen Yoshida.
- \$16,000 grant awarded by the Réseau Santé Mentale et Neuroscience, Fonds de Recherche en Santé du Québec
  - principal applicant - funding received to complete analysis on peer study previously funded by the Bloorview Children's Hospital Foundation
  - primary responsible for completion of data analysis and dissemination
- 2004-2006 AN EVALUATION OF THE RELEVANCE, FEASIBILITY AND VALIDITY OF WEB-BASED DATA COLLECTION FOR CHILDREN.** David Nicholas, Nancy Young, Catherine Boydell, Ross Hetherington, James Varni, Laurie Snider, **Lucyna M. Lach**, & Gillian King.
- \$125,384 grant awarded by the Canadian Institutes for Health Research. Operating Grant – Advancing Theories, Frameworks, Methods and Measurement in Health Services and Policy.
  - co-applicant – study funded to examine relevance, feasibility and validity of gathered using web-based versus paper and pencil or face to face data gathering techniques;
  - sharing responsibility for the data gathered from the Montreal site with Laurie Snider
- 2004-2006 INTERSECTING BARRIERS TO HEALTH FOR IMMIGRANT WOMEN WITH PRECARIOUS STATUS.** Jacqueline Oxman-Martinez, Nazilla Khanlou, Swarna Weerasinghe, Vijay Agnew, **Lucyna M. Lach**, Louise Poulan de Courval, Jill Hanley, Merle Jacobs.
- \$100,000 grant awarded by the Canadian Institutes for Health Research. Operating Grant – Reducing Health Disparities and Promoting Equity for Vulnerable Populations.
  - co-investigator – initially invited as a collaborator but status has been officially revised with CIHR to that of a co-applicant;
  - development, implementation and analysis of interviews conducted with health care providers about services offered to women with precarious immigration status
- 2003-2006 PRÊT! PAS PRÊT! JE VIEILLIS! COMMENT L'ENTOURAGÉ DE L'ADOLESCENT AYANT UNE INCAPACITÉ MOTRICE LE SOUTIEN DANS SA PARTICIPATION SOCIALE.** Sylvie Tétrault, Monique Carrière
- \$134,856 grant awarded by the Fonds Québécois de la Recherche sur la Société et la Culture.
  - collaborator – study funded to examine factors that facilitate and impede transition from adolescence into young adulthood in those with physical disabilities
  - responsible for Montreal site (English component); supervision of RAs who will be interviewing adolescents, young adults, parents, and health care professionals; supervision of data analysis.

- 2003-2004 FEASIBILITY STUDY FOR MULTI-SITE RANDOMIZED TRIAL OF INTERVENTION FOR DEPRESSED OLDER PATIENTS IN PRIMARY CARE SETTINGS.** Jane McCusker, Martin Cole, Mark Yaffe, Dendukuri Nandini, Maida Sewitch, Martin Dawes, Philippe Cappeliez
- \$180,812 research grant awarded by the Canadian Institutes For Health Research
  - collaborator; pilot project funded to examine the feasibility of a randomized trial of problem solving therapy for older patients diagnosed with depression.
  - I was invited to participate in this project after it was funded. My contribution has included the following: process analysis of the delivery of the intervention; administering focus groups with allied health professionals, primary care physicians, and psychiatrists; analysis of focus group data.
- 2003-2005 QUALITY OF LIFE IN CHILDREN WITH EPILEPSY: WHAT CONSTELLATION OF FACTORS IS IMPORTANT?** Gabriel M. Ronen, David L. Streiner, Charles Cunningham, Michael H. Boyle, Peter L. Rosenbaum, **Lucyna M. Lach**, and Joan K. Austin.
- \$80,000 research grant awarded by the Child Neurology Society/Foundation.
  - co-applicant; pilot project funded to examine the feasibility of launching a longitudinal study of moderators and mediators of quality of life of children between the ages of 8 and 13 diagnosed with epilepsy.
  - development of the theoretical model; selection of measures to be used in the study.
- 2000–2003 CHILD AND FAMILY ADAPTATION TO CHILDHOOD CHRONIC HEALTH CONDITIONS: A COMPREHENSIVE CONCEPTUAL FRAMEWORK OF PSYCHOSOCIAL RISK AND RESILIENCE.** Judith Globerman, Jan Wallander, Gillian King, Pat McKeever, Jeff Jutai, Beverley Antle, **Lucyna M. Lach**, Ted McNeill, and David Nicholas
- \$293,000 research grant awarded by the Social Sciences and Humanities Research Council, Strategic Themes Competition: Society, Culture and the Health of Canadians
  - co-applicant; development of a theoretical model for the study and understanding of psychosocial risk and resilience factors in the adjustment of children with chronic health conditions and their families
  - development of the structure for the data collection (both quantitative and qualitative); conceptual analysis of over 500 measures; synthesis of information generated in the meta-analysis and meta-synthesis.
- 2000–2003 SOCIAL EXPERIENCES IN SCHOOL: PERCEPTIONS OF STUDENTS WITH PHYSICAL DISABILITIES AND CHRONIC HEALTH CONDITIONS.** Beverley Antle, **Lucyna M. Lach**, Janice Hansen, Catherine Frazee, Karen Yoshida
- \$80,215 research grant awarded by the Bloorview Children’s Hospital Foundation
  - co-principal investigator; study examines perceptions of peer relationships among children with cerebral palsy and epilepsy, and nominated peers
  - development of methodology; management of data collection; data analysis.

**2001-2003      LONGITUDINAL OUTCOME OF PAEDIATRIC EPILEPSY SURGERY.** Mary Lou Smith, **Lucyna M. Lach**, Irene I. Elliott, Sharon Whiting, Lynn McCleary

- \$117,594 research grant awarded by the Ontario Mental Health Foundation
- study examines long term quality of life and neurocognitive outcomes in young adults (18-31) who received epilepsy surgery during childhood or adolescence
- co-investigator; involves 2 sites: Hospital For Sick Children in Toronto and Children's Hospital of Eastern Ontario in Ottawa
- responsible for qualitative interviews conducted with young adults who have intractable epilepsy but did not undergo epilepsy surgery; data analysis pertaining to social outcomes.

**1999–2001      LONGITUDINAL STUDY OF OUTCOME FOR CHILDREN UNDERGOING EPILEPSY SURGERY.** Mary Lou Smith, **Lucyna M. Lach**, Irene Elliott

- \$100,664 research grant awarded by the Ontario Mental Health Foundation
- co-investigator; continuation of a multi-method study examining the biopsychosocial outcome of epilepsy surgery in children, adolescents and their families
- shared responsibility for psychosocial (behavioural, emotional and family) component of the study; interviews with caregivers of children with epilepsy; analysis of psychosocial and qualitative data (parent-based).

**1997-1999      OUTCOME OF EPILEPSY SURGERY: A MULTI-METHOD MULTIDIMENSIONAL APPROACH.** Mary Lou Smith, **Lucyna M. Lach**, Irene Elliott

- \$98,000 research grant awarded by the Ontario Mental Health Foundation
- co-investigator; a longitudinal, multi-method study examining the biopsychosocial outcome of epilepsy surgery in children, adolescents, their families
- shared responsibility for psychosocial (behavioural, emotional and family) component of the study; interviews with caregivers of children with epilepsy; analysis of psychosocial and qualitative data (parent-based).

## **PUBLICATIONS**

Finlay, B., Wittevrongel, K., Materula, D., Hébert, M.L., O'Grady, K., **Lach, L.M.**, Nicholas, D., and Zwicker, J.D. (2023). Pan-Canadian caregiver experiences in accessing government disability programs: A mixed methods study *Research in Developmental Disabilities*.

