Parenting Children with Neurodevelopmental Disorders: Overview of a Program of Research and Preliminary Findings

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Center for Research on Children and Families
Objectives

- Find out what Aline, Gina, Sacha, Traci, Heather and Kristin have been doing besides decorating their office???

- Gain an understanding of:
  - what constitutes an emerging team
  - the structure of each project
  - the status of each project
Rationale for the Research

Where did this project come from?
- Media portrayals – villain to victim
- Clinical observation
  - Assumptions about parenting
- Previous studies
  - Social science literature – empowered advocates vs. Enmeshed and overprotective caregivers
  - Hunt and peck method of literature reviews
  - Focus on specific diagnoses
- Motor, cognitive, behavioural, and/or language functioning are affected by central nervous system impairments, resulting in a variety of challenges associated with ambulation, information processing, self-regulation and communication.
- Results of NLSCY analysis (Lach et al., 2009)
Main Research Questions:

Does parenting children with NDD differ from parenting children without NDD?
Main Research Questions:

What makes a difference to how parents parent their child with NDD?
Main Research Questions:

What difference does parenting make to child outcomes?
4 Projects

- Systematic Review
- Policy Analysis
- Population-Based Survey: NLSCY
- Clinical Project
The Team

- **Principal Investigators:**
  - Peter Rosenbaum; McMaster University
  - Lucyna Lach; McGill University
  - Dafna Kohen; Statistics Canada, Université d’Ottawa

- **Team Leaders:**
  - Rachel Birnbaum; King’s University College, UWO
  - Rochelle Garner; Statistics Canada, Université d’Ottawa
  - David Nicholas; University of Calgary
  - Michael Saini; University of Toronto

- **Team Members:**
  - Jamie Brehaut; Ottawa Hospital Research Institute, Université d’Ottawa
  - Delphine Collin-Vezina; McGill University
  - Michael MacKenzie; Columbia University
  - Ted McNeill; Hospital For Sick Children Research Institute, U of T
  - Alison Niccols; McMaster University
The Team

- **Parents and Advocates:**
  - Frank Gavin; Co-Chair, Canadian Family Advisory Network
  - Sue Robins; Member, Canadian Family Advisory Network
  - Joanne Ganton; President, Calgary Cerebral Palsy Association

- **Young Adults:**
  - Lindsay Yeo; Member, Canadian Family Advisory Network

- **Institutional/Clinical Leaders:**
  - Elaine Orrbine; Canadian Association of Paediatric Health Centres
  - Diane Calce; Marie Enfant Rehabilitation Centre of CHUM Ste. Justine

- **Policy Makers**
  - Nancy Reynolds; President, Alberta Centre For Child, Family, and Community Research
  - Linda Burnside; Executive Director, Disability Programs, Ministry of Family Services and Housing Government of Manitoba
The Team

■ Students:
  ■ Rubab Arim, PhD; Statistics Canada and OHRI
  ■ Sacha Bailey, MSW, McGill University
  ■ Aline Bogossian, BSW, McGill University
  ■ Kristin Gionfriddo, BSW, McGill University
  ■ Heather Mah, BSW, McGill University
  ■ Riel Dupuis-Rossi, BSW, McGill University
  ■ Stephanie Chippeur, BA, University of Western Ontario
  ■ Japneet Kaur, Faculty of Arts student, McGill University

■ Research Assistants:
  ■ Traci Cimino, MSW, McGill University
  ■ Gina Glidden, BSW, McGill University
  ■ Kate Mechan, MSW, McGill University
What is a Systematic Review?

- A way of representing what is known about a particular topic
- Typically conducted with intervention studies following an established protocol
- Observational studies of parenting of children with NDD
- Anti-thesis to ‘cherry-picking’ method
- Using systematic and explicit methods to identify, select and critically appraise relevant primary research
- Synthesizing quantitative and qualitative studies
Parenting Matters! Systematic Review

- Description of the research on parenting
- Does parenting differ between parents of children with NDD and parents of children without NDD and by how much?
- What is it about the child, the family, and the social environment that parenting is related to and how strong are those relationships?
- What child health outcomes does parenting predict?
Project Map

Parenting Matters Project Summary

Initial Screening Stage
- 10466 Abstracts Generated
- 214 Duplicates Removed
- 6218 Abstracts Excluded
  Kappa = 0.68 Non Adjusted = 0.74

NDD Qualitative
- 1075 Abstracts

CHCD Qualitative
- 810 Abstracts

4034 Passed

Initial 2nd Screening Stage
- 494 Abstracts Excluded
- 494 Abstracts Quarantined (duplicates, inaccurate references, & published before 1985)
  Kappa = 0.80 Non Adjusted = 0.81

