



# Childhood Disability from the standpoint of Indigenous families: Understanding early childhood education, care and intervention across nations

Kathryn Underwood and Renee Sanderson, March 22-24, 2019, 8th International Meeting on Indigenous Child Health (IMICH)

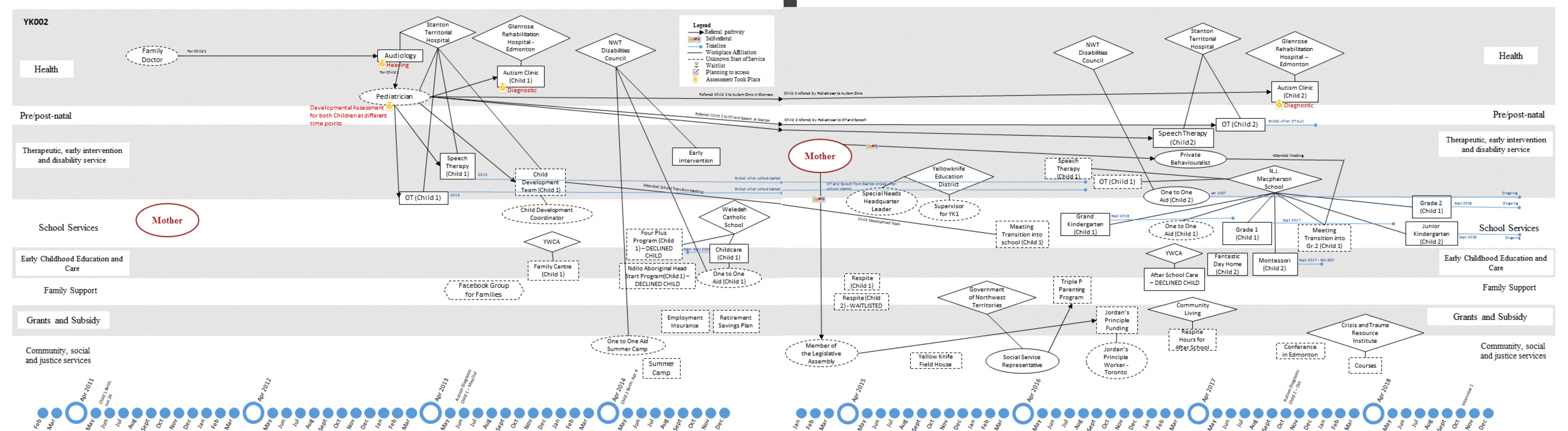
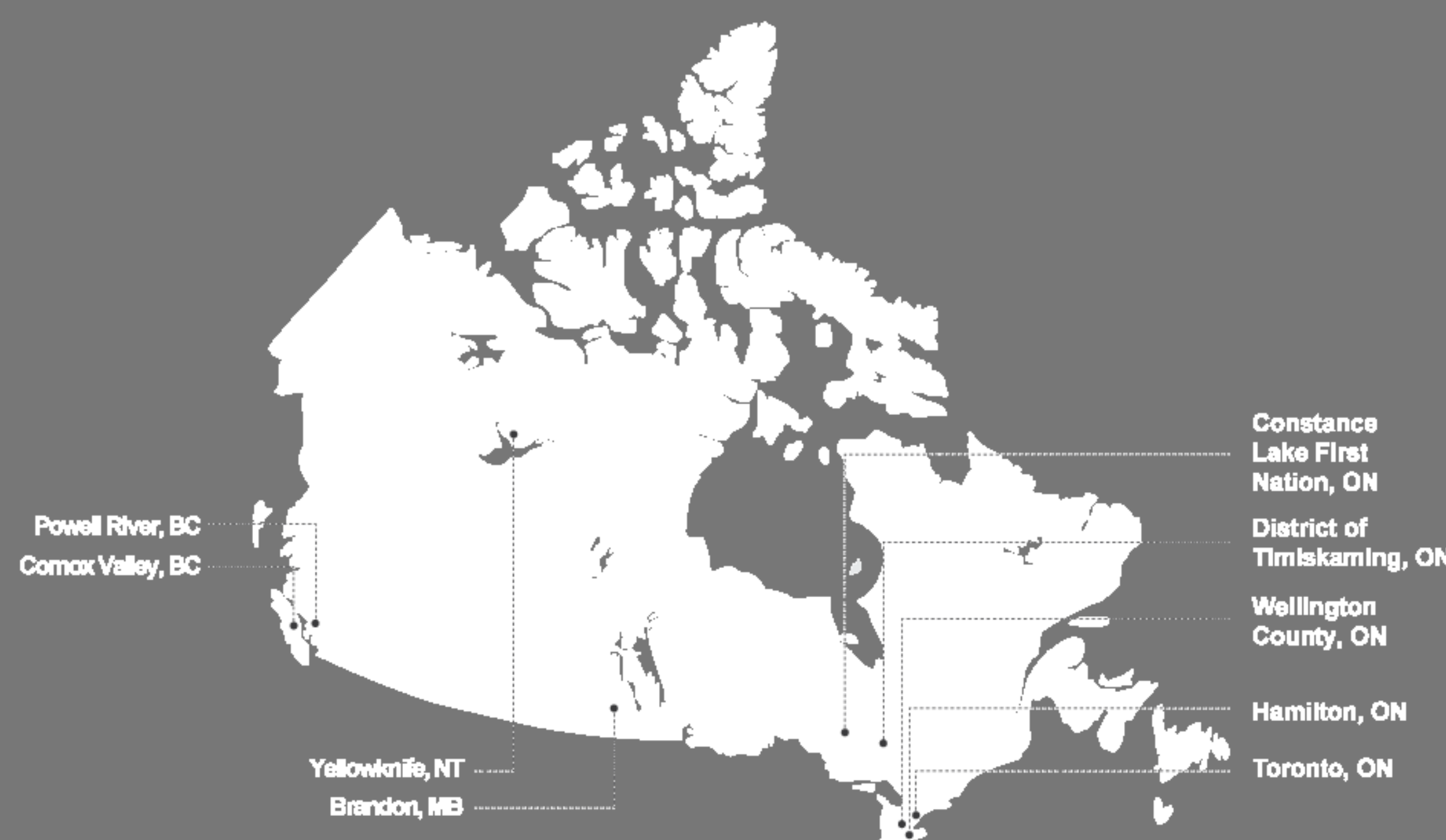
## Introduction