<https://doi.org/10.1016/j.ridd.2022.104420>.

McCrossin, J., **Lach, L.** (2022). Parent-to-parent peer support for families of children with neurodisabilities: Applications of family resilience theory. *Child: Care, Health & Development*. <https://doi.org/10.1111/cch.13069>.

Currie, G., Finlay, B., Seth, A., Roth, C., Elsabbagh, M., Hudon, A., Hunt, M., Jodoin, S., **Lach, L.**, Lencucha, R., Nicholas, D. B., Shakako, K., & Zwicker, J. (2022). Mental health challenges during COVID-19: Perspectives from parents with children with neurodevelopmental disabilities.

*International Journal of Qualitative Studies on Health and Well-Being*, 17(1).  
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Nicholas, D. B., Mitchell, W., Ciesielski, J., Khan, A., & **Lach, L.** (2022). Examining the Impacts of the COVID-19 pandemic on service providers working with children and youth with neurodevelopmental disabilities and their families: Results of a focus group study. *Journal of Intellectual Disabilities*, <https://doi.org/10.1177/17446295221104623>

McCrossin, J., Filipe, A.M., Nicholas, D., & **Lach, L.** (2022). The allegory of “navigation as a concept of care: The case of child neurodevelopmental disabilities. *Journal on Developmental Disabilities for the Special Edition focused on Changing Social Welfare Provisions and Shifting Family Dynamics*, 27(2). <https://doi.org/10.5281/zenodo.7017122>

McCrossin, J., Clancy, A., Grantzidis, F., & **Lach, L.** (2022). “They may cry, they may get angry, they may not say the right thing”: A case study examining the role of peer support when navigating services for children with neurodisabilities. *Journal on Developmental Disabilities for the Special Edition focused on Changing Social Welfare Provisions and Shifting Family Dynamics*, 27(2). <https://doi.org/10.5281/zenodo.7017122>

Hebert, M., Nicholas, D., **Lach, L.M.**, Mitchell, W., Zwicker, J., Bradley, W., Litman, S., Gardiner, E., & Miller, A.R. (in press). Lifespan navigation-building framework for children/youth with neurodisabilities and their families. *Families in Society*. DOI:10.1177/10443894221081609.

Salvino, C., Spencer, C., Filipe, A. M., & **Lach, L. M.** (2022). Mapping of financial support programs for children with neurodisabilities across Canada: Barriers and discrepancies within a patchwork system. *Journal of Disability Policy Studies*, 33(3), 168–177.  
<https://doi.org/10.1177/10442073211066776>

McCrossin, J. McGrath, P., & **Lach, L.** (2022). Content analysis of parent training programs for children with neurodisabilities and mental health or behavioral problems: A scoping review. *Disability & Rehabilitation*. DOI:10.1080/09638288.2021.2017493.

Brotman, S., Sussman, T., Pacheco, L., Dickson, D., **Lach, L.**, Raymond, E., Deshaies, M.H., Freitas, Z., & Milot, E. (2021): The crisis facing older people living with neurodiversity and their aging family carers: A social work perspective. *Journal of Gerontological Social Work*, DOI:10.1080/01634372.2021.1920537

Filipe, A.M., Bogossian, A., Zulla, R., Nicholas, D., & **Lach, L.M.** (2021). Developing a Canadian framework for social determinants of health and wellbeing among children with

neurodisabilities and their families: an ecosocial perspective. *Disability & Rehabilitation*, 43(26), 3856-3867. DOI:10.1080/09638288.2020.1754926

Gardiner, E., Miller, A., & **Lach, L.** (2021). Behavioral strength and difficulty profiles among children with neurodisability. *Journal of Developmental and Physical Disabilities*, 33(2), 1-17. DOI:10.1007/s10882-020-09742-0.

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Rothwell, D., **Lach, L.M.**, Kohen, D., Findlay, L., & Arim, R. (2020). Income trajectories of families raising a child with a neurodisability. *Disability & Rehabilitation*. DOI: 10.1080/09638288.2020.1811782.

Gardiner, E., Miller, A. R., & **Lach, L. M.** (2020). Service adequacy and the relation between child behavior problems and negative family impact reported by primary caregivers of children with neurodevelopmental conditions. *Research in Developmental Disabilities*, 104, 103712. DOI:10.1016/j.ridd.2020.103712.

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- Bogossian, A, King, G, **Lach, L**, Currie, M, Nicholas, D, McNeill, T, & Saini, M. (2019). (Unpacking) father involvement in the context of childhood disability research: A scoping review. *Disability and Rehabilitation*, *41*(1), 110-124. DOI:10.1080/09638288.2017.1370497.
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Shikako-Thomas, K., Shevell, M., **Lach, L.**, Law, M., Schmitz, N., Poulin, C., Majnemer, A. & the QUALA group (2015). Are you doing what you want to do? Leisure preferences of adolescents with cerebral palsy. *Developmental Neurorehabilitation*, 18(4), 234-240, DOI:10.3109/17518423.2013.794166.

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Smith, M.L., Olds, J., Snyder, T., Elliott, I., **Lach, L.M.**, & Whiting, S. (2014). A follow up study of cognitive function in young adults who had resective epilepsy surgery in childhood. *Epilepsy & Behavior*, 32, 79-83, DOI:10.1016/j.yebeh.2014.01.006.

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## **Dissertation**

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## **Book Chapters**

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**Lach, L.M.** & Birnbaum, R. (2016). Obligation to Report Child Abuse/Neglect is More Complex Than It Seems. In P. Rosenbaum, G. Ronen, E. Racine, J. Johannesen & B. Dan (Eds.), *Ethics in Child Health: Principles and Cases in Neurodisability*. MacKeith Press.

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Bogossian, A., **Lach, L.**, Nicholas, D., & McNeill, T. (*accepted*). Fathers of children with intellectual and developmental disabilities: Where are they and why does it matter? In A. Fudge-Schorman and K. Stoddard (Eds.), *Social Work, Intellectual and Developmental Disabilities in Canada*. Waterloo Canada: Wilfred Laurier Press.

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Parents Empowering Neurodiverse Kids: The Strongest Families Neurodevelopmental Program to Help Parents Manage Challenging Behaviours. Webinar given on January 10, 2019 for Children's Healthcare Canada Knowledge Exchange Network.

<https://ken.childrenshealthcarecanada.ca/xwiki/bin/view/CAPHC+Presents%21/Parents+Empowering+Neurodiverse+Kids%3A+The+Strongest+Families+Neurodevelopmental+Program+to+Help+Parents+Manage+Challenging+Behaviours>.

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**Bogossian, A.**, Rothwell, D., Lach, L., Nicholas, D., Bailey, S., Kohen, D., & Rosebaum, P. (2014). Financial stress among parents of children with neurodisabilities in Canada: the role of 'complexity' [Abstract]. *Developmental Medicine and Child Neurology*, 56(Supplement 5), 7.

**Lach, L.**, Bogossian, A., Bailey, S., Kohen, D., & Rosebaum, P. (2014). Building a model to address the role of parenting in the lives of children with neurdevelopmental disorders (NDD): does

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**Lach, L.M.**, Garner, R., Arim, R., Kohen, D., & Rosenbaum, P. (2012). Rates of separation/divorce of children with neurodevelopmental disorders: Results from a Canadian longitudinal population-based study. [Abstract]. *Developmental Medicine and Child Neurology*, 54(Supplement 6), 49.