Total = 3046 Passed

1851 Passed

1886 Passed

CHCD and “CHCD & NDD” Quant. Strict Screening Stage
- 1371 Abstracts Excluded
- 62 Unable to Locate
  Kappa = 0.81 Non Adjusted = 0.86

418 + 75 Passed

CHCD Handsearch
- 75 Included

CHCD Data Extraction
- 493 Included

NDD Quant Strict Screening Stage
- 1302 Abstracts Excluded
- 114 Unable to Locate
  Kappa = 0.72 Non Adjusted = 0.77

516 + 44 Passed

NDD Handsearch
- 44 included

“CHCD & NDD”
- 891 Reviewed
- 185 Duplicates Passed

540 Parenting Measures Included
- 300 Measures Located
- 55 Measures Excluded
- 45 Measures Unable to Locate

NDD Data Extraction
- 560 Included

Version 03/04/10
Why develop a model of parenting?
- Needed to be able to group measures together for analysis
- Wanted to conceptually unpack what is meant by ‘parenting’
- Inductive process going from measure/subscale to concept

Parental Bonding Instrument (Measure)
- Parent-Child Relationship (Concept)
- Over-protection and lack of care (Subscales)
  - Redefinition: Parenting Enacted

COPE (Measure)
- Coping (Concept)
- Parent coping style (Variable)
  - Redefinition: Disability Related – Parenting Enacted
Working Model of Parenting
Where Are We Now?

- Data Extraction Phase
  - Developing software for data extraction
  - What is data extraction?
  - Why are we doing it?

- Meta-Synthesis of Qualitative Studies
  - Still in the planning phase
What are the federal/provincial/territorial and regional policies, programs and services related to:
- income support,
- case management
- respite care for children with NDD.

Where are we now?
- We have collected information on legislation, and programs
  - We have validated this information
  - We plan to develop a website
- We have developed a database of case law
- We plan to do key informant interview with policy makers and institutional leaders in 3 provinces
National Longitudinal Survey of Children and Youth (NLSCY)

- Long-term study of the physical and social development of Canadian children from birth into early adulthood.
- Began in 1994, and is repeated biennially
- Nearly 23,000 children ages 0 through 11 were interviewed in Cycle 1 (1994/95)
- Children in institutions and northern territories were excluded
- Person most knowledgeable (PMK) of the child provided information about the child as well as about himself/herself, and his/her spouse/partner
  ✓ In 90% of cases, the PMK was child’s biological mother
Data Source and Participants

- **Participants**
  - Four groups of children and their caregivers

<table>
<thead>
<tr>
<th>Externalizing Behaviour Problems</th>
<th>Neurodevelopmental Disorders (NDD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Neither</td>
</tr>
<tr>
<td></td>
<td>NDD Only</td>
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<tr>
<td></td>
<td>BP Only</td>
</tr>
<tr>
<td></td>
<td>Both</td>
</tr>
</tbody>
</table>

- \( N = 14,226 \) children between the ages of 4-11 (Cycle 1)
- This sample is representative of Canadian *children* and not Canadian caregivers
Measures

- **Child Health and Well-Being**
  - Identifying the presence of a NDD:
    - ✓ A checklist of chronic conditions diagnosed by a physician (epilepsy, cerebral palsy, mental handicap, learning disability)
    - OR -
    - ✓ Health Utilities (speech, mobility, dexterity, cognition)

- Identifying the presence of a BP:
  - ✓ PMK-reported child behaviour rating scale; items mostly derived from the Child Behaviour Checklist
  - ✓ High scores on at least one of: hyperactivity-inattention (8 items), conduct disorder-physical aggression (6 items), indirect aggression (5 items)
## Categorization of Child Health

| Externalizing Behaviour Problems | No | Ne...
Measures

- **Parenting Behaviours**
  - Three scales used:
    - Positive interaction (5 items, scale 0 to 20)
      - Higher score = More positive interactions
    - Consistent parenting (5 items, scale 0 to 20)
      - Higher score = More consistent parenting
    - Hostile/ineffective parenting (7 items, scale 0 to 28)
      - Higher score = More hostile/ineffective parenting
  
- Items based on the Parenting Practices Scale (Strayhorn & Weidman, 1988)

- Parenting behaviour is specific to child; siblings in same family can be parented differently
Measures: Sample Parenting Items

- Positive interaction
  - “How often do you and <child> talk or play with each other, focusing attention on each other for five minutes or more, just for fun?”