The Inclusive Early Childhood Service System (IECSS) is a 7-year partnership that seeks to understand the institutional interactions of families who have young children with disabilities. The study begins with the premise that understanding families' earliest experiences with early childhood services helps us as a society to understand the construction of some children as disabled. Through annual interviews with families over a 6-year period our ultimate goal is to inform social policy, and theoretical understanding of childhood disability from the perspective of families, and to create a more complex discourse on early childhood disability that is grounded in recognition of the value of diverse childhoods.

Wisdom Keepers from the District of Temiskaming have guided the work of the "Inclusive Early Childhood Service System Project: a longitudinal study of familial viewpoints of early childhood disability services" from the outset. Their decision was influenced by several factors, chief among them being the care and concern they have for their children and grandchildren with disabilities who often experience marginalization and exclusion in accessing services. The focus of this 7-year study on hearing directly from Indigenous parents and other caregivers regarding their experiences in accessing services for their children was key to their decision. The Wisdom Keepers recognized the early years of childhood as a critical time of rapid development predictive of many social and developmental outcomes later in life. They concluded that the examination of how institutional differences in the early years affect Indigenous children with disabilities where the rates are almost double that of the general population was essential to the health and welfare of children.<sup>3</sup>

Is this experience different for Indigenous children and families?

How do colonial borders and relationships impact this experience?



## Method

Our key methodological approach in this research is Institutional Ethnography (IE). The intention of IE is to understand institutional cultures and practices from the standpoint of families. Institutional ethnography is concerned with how "ruling relations" shape everyday lives. Ruling relations are the administrative, managerial, professional, and discursive organization of the regulations, and the governing structures of a society (Smith, 2006 and 2009).