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- Kelly, K., Smith, M.L., Elliott, I.E., Olds, J., McCleary, L., Whiting, S., **Lach, L.**, Lowe, A., & Snyder, T. (2003). Long-term effects of pediatric epilepsy surgery: The influence of seizure status on psychiatric outcome in young adults. [Abstract], *Epilepsia*, *44*(Suppl. 9), 318.
- Kadis, D.S., Smith, M.L., Stollstorff, M., **Lach, L.M.** & Elliott, I.E. (2003). Cognitive and psychological predications of everyday memory in children with epilepsy. [Abstract], *Epilepsia*, *44*(Suppl. 9), 237-238.
- Lach, L.M.** Elliott, I.E., & Smith, M.L. (2003). Family adjustment after epilepsy surgery: Longer-term findings from a prospective longitudinal study of children. [Abstract], *Epilepsia*, *44*(Suppl. 9), 154-155.
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**Lach, L.M.**, Elliott, I.M., & Smith, M.L. (2002). Predictors of social adjustment after paediatric epilepsy surgery. [Abstract], *Epilepsia*, 43(Suppl. 7), 327-328.

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**Lach, L.M.**, Elliot, I., & Smith, M.L. (2001). Does life for children and families change after epilepsy surgery? [Abstract], *Epilepsia*, 42(Suppl. 7), 302.

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Hoosen-Shakeel, S., Smith, M.L., Elliott, I. & **Lach, L.M.** (2000). Usefulness of the Children's Memory Scale for predicting memory abilities in children with epilepsy. [Abstract], *Epilepsia*, 41(Suppl. 7), 155.

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Smith, M.L., **Lach, L.M.**, & Elliott, I. (2000). Reasoning, remembering, and academics in children with epilepsy: Does surgery make a difference? [Abstract], *Epilepsia*, 41(Suppl. 7), 81-82.

Elliott, I., **Lach, L.M.**, & Smith, M.L. (1999). Impact of intractable epilepsy on quality of life in children: Child, adolescent and parent pre-surgical perspectives. [Abstract], *Epilepsia*, 40(Suppl. 7), 112.

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Elliott, I., **Lach, L.**, & Smith, M.A. (1997). Adolescents' perceptions of their lives after epilepsy surgery. [Abstract], *Epilepsia*, 38(Suppl. 8), 234.

Krogh, K., **Lach, L.** & Humphries, T. (1997). Change in parent perceptions: Impact of a clinical classroom program for children with epilepsy. [Abstract], *Epilepsia*, 38(Suppl. 8), 240.

**Lach, L.**, Elliott, I., & Smith, M.L. (1997). Life after paediatric epilepsy surgery: The parent view. [Abstract], *Epilepsia*, 38(Suppl. 8), 233.

## **TEACHING**

### **University Courses Given**

Introduction to Practicum, SWRK222, McGill University, Faculty of Arts, School of Social Work, Undergraduate social work course, Winter 2020.

Integrative Seminar, SWRK422, McGill University, Faculty of Arts, School of Social Work, Undergraduate social work course, Winter 2021, Winter 2022, Winter 2023

\*Thought and Theory Development in Social Work, SWRK702, McGill University, Faculty of Arts, School of Social Work, PhD level required course, Fall 2020, Fall 2021, Fall 2022

\*Critical Thought and Ethics, SWRK 525, McGill University, Faculty of Arts, School of Social Work, Undergraduate Required course, Fall 2009 to 2019.

\*Knowledge and Values, SWRK 612, McGill University, Faculty of Arts, School of Social Work, Graduate level required course, Fall 2009

Practice with Individuals and Families, SWRK 320 D1/D2 (changed to SWRK 320 and SWRK 326), McGill University, Faculty of Arts, School of Social Work, Undergraduate Social Work Course, Winter 2007 & Winter 2008

\*Disabilities and Rehabilitation, SWRK 669, McGill University, Faculty of Arts, School of Social Work, Graduate Social Work Course, Winter, 2005-2009

Family Assessment, SWRK 472, McGill University, Faculty of Arts, School of Social Work, Undergraduate Social Work Course, Fall, 2001-present

Health and Social Work, SWRK-609, McGill University, Faculty of Arts, School of Social Work, Graduate Social Work Course, Fall, 2001-2003

School Social Services, SWRK-465, McGill University, Faculty of Arts, School of Social Work, Undergraduate Social Work Course, Winter, 2002-2004

Social Work in the Health Field, McGill University, Faculty of Arts, School of Social Work, Undergraduate Social Work Course, Winter, 2002-present

Elements and Lab, 4103H, University of Toronto, Faculty of Social Work, Graduate Social Work Course, Fall, 2000.

Social Work Practice With Individuals and Families, SWK 4601S, University of Toronto, Faculty of Social Work, Graduate Social Work Course, Winter, 1999

\*Graduate Level Courses

### Graduate Supervision – Post Doctorate

Angela Filipe (2017-2020). Current position: Assistant Professor, Health and Social Theory, Department of Sociology, Durham University, Durham, UK.

Emily Gardiner (2015-2021) – co-supervision with Dr. Anton Miller (UBC/BC Children’s Hospital)

### Graduate Supervision – PhD Thesis Supervision

Student Name	Years Registered	Title of Dissertation	Current Employment
Samuel Ragot	2022-present	TBD	N/A
Kifah Baniowda	2021-present	Barriers and facilitators to inclusive education for children with neurodisabilities in Palestine.	N/A
Jeff McCrossin	2019-present	Parent Training for Children with Neurodisabilities: The Role of Family	N/A
Gina Glidden	2013-2019	The Journey of Ladders and Snakes: Help-Seeking Among Mothers and Fathers of Children with Neurodisabilities (ND)	West Island Therapy and Wellness Centre, Counsellor, Private Practice
Sara Quirke	2012-2017	Exploring parenting factors as possible predictors and moderators of mothers’ cognitive appraisals of the family impact of raising their child with a neurodisability.	Lester B. Pearson School Board, Psychologist
Radha MacCulloch	2011-did not complete	Exploring how Transition Programs Understand and Support the Meaningful Transition to Adulthood for Youth with a NDD: Insights from Service Providers, Youth, and their Parents	Specialisterne, Vice President, Head of Canada
Aline Bogossian	2011-2017	Exploring ‘Father Involvement’ among Caregiving Fathers of Children and Youth with Neurodisabilities	Universite de Montreal, Associate Professor
Anne Ritzema	2010-2015	Predictors of Child Well-Being; Parenting Children	Lighthouse Child and Adolescent

		with NDD	Psychology, Psychologist and Director
Sacha Bailey	2009-2017	The experience of hope among parents of children with Neurodisabilities	BC Centre for Ability; Pediatric Social Worker and Clinical Researcher
Judith Sabetti	2008-2013	Employment and Recovery in Mental Illness	unknown
Anne Marie Piche	2005-2011	Parental Practices in the Context of Caregiving Disruption: The Case of Post-Institutional Adoption	UQAM, Associate Professor
Janet Kuo	2001-2008	Caregiving Identities of Women with a Brother or Sister with Cerebral Palsy in Taiwan	Associate Professor, National Taipei University of Education

### **Graduate Supervision – PhD Thesis Committee Member**

John Aspler

(2015-2020)

Fetal Alcohol Spectrum Disorder and Cerebral Palsy in the Canadian Media: A qualitative analysis of Media Discourse and Stakeholder Perspectives. (Integrated Program in Neuroscience)

Ro'fah Mudzakir

(2003-2011)

Education for Children with Disabilities in Indonesia: Moving Toward Inclusion (School of Social Work)

Denise Keiko Thomas

(2007-2012)

Determinants of Participation in Leisure Activities in Adolescents with Cerebral Palsy (School of Physical and Occupational Therapy, Faculty of Medicine)

Nancy Miodrag

(2009)

Predictors of stress and Symptoms of Psychopathology in Parents of Children with Developmental Disabilities within Early Intervention (Department of Educational and Counselling Psychology)

Jennifer Saracino

(2007-2011)

Early Intervention in Canada: Perceptions of Parents and Service Providers (Department of Educational and Counselling Psychology)

### **Graduate Supervision – MSW Thesis Supervision**

Phoebe Johnston

(2016-2018) An Issue of Transparency: Comparing Respite Funding Programs for Families Raising a Child with a Neurodisability Across Canada. Current position: Clinical Social Worker, Nova Scotia Health Authority, Halifax, Nova Scotia.

Nadine Powell  
(2006-2013) Transitioning from paediatric to adult centred care: A review of the research on transition interventions for adolescents and young adults with chronic conditions. Current position: unknown

Gina Glidden  
(2010-2013) Intensity of Participation Among Children With Epilepsy: An Exploratory Factor Analysis of Child Components. Current position: West Island Therapy and Wellness Centre, Counsellor, Private Practice

Aline Bogossian  
(2011) The Role of Family Environment in Parenting Children with NDD: Results of a Systematic Review. Current position: Associate Professor, Universite de Montreal.

Shirley Hopwood-Wallace  
(2010) Documented Symptoms in Children Exposed to Domestic Violence. Current position: retired

Linda Shames  
(2007) Rate of symptoms of dual diagnosis in the Child Welfare system in Canada: Profile of adolescents and their caregivers in the CIS-2003. Current position: Social Worker, CIUSSS Centre-Ouest, Montreal, Quebec.

Glenda O'Reilly  
(2002) Families in Today's Health Care System: The Experience of Families During a Paediatric Admission. Current position: unknown.

Tracey Kent  
(2002) Evaluation of the National Alliance for the Mentally Ill--Professional Education Program: Changes in Perception and Practice. Current position: Clinical social worker at Royal Ottawa Mental Health Centre, Brockville, Ontario.

### **Graduate Supervision – Masters Thesis Committee Member**

Nathalie Chokron  
(2008-2011) Factors associated with participation in leisure activities among school-aged children with developmental delay (School of Physical and Occupational; Faculty of Medicine).



## Graduate Supervision – PhD Thesis Examiner

Boychuck, Zachary (2019). *Creating the Content for Knowledge Translation Tools to Prompt Early Referral for Diagnostic Assessment and Rehabilitation Services for Children with Suspected Cerebral Palsy*. School of Physical and Occupational Therapy, Faculty of Medicine, McGill University.

Fontil, Laura (2019). *Transition to School for Children with Autism Spectrum Disorders: Review of the Literature, Policy Implications, and Intervention Efficacy*. Department of Educational Counselling and Psychology, Faculty of Education, McGill University.

Ryan, Stephanie (2018). *Sport Involvement for Youth with Autism Spectrum Disorders and Intellectual Disabilities*. Department of Psychology, York University.

Roy St. Jean, Sean Armand (2018). *Today in Light of Yesterday: A Phenomenological Study of Child Protection Workers' Vocational Experiences as Informed by Memories of Childhood*. School of Social Work, UBC (Okanagon).

Foley, Veronique (2017). *Comment les services de santé et de réadaptation permettent-ils de répondre aux besoins des familles d'enfant présentant une déficience physique motrice? Repenser nos services sous l'angle de l'intersectionnalité*. Université Sherbrooke, Faculté de Médecine et des Sciences de la Santé.

Dahan Oleil, Noemi (2014). *Participation in Leisure Activities Among Adolescents Born Extremely Pre-Term*. McGill University, School of Occupational and Physical Therapy.

Mantulak, Andrew (2012). *The Lived Experience of Mothers of Children Who Have Undergone Kidney Transplantation*. Faculty of Social Work, Wilfrid Laurier University.

Vinay, Marie-Claude (2010). *Le point de vue des enfants diabétiques sur le bien-être*. Department of Psychology, UQAM.

Peterson, Leah (2009). *A Qualitative Examination of the Experiences of Taiwanese Transnational Youth in Vancouver*. Department of Educational and Counselling Psychology, Faculty of Education, McGill University.

August, Pam (2009). *The Role of Expression Recognition in Social Information Processing and Poor Social Adjustment*. Department of Educational and Counselling Psychology, Faculty of Education, McGill University.

Saros, Nicole (2008). *Consultation for Children with Developmental Delays*. Department of Educational and Counselling Psychology, Faculty of Education, McGill University.

Saleh, Maysoun (2007). *Actual versus Best Practices for Young Children with Cerebral Palsy: A Survey of Paediatric Occupational Therapists and Physical Therapists in Quebec, Canada*. School of Occupational and Physical Therapy, Faculty of Medicine, McGill University.

Assunta de Iaco, Gilda (2006). *Juvenile Street Gang Members and Ethnic Identity in Montreal, Canada*. Department of Sociology, Faculty of Arts, McGill University.

O'Shea, Joseph (2006). *Re-Defining Risk Behaviours Among Gay Men: What Has Changed?* Department of Sociology, Faculty of Arts, McGill University.

Sarkissian, Sonia (2006). *Illness Intrusiveness, Quality of Life and Self-Concept in Epilepsy*. Institute of Medical Sciences, Faculty of Medicine, University of Toronto.

Glen, Tamara (2005). *Exploring Perceptions of Attention Deficit Hyperactivity Disorder*. Department of Educational and Counselling Psychology, Faculty of Education, McGill University.

Globe, Patricia (2005). *The Use of Child-Based Consultation: Changing Problematic Behaviours in Children Altering Interactions with Teachers in the Classroom*. Department of Educational and Counselling Psychology, Faculty of Education, McGill University.

Nedlham, Carolyn (2005). *A Narrative Analysis Exploring the Effects of Long-Term Caregiving on the Female Caregiver's Sense of Self*. Department of Counselling Psychology, Faculty of Education, McGill University.

Levy, Jonathan. (2004). *Deviance and Social Control Among Haredi Adolescent Males*. School of Social Work, McGill University.

Malowaniec, Leah. (2003). *Determining Community Attitudes and Concerns with Respect to the Establishment of Safer Injection Facilities in Vancouver's Downtown Eastside*. School of Social Work, McGill University.

### **Graduate Supervision – MSW Thesis Examiner**

Bastien, Laurianne (2021). *Evaluating an Online Mental Health Outreach Program for University Students During the COVID-19 Pandemic*. Department of Educational and Counselling Psychology, Faculty of Education, McGill University.

Quirke, Sara (2011). *Parents' Positive and Negative Cognitive Appraisals in Raising a Child with An Autism Spectrum Disorder*. Department of Educational and Counselling Psychology, Faculty of Education, McGill University.

Knight, Patsi Leila (2007). *Vision Impairment in Older Adults: Adaptation Strategies and the Charles Bonnet Syndrome*. School of Social Work, Faculty of Arts, McGill University.

Cox, Judith (2006). *Children with Developmental Disabilities: Finding Permanent Homes*. School of Social Work, Faculty of Arts, McGill University.

Graziani, Sylvie (2005). *Early Adolescent Experiences of Friendships, Peer Relations and Stress: Drawing on Girls' Impressions*. School of Social Work, Faculty of Arts, McGill University.

Spinner, David (2005). *The Edmonton Arts and Youth Feasibility Study: A Qualitative Look At Running an Arts Education Program for Youth in Conflict with the Law*. School of Social Work, Faculty of Arts, McGill University.

Kromer, Anna (2004). *The Impact of Ethnic Identity on Nursing Home Placement Among Polish Older Adults*

Melrose, Heather (2003). How Do Resource Foster Parents Conceptualize Concurrent Planning.

Tanner, Gordon (2003). *Street Outreach Programs For Homeless and Underhoused People: A Grounded Theory Study*.