## Research Questions:

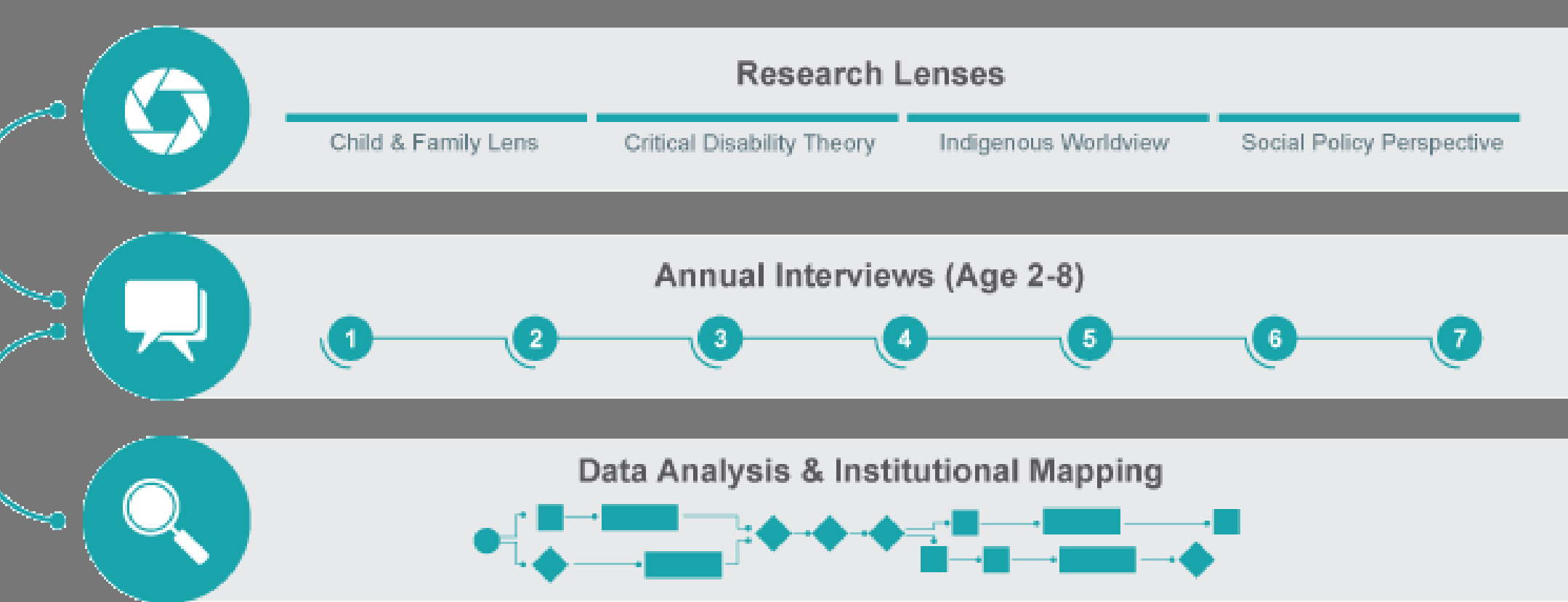
- 1. How do the institutions work/hold power?**  
The system works because families and mothers work. The institutions have processes that families and frontline workers must comply with in order to gain and maintain access.
- 2. What processes lead to action in the system?**  
The early intervention system operates on a medical model that is deeply entrenched
- 3. What do families contribute to the system?**  
The more services a family has, the more the system needs from them (time, money, energy, relationships, etc.).

## Findings<sup>6</sup>:

- In order to improve **access and inclusion** in early childhood education, care, family support and intervention services, there needs to be better funding for and understanding of **Indigenous specific experiences of childhood disability** in both mainstream services, and Indigenous services.
- Indigenous-led **family support** is a critical service within early childhood education care and intervention if it is to be consistent with First Nation, Inuit and Metis cultural practices.
- Recognition of the role that institutions play in **defining disability**, helps us to see the power that institutions hold in the daily lives of children with disabilities and their families
- Differences in children are part of the **gifts** that they hold and they give to their community. Indigenous culture is at the centre of any understanding of Indigenous childhood and family experience.
- Ongoing research on specific disability experiences should integrate clinical studies with **cultural knowledge** of Indigenous specific experiences of childhood disability. While some literature discusses specific childhood disabilities in Indigenous communities, this literature is largely focused on prenatal and environmental causes of disability, with little research on the cultural construct of disability or Indigenous childhoods in Indigenous communities, and the **colonial relationship** to early childhood education, care, family support and intervention services.

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## Mapping

Social relations are illuminated through research. Institutional mapping examines the ideology behind the institution, and the processes that are in place to do the work of the institution. Our aim is to provide empirical evidence of the ideology, the processes, and the social relations (Graheme, 1998) through documenting the work of families as they interact with early intervention and education. Fundamental to the approach is mapping the actual activities of the institution (Campbell & Gregor, 2008).