## **Presentations**

### **Peer Reviewed Conferences**

Kohen, D. E., Arim, R. G., Miller, A. R., Guèvremont, A., **Lach, L. M.**, & Brehaut, J. C. (2018, October). *Children with neurodevelopmental disabilities: Identification and patterns of health services using Canadian administrative data*. Poster presentation at the DEVSEC: Conference on the Use of Secondary and Open Source Data in Developmental Science. Phoenix, Arizona.

**Lach, L.M.**, Kohen, D., Arim, R., Miller, A., Tough, S., McDonald, S., Fayed, N., Cohen, E., Guttman, A., Kitchen, L., Nicholas, D., Rosenbaum, P., & Bogossian, A. (2017). Indicators for children with neurodisabilities in Canada. Panel presentation given at the 6<sup>th</sup> Conference of the International Society for Child Indicators (ISCI) entitled 'Children in a World of Opportunities: Innovations in Research, Policy and Practice' in Montreal, Quebec on June 29, 2017

Sentenac M., **Lach L.**, Garipey G. Elgar F. Social inequalities in educational trajectories of children with neurodisabilities in Canada. Annual Conference of ALTER- European Society of Disability Research. Lausanne, 6-7 July 2017.

Sentenac M., **Lach L.**, Garipey G. Elgar F. Educational trajectories of children with neurodisabilities in Canada. 6<sup>th</sup> Conference of the International Society of Child Indicators (ISCI). Montreal, 28-30 June 2017.

Bogossian, A., **Lach, L.**, Nicholas, D., & McNeill, T. (2017). Connecting: The parenting experiences of fathers of children with neurodisabilities. Scientific poster presentation at the 71<sup>st</sup> annual

meeting of the American Academy of Cerebral Palsy and Developmental Medicine, September 13-16, 2017, Montreal, QC.

Nicholas, D., **Lach, L.**, Bogossian, A., & Rosenbaum, P. (2017). The biopsychosocial context of parenting children with neurodevelopmental disorders in Canada. Oral presentation at the 6<sup>th</sup> Conference of the International Society for Child Indicators, June 28-30, 2017, Montreal, QC.

Gariepy, G., Rothwell, D., & **Lach, L.** (2017). Does having a child with a neurodevelopmental disorder impact the trajectory of economic hardship of families? Oral presentation at the Society for Social Work Research Conference, January 13, 2017, New Orleans, Louisiana.

Ketelaar, M., Bogossian, A., Saini, M., Visser-Meily, A., & **Lach, L.** (2016). Why and how to assess family in the context of practice and research. Oral presentation at the joint meeting of the 5<sup>th</sup> International Conference of Cerebral Palsy, 28<sup>th</sup> Annual Meeting of the European Academy of Childhood Disability and the 1<sup>st</sup> Biennial Meeting of the International Alliance of Academies of Childhood Disability, June 1 – 4, 2016 Stockholm, Sweden.

**Lach, L.**, Bogossian, A., Quirke, S., Nicholas, D. Improving the lives of children with neurodisabilities: Does parenting matter? Oral presentation at ISPCAN International Congress on Child Abuse and Neglect, August 28 – 30, 2016 Calgary, Canada

**Lach, L.**, Bailey, S., Bogossian, A, Panel entitled Artifacts of Catalysts? Moving doctoral dissertations from the shelf to the practice community. (2015) Presentation 1: Disseminating Doctoral Dissertations: State of Affairs in Canada. Presented during the 2015 National CASWE-ACFTS Conference, June 1 – 4, 2015, University of Ottawa, ON, Canada.

**Lach, L.M.**, Ritzema, A., Bailey, S., Bogossian, A., MacCulloch, R., Glidden, G. Kohen, D., & Rosenbaum, R. (2014). The CIHR Team in Parenting Matters! Canadian Family Advisory Network (CFAN) Annual Symposium. Canadian Association of Pediatric Health Centres Annual Conference, October 19, 2014. Calgary, Alberta.

**Lach, L.M.**, Bogossian, A., Bailey, S., Nicholas, D., Kohen, D., & Rosenbaum, P. (2014). Oral Building a model to address the role of parenting in the lives of children with neurodevelopmental disorders (NDD): Does overprotectiveness matter? Paper presented at the 68<sup>th</sup> Annual Meeting of the American Academy of Cerebral Palsy and Developmental Medicine, September 10-14, 2014, San Diego, California.

Bogossian, A., Rothwell, D., **Lach, L.**, Bailey, S., Nicholas, D., Kohen, D., & Rosenbaum, P. (2014). Financial stress among parents of children with neurodevelopmental disabilities in Canada: The role of 'complexity'. Poster presentation at the 68<sup>th</sup> Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine, September 10 – 14, 2014, San Diego, California.

**Lach, L.M.**, Rothwell, D., & Blumenthal, A. (2014). Scoping review of doctoral scholarship in Canada: Implications for the discipline. Poster presentation at the Society for Social Work

Research Conference, January 15-19, 2014, San Antonio, Texas. January 17, 2014. Poster presentation at the Congress for Humanities and Social Sciences, May 25-29, 2014. St. Catharines, Ontario. May 29, 2014.

Kohen, D.E., Arim, R.G., Guevremont, A., Brehaut, J.C., Miller, A.R., McGrail, K., Brownell, M., **Lach, L.M.**, & Rosenbaum, P. (2013). Implementing the children with special health care needs (CHSCN) screener using Canadian administrative health data. Poster presentation at the Canadian Association of Paediatric Health Centres conference, October 20 – 23, 2013. Toronto, Ontario. October 21, 2013.

Arim, R., Guevremont, A., Kohen, D.E., Brehaut, J.C., Miller, A.R., McGrail, K., Brownell, M., **Lach, L.M.**, & Rosenbaum, P. (2013). The implementation of case-mix system approach to categorizing child health using Canadian administrative health data. Poster presentation at the Canadian Association of Paediatric Health Centres conference, October 20 – 23, 2013. Toronto, Ontario. October 21, 2013.

Bogossian, A., **Lach, L.M.**, & Saini, M. Measures of fathering children with neurodevelopmental disorders: What is known and what is missing? Poster presentation during the Pediatric Scientist Development Program (PSDP) Annual Meeting, February 28 – March 1, 2013 at the Hyatt Regency Atlanta, Atlanta, GA

**Lach, L.M.**, Garner, R., Arim, R., Kohen, D., & Rosenbaum, P. Rates of separation/divorce of children with neurodevelopmental disorders: Results from a Canadian longitudinal population-based study (2012). Paper presented at the American Academy of Cerebral Palsy and Developmental Medicine 66<sup>th</sup> Annual Meeting. Toronto, Ontario. September 14, 2012.

Shikako-Thomas, K., Majnemer, A., **Lach, L.M.**, Shevell, M., Law, M., Schmitz, N., & Poulin, C. (2012). Personal and environmental factors associated with participation in leisure activities in adolescents with Cerebral Palsy. Poster presented at the American Academy of Cerebral Palsy and Developmental Medicine 66<sup>th</sup> Annual Meeting. Toronto, Ontario. September 15, 2012.

Bogossian, A., Bailey, S., MacCulloch, R., Cimino, T., Saini, M., **Lach, L.M.**, & Rosenbaum, P. (2012). Distilling the data: Development of a method for data extraction within a systematic review of observational studies. Poster presented at the American Academy of Cerebral Palsy and Developmental Medicine 66<sup>th</sup> Annual Meeting. Toronto, Ontario. September 15, 2012.

MacCulloch, R., Glidden, G., Birnbaum, R., **Lach, L.M.**, & Rosenbaum, P. (2012). Exploring the tension between written and enacted policy: Provincial legislation, policies and programs that affect Canadian parents of children with a neurodevelopmental disorder. Poster presented at the NeuroDevNet 2012 Brain Development Conference, September 22, 2012, Toronto, Ontario.

MacCulloch, R., Glidden, G., Birnbaum, R., **Lach, L.M.**, & Rosenbaum, P. (2012). Exploring the tension between written and enacted policy: Provincial legislation, policies and programs that

affect Canadian parents of children with a neurodevelopmental disorder. Poster presented at the 18th Qualitative Health Research Conference, October 23, 2012, Montreal, QC.

Bogossian, A., **Lach, L.**, Nicholas, D., McNeill, T., Saini, M. (2012). Integrating qualitative research on the experience of fathers of children with neurodevelopmental disorders. Poster presented at the 18th Qualitative Health Research Conference, October 25, 2012, Montreal, QC.

Arim, R.G., Kohen, D.E., Garner, R., & **Lach, L.M.** (2012). Whether and when children with complex health problems experience parental separation: An application of survival analysis to developmental research. Poster presented at the Society for Research in Child Development Themed Meeting– Positive Development of Minority Children: Developmental Methodology Meeting. Tampa, Florida. February 10, 2012.

Nicholas, D.B., Zwaigenbaum, M., Clarke, M., Roberts, W., Magill-Evans, J., Saini, M., **Lach, L.**, MacCulloch, R., Ing, S., Barrett, D., & Spoelstra, M. (2011). Stage I of a synthesis review of interventional outcomes for Autism: Systematic descriptive mapping. Poster presented at the International Meeting for Autism Research (IMFAR). San Diego, California. May 12, 2011.

Arim, R.G., Kohen, D.E., Garner, R.E., **Lach, L.M.**, MacKenzie, M.J., Brehaut, J.C., & Rosenbaum, P.R. (2011). Longitudinal associations between parenting behaviours and child psychosocial outcomes for children with complex health conditions. Poster presented at the Society for Research in Child Development conference. Montreal, Quebec. April 2, 2011.

**Lach, L.M.**, Saini, M., Bailey, S., Bogossian, A., Cimino, T., Gionfriddo, K., & Nimigon-Young, J. (2010). Systematic review methods for observational studies: Challenges and solutions. Poster session presented at the Joint Colloquium of the Cochrane & Campbell Collaborations Meeting. Keystone Colorado. October 18-22, 2010.

Arim, R. G., Garner, R. E., Kohen D. E., **Lach, L.M.**, Brehaut, J.C., MacKenzie, M., & Rosenbaum, P. L. (2010). Differences in parenting behaviors for children with and without neurodevelopmental disabilities and behavior problems. Poster presented at the Canadian Congenital Anomalies Surveillance Network (CCASN) 8th Annual Scientific Meeting: Environmental & Nutritional Vulnerability for Congenital Anomalies. Ottawa, Ontario. November, 2010.

**Lach, L.M.**, Kohen, D., Rosenbaum P., Arim, R., et al. (2010). Parents of children with chronic health conditions and disabilities: A multi-method approach to studying health and parenting. Presented at Oxford-Brookes University, Oxford, UK (May 18, 2010); Trinity College University of Dublin (May 21, 2010); and at the European Academy of Childhood Disability conference in Brussels, Belgium (May 26-29, 2010). Also presented at the Congress of Humanities and Social Sciences conference. Montreal, Quebec. June 1, 2010.

Shikako-Thomas, K., **Lach, L.**, Majnemer, A., Nimigon, J., Cameron, K., & Shevell, M. Engagement in preferred occupations promotes well-being in adolescents with CP. (2010). Presentation at

the Canadian Association of Occupational Therapists National Conference. Halifax, Nova Scotia. May 26-29, 2010.

Nicholas, D., Koller, D., Bruce-Barrett, C., Matlow, A., Zlotnik-Shaul, R., & **Lach, L.** Pandemic planning for paediatric care. Platform presentation at the Canadian Association of Paediatric Health Centres conference. Edmonton, Alberta. October, 2008.

Shikako-Thomas, K., Majnemer, A., **Lach, L.**, Cameron, K., Nimigon, J., & Shevell, M. (2008). Quality of life in adolescents with Cerebral Palsy – A qualitative study. Poster presentation at the American Academy of Cerebral Palsy and Developmental Medicine. Atlanta, Georgia. September 19, 2008.

**Lach, L.M.**, Elliott, I.M., Smith, M.L., Whiting, S., Olds, J., McCleary, L., Lowe, A., & Snyder, T. (2004). Long term social outcomes of paediatric epilepsy surgery: The Role of seizure control and measures. Platform presentation given at the American Epilepsy Society conference. New Orleans, Louisiana. December 6, 2004.

A 30 Year Review of Paediatric Literature Addressing Psychosocial Adaptation to Chronic Illness: Results of a Meta-Analysis and Meta-Synthesis. Platform presentation given with Dr. David Nicholas and Dr. Beverley Antle at the 4<sup>th</sup> International Conference on Social Work in Health and Mental Health. Quebec City, Quebec. May 26, 2004.

Social Inclusion? Experiences of Students with Chronic Health Conditions or Disabilities and their Peers. Platform presentation given with Dr. Beverley Antle at the 4<sup>th</sup> International Conference on Social Work in Health and Mental Health. Quebec City, Quebec. May 26, 2004.

What Really Makes a Difference? 30 Years of Research on How Children and Families Adapt to Chronic Health Conditions and Disabilities. Poster presentation with Dr. Beverley Antle, Dr. J. Globerman, Ms. Laura Beaune and Dr. T. McNeill at the 4<sup>th</sup> International Conference on Social Work in Health and Mental Health. Quebec City, Quebec. May 26, 2004.

Children and Adolescents With Intractable Epilepsy: How Do These Youth View Their Quality of Life (QOL)? Elliott, I.M., Lach, L.M., & Smith, M.L. Platform presentation given at the 9<sup>th</sup> International Paediatric Nursing Research Symposium. Montreal, Quebec. April 12, 2002.

Does Life For Children and Families Change After Epilepsy Surgery? Lach, L.M., Smith, M.L., & Elliott, I.M. Platform presentation given at the American Epilepsy Society Conference. Philadelphia, PA. December 5, 2001.

I Just Want To Be Normal: Quality of Life (QOL) In Children With Intractable Epilepsy. Elliott, I.M., Lach, L.M., & Smith, M.L. Presentation given at the Canadian Association of Neuroscience Nurses National Conference, June 13, 2001.

On Becoming A Successful Qualitative Researcher: Integrity, Perseverance...and Then There is Reality. Alaggia, R., Lach, L.M., & Tsang, T. Presentation given at the Qualitative Analysis Conference, McMaster University. May 17, 2001.

Baseline Findings From a Prospective Study of Children Undergoing Epilepsy Surgery - The Gap Between Quantitative and Qualitative Findings: Do Measures Measure Up? Lach, L.M., Elliott, I.M., & Smith, M.L. Platform presentation given at the American Epilepsy Society Conference, Los Angeles, CA, December 4-8, 2000.

Reasoning, Remembering, and Academics in Children With Epilepsy: Does Surgery Make a Difference? Smith, M.L., Lach, L.M., & Elliott, I. Platform presentation given at the American Epilepsy Society Conference, Los Angeles, CA, December 4-8, 2000.

Paddling Upstream: Issues, Opportunities, and Pitfalls in Patient and Family-Focused Care Redesign. Association For The Care of Children's Health Conference. Washington, D.C. May 27, 1997.

Empowerment of Families in a Paediatric Health Care Setting. Lach, L.M., Elliott, I.M. Association For The Care Of Children's Health (ACCH) Conference. Toronto, Ontario. May 1994.

### **Invited Speaker**

Neurodevelopmental Disabilities Resources and Navigation Initiative: Building National Capacity. Invited presentation given to Fetal Alcohol Spectrum Disorders group at Policywise in Calgary, AB. February 21, 2019.

Thinking Critically and Pragmatically About Practice with Parents of Children with Neurodisabilities: Research as a Bridge? Presentation given at Sunny Hill Children's Health Centre, Vancouver, BC. July 12, 2018.

Parent Well-Being, Positive Parenting, and Mindfulness. Presentation given at the Implementing Early Detection and Intervention in CP Conference (in collaboration with Courtney Rice). Columbus Ohio. April 6-7 2018.

KBHN-CB November 6, 2017.

### **CPNet**

Community Engagement: Setting an Agenda for ASD Research. 2<sup>nd</sup> Biennial Winter Institute, Banff Alberta, March 6-9, 2013.

Mothering and Children with Epilepsy: Tensions and Rewards. Presentation at the Hospital For Sick Children, June 22, 2011.



Health, psychosocial function, and parenting of caregivers of children with neurodevelopmental disorders: Results from the NLSCY . Presentation at Department of Pediatrics Grand Rounds, Montreal Children's Hospital, February 23, 2011.

Caring to Caregiving: Parents of Children with Neurodevelopmental Disorders. Homecoming lecture, School of Social Work, McGill University. October 13, 2011.

Families of children with chronic health conditions and disabilities: Operationalizing family-centred care. School of Occupational and Physical Therapy, McGill University. April 7, 2010.

Parenting children with neurodevelopmental disorders: Overview of a program of research and preliminary findings. Centre for Research on Children and Families, McGill University. March 10, 2010. Centre de recherche interdisciplinaire en réadaptation du Montréal. November 16, 2010.

Turning clinical issues into qualitative research questions. Department of Paediatrics Clinical Research Retreat, Faculty of Medicine, McGill University. Brome, QC, September 26 & 27, 2009.

Theoretical frameworks to guide assessment of quality of life and health-related quality of life. Quality of Life in Childhood Onset Chronic Conditions and Disorders. Niagara-on-the-Lake, Ontario, May 3-5, 2009. Quality of Life in Childhood Onset Chronic Conditions and Disorders Health and Psychosocial Functioning of Caregivers of Children with Neurodevelopmental Disorders: Results from the NLSCY. Paper presented at the following:  
Clinical Research Rounds, Montreal Children's Hospital, Montreal, QC. March 2, 2007.  
Research Seminar, Centre for Research on Children and Families, McGill University, Montreal, QC. April 18, 2007.  
Quality of Life Conference, Novartis Foundation. London, UK. May 9, 2007.

Mentoring Students in Research Methodologies that go "Against the Grain" of Conventional Health Research. Panel presentation at the McGill Qualitative Health Research Group (MQHRG) Spring Conference entitled Ensuring Quality in Qualitative Health Research, Montreal, Quebec. April 5, 2007.

Moving the Profession Forward: False Dichotomies and the Future of Social Work in Canada. Keynote Address, Social Work Week, Ottawa, Ontario. March 8, 2007.

Children with Chronic Health Conditions and Their Families: What are the Pressing Research Questions? Child Development Research Group Inaugural Conference, MUHC and Montreal Children's Hospital, April 20, 2005.

A 30-Year Review of Paediatric Literature Addressing Psychosocial Adjustment to Chronic Health Conditions : Preliminary Findings from a Meta-Analysis and Meta-Synthesis. First Annual McGill Psychosocial Oncology Research Day, March 11, 2005.

The Status of Psychosocial Research in Canada: The Case of Epilepsy. Presentation given at the Canadian Epilepsy Research Initiative Meeting, Montreal, May 20, 2004.

Families of Children and Adolescents with Epilepsy: What Matters? Presentation given at the Family: Building, Bridging, and Becoming conference sponsored by St. Amant Centre, Winnipeg, Manitoba. October 8, 2004.

Multi-Systemic Therapy. Presentation given at the Argyle Family Institute, March 31, 2004.

Does Life Improve After Epilepsy Surgery? Presentation given to the School of Occupational and Physical Therapy, McGill University Research Seminar Series, November 18, 2002; Presentation given at the Montreal Children's Hospital, Rehabilitation Department Lecture Series, November 19, 2002.

Social Sciences and Epilepsy. Presentation given at the Canadian League Against Epilepsy – Canadian Epilepsy Research Initiative Meeting. Vancouver, B.C. June 17, 2002.

Behaviour, Affect and Cognition in Children Diagnosed With Epilepsy: The Complex Interaction of Biologic and Social factors. Presentation given to the Department of Child Psychiatry, Institute for Child and Family, Jewish General Hospital. Montreal, Quebec. January 31, 2002.

Psychosocial and Quality of Life Issues in Epilepsy. Presentation given at the Canadian Epilepsy Consortium Meeting, Montreal, Quebec. September 29, 2001

Neuropsychological and psychosocial adjustment of children and adolescents with intractable epilepsy: A multimethod approach. Lach, L.M., Elliott, I.M., & Smith, M.L. Presented at:  
Neurology Grand Rounds, Hospital For Sick Children, November 15, 2000  
Bloorview Epilepsy Research Program Grand Rounds, Toronto, July 27, 2000  
Research Institute Grand Rounds, Children's Hospital of Eastern Ontario, Ottawa, June 30, 2000.

Quality of Life of Children With Intractable Epilepsy. Presented to Bloorview Parent Support Group, Bloorview Children's Hospital, May 15, 2000.

Psychosocial Outcome of Epilepsy Surgery: Preliminary Findings. Snead, O.C., Lach, L.M., & Elliott, I. Research rounds at the Bloorview MacMillan Centre, April 4, 2000.

Quality of life after paediatric epilepsy surgery: A multidimensional, multi-method study - baseline and preliminary year 1 findings. Grand Rounds, Bloorview MacMillan Centre Research Group. January 18, 2000.

### **Other Presentations**

**Lach, L.M.**, McGrath, P. Thomson, D., & Turner, K. Strongest Families™ Neurodevelopmental: Parent Involvement in Modifying an Online Parenting Program for Children with Neurodisabilities and Challenging Behaviour. Poster presented at Canadian Association for Pediatric Health Centres Conference, October 21-23, 2018.

**Lach, L.M.** Quality of Life as an Outcome in Children and Youth with Epilepsy. Presentation given to NeuroDevNet trainees on February 16, 2016.

Rosenbaum, P., **Lach, L.M.**, Kohen, D., & Arim, R. Parenting children with neurodevelopmental disorders: What do we know & what are the opportunities? Canadian Association of Paediatric Health Centres webinar, <http://ken.caphc.org/xwiki/bin/view/ChildDevelopmentRehab/Parenting+Matters%21+Part+1+-+Parenting+Children+with+Neurodevelopmental+Disabilities%3A+What+Do+We+Know%2C%2%A0and+What+are+the+Opportunities%3F>, on February 28, 2012.

Doing Mixed Methods Research: Epistemology, Methodology, and Method. Presentation given to doctoral students at the School of Social Work, McGill University. April 28, 2011.

Mentoring Students in Research Methodologies that go “Against the Grain” of Conventional Health Research. Panel presentation at the McGill Qualitative Health Research Group (MQHRG) Spring Conference entitled Ensuring Quality in Qualitative Health Research, Montreal, Quebec. April 5, 2007.

The Case of Case Management: Case Management in the Context of Chronic Care. Presentation given to Spina Bifida Continuum on May 8, 2006.

Transition from Adolescence to Young Adulthood: Youth With Disabilities. Presentation given to Physical and Occupational Therapy graduate class on March 28, 2006.

The Case of Case Management: Case Management in the Context of Chronic Care. Presentation given to Stroke Network on December 14, 2005.

Social Outcomes and Experiences from Childhood to Young Adulthood: The Case of Intractable Epilepsy. Presentation given at the Constance-Lethbridge Rehabilitation Centre, Member of the Centre for Research in Interdisciplinary Rehabilitation (CRIR). June 7, 2005.

Children With Chronic Health Conditions and Disabilities: An Overview of Current Research Trends. Presentation given at the Child Development Research Group Meeting, April 20, 2005.

Families of Youth with Epilepsy: Practice to Research and Research to Practice. Presentation given in Psychiatry Grand Rounds, Montreal Children’s Hospital, April 7, 2005.

Epilepsy in Childhood: Impact on Cognition, Affect/Behaviour and Social Development. Elliott, I., Lach, L., & Smith, M.L. Presentation given at Paediatric Update 2001, Department of Pediatrics, Faculty of Medicine, University of Toronto. May 2-5, 2001.

Does Life Change For Children and Families After Epilepsy Surgery? Lach, L.M. Elliott, I.M. Neurology Subspecialty Rounds, University of Toronto. April 10, 2001.

A Family Centred Approach To The Assessment and Treatment of Children With Intractable Epilepsy. Deutsch, J., Weiss, S., Lach, L.M., & Elliott, I.M. Presented at the 4<sup>th</sup> Annual Child and Adolescent Psychiatry Update, HSC. November 4, 2000.

Nature and Nurture Issues Surrounding Epilepsy in Children and Youth. Lach, L.M. & Elliott, I.M. Presented to parents and professionals at Epilepsy Mississauga on April 13, 2000 and to professionals at Thistletown Regional Centre in Toronto on May 25, 2000.

Baseline Findings From a Prospective Study of Children Undergoing Epilepsy Surgery: Quantitative and Qualitative Results. Presented at social work rounds, Department of Social Work, Hospital For Sick Children, April 10, 2000.

Psychosocial Adjustment of Children with Epilepsy, Lach, L.M., & Elliott, I. Presentation given at Epilepsy Mississauga, March, 28, 2000.

## **CLINICAL APPOINTMENTS**

May 1988 -

Aug. 2001 DIVISION OF NEUROLOGY, Hospital For Sick Children

- assessment and treatment of children with neurological disorders and their families
- crisis, adjustment and supportive counselling regarding developmental, behavioural and illness-related issues experienced by children diagnosed epilepsy, children undergoing epilepsy surgery, and their families
- individual, couple, family and group psycho-educational modalities of treatment
- consultation to schools regarding classroom management issues
- member of an interdisciplinary team
- supervise and teach M.S.W. students
- conduct clinical research related to psychosocial outcomes and quality of life in this population

Febr. 1990 -

Dec. 1997 PRIVATE PRACTICE

- part-time private practice
- counselling individuals, couples and families regarding relationship difficulties, loss and bereavement, parenting, school and career problems, adoption issues, anxiety and depression

Febr. 1994 -

May 1996 KINARK CHILD AND FAMILY SERVICES (Newmarket)

- part-time contract position
- provided brief therapy intervention to clients on waiting list for family therapy

May 1986 -

May 1988 CYSTIC FIBROSIS SERVICE, Hospital For Sick Children

- assessment and treatment of children and families
- counselling individuals, couples and families regarding issues related to living with a chronic terminal illness
- clinical issues included loss and bereavement, behaviour problems, school problems, eating disorders and parent/child interaction
- adolescent support group
- member of a multidisciplinary team

January 1985 -

May 1986 MEDICAL OUTPATIENT SERVICE, Hospital For Sick Children (MSW Placement)

- assessment and treatment of individuals, families and group at medical or psychosocial risk

January 1985 -

May 1986 NEPHROLOGY SERVICE, Hospital For Sick Children (MSW Placement)

- assessment and treatment of children who were undergoing life sustaining dialysis treatment or kidney transplants
- established a peer support network for parents of children with nephrotic syndrome
- group for adolescents

## **SUMMARY of AWARDS RECEIVED**

Li Ka Shing Fellowship, Faculty of Arts, McGill University. May 2019.

Montreal Children's Hospital Research Institute. Rising Researcher Award. February, 2004.

American Epilepsy Society Young Investigator's Award, American Epilepsy Society Conference, Philadelphia, PA. December, 2001.

Hospital For Sick Children, Research Institute, Research Training Competition Graduate Award (RESTRACOMP)

1999-2000 - \$35,000; 2000-2001 - \$35,000

University of Toronto Fellowship Award  
1996-1997 - \$10,000; 1995-1996 - \$10,000

## REVIEWS

Canadian Institutes for Health Research, invited member of Social and Developmental Aspects of Children's & Youth's Health Committee, *Grant Reviewer, May and November 2005, May 2006, November 2010, May 2013, September 2013, May 2014, May 2015, May 2016 (Virtual Chair),*

*May 2017, December 2019, June 2021, November 2021 – Scientific Officer, Child Health Committee*

Social Sciences and Humanities Research Council, *Invited Grant Reviewer*

Brain Canada, *Grant Reviewer*

Canada Research Chair

Canadian Kidney Foundation, *Grant Reviewer*

Hospital For Sick Children Foundation, *Grant Reviewer*

Montreal Children's Hospital Research Institute, *Grant Reviewer*

Montreal University Health Centre (MUHC) Research Institute, *Grant Reviewer*

MITACS, *Grant Reviewer*

Canadian Social Work Journal, *Reviewer for journal*

Child Care Health and Development, *Reviewer for journal*

Child and Youth Services Review, *Reviewer for journal*

Developmental Medicine and Child Neurology, *Reviewer for journal*

Development and Psychopathology, *Reviewer for journal*

Disability & Rehabilitation, *Reviewer for journal*

Epilepsia, *Reviewer for journal*

Epilepsy and Behaviour, *Reviewer for journal*

Human Development, Disability and Social Change, *Editorial Board, 2008-present*

Journal of Abnormal Child Psychology, *Reviewer for journal*

Journal of American Medical Association (JAMA), *Reviewer for journal*

Paediatric Research, *Reviewer for journal*

Psychiatric Research, *Reviewer for journal*

Physical & Occupational Therapy in Pediatrics, *Editorial Board, 2007-2017*

Research for Social Work Practice, *Editorial Board, 2015-2019*

Royal Canadian Society, *Reviewer for journal*

## PROFESSIONAL AFFILIATION

Réseau Provincial de Recherche en Adaptation-Réadaptation (REPAR). Full Research Member. 2006-2012.

Canadian Epilepsy Research Initiative – International League Against Epilepsy (CERI-ILAE). 2002-2012

Centre de Recherche Interdisciplinaire en Réadaptation du Montréal Métropolitain (CRIR). Full Research Member of Research Domain 3 (Social Participation and Health Care Delivery). 2004-present.

Centre for Research on Children and Families (CRCF). Full member. 2006-present.

Ontario Association for Professional Social Workers, 1988-2001

Ontario College of Social Workers, 1988-2001

### **OTHER SERVICE**

Integrated University Health and Social Service Centre (CIUSSS- Centre-Ouest Montreal. Board Member; Chair of Vigilance and Quality Committee. November 2015-present.

Centre Miriam, Montreal, QC. Board of Governors, Member. 2014-present.

Dans La Rue, Montreal, QC. Board of Directors, Member. 2016-present.

Yaldei Child Development Centre, Montreal, QC. Member of the Medical Advisory Board. 2004, 2015

Canadian Association of Schools of Social Work. Board of Accreditation member. 2004-2008.

Canadian Association for Social Work Education (CASWE). Governance Task Force. 2010 – 2011.