- Consistent parenting
  - “When you give <child> a command or order to do something, what proportion of the time do you make sure that he/she does it?”

- Hostile/ineffective parenting
  - “How often do you get angry when you punish <child>?”
RQ1: Does parenting differ for children with and without NDDs and/or externalizing behaviour problems?

- Pair-wise comparisons were performed to examine differences in parenting among our 4 groups of children.
RQ1: Parenting Behaviours

- Positive interactions
  - NDD only
  - BP only
  - Both
- Consistent parenting
  - NDD only
  - BP only
  - Both
- Hostile/ineffective parenting
  - NDD only
  - BP only
  - Both

Scale score:
- NDD only = BP only = Both
- NDD only < Neither
- BP only < Neither
- Both < Neither

All groups different from each other.
RQ2: How are social, family, parent, and child factors associated with parenting behaviours? Does their impact differ for children with a NDD and/or behaviour problems?

- Regression analyses were performed to examine these relationships.
## RQ2 Results: Child Factors

<table>
<thead>
<tr>
<th></th>
<th>Positive</th>
<th>Consistent</th>
<th>Hostile</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child health</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neither</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>NDD Only</td>
<td>ns</td>
<td>ns (+)</td>
<td>+</td>
</tr>
<tr>
<td>BP Only</td>
<td>-</td>
<td>-</td>
<td>+</td>
</tr>
<tr>
<td>Both</td>
<td>ns</td>
<td>-</td>
<td>+</td>
</tr>
<tr>
<td><strong>Child’s age</strong></td>
<td>-</td>
<td>+</td>
<td>-</td>
</tr>
<tr>
<td><strong>Child is boy</strong></td>
<td>ns</td>
<td>ns</td>
<td>+</td>
</tr>
<tr>
<td><strong>Birth order</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Only child</td>
<td>+</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Firstborn</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>Not firstborn</td>
<td>-</td>
<td>ns</td>
<td>-</td>
</tr>
</tbody>
</table>
## RQ2 Results: Parent Factors

<table>
<thead>
<tr>
<th></th>
<th>Positive</th>
<th>Consistent</th>
<th>Hostile</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PMK age</strong></td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td><strong>PMK is male</strong></td>
<td>ns</td>
<td>ns</td>
<td>-</td>
</tr>
<tr>
<td><strong>PMK is not biological parent of child</strong></td>
<td>ns</td>
<td>+</td>
<td>-</td>
</tr>
<tr>
<td><strong>PMK educational attainment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than secondary</td>
<td>ns</td>
<td>-</td>
<td>ns</td>
</tr>
<tr>
<td>Secondary grad.</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>Beyond high school</td>
<td>ns</td>
<td>+</td>
<td>ns</td>
</tr>
<tr>
<td>College or university degree</td>
<td>+</td>
<td>+</td>
<td>ns</td>
</tr>
</tbody>
</table>
### RQ2 Results: Parent Factors

<table>
<thead>
<tr>
<th>PMK marital status</th>
<th>Positive</th>
<th>Consistent</th>
<th>Hostile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single, never married</td>
<td>ns</td>
<td>ns</td>
<td>+</td>
</tr>
<tr>
<td>Married, incl. common-law</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>Divorced, separated, widowed</td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Depressive symptoms</th>
<th>-</th>
<th>-</th>
<th>+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presence of activity limitation</td>
<td>+</td>
<td>+</td>
<td>-</td>
</tr>
<tr>
<td>Social support</td>
<td>+</td>
<td>ns</td>
<td>+</td>
</tr>
</tbody>
</table>
## RQ2 Results: Family Factors

<table>
<thead>
<tr>
<th>Household income relative to low-income cut-off (LICO)</th>
<th>Positive</th>
<th>Consistent</th>
<th>Hostile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less then or equal to 1.0 (living in low-income)</td>
<td><em>ns</em></td>
<td><em>ns</em></td>
<td><em>ns</em></td>
</tr>
<tr>
<td>Greater than 1.0, less than 2.0</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>Equal to or greater than 2.0 (living in high income)</td>
<td><em>ns</em></td>
<td>+</td>
<td><em>ns</em></td>
</tr>
<tr>
<td><strong>Family dysfunction</strong></td>
<td><strong>-</strong></td>
<td><strong>-</strong></td>
<td><strong>+</strong></td>
</tr>
</tbody>
</table>
RQ2 Results: Social Factors

<table>
<thead>
<tr>
<th>Help with personal problems received from:</th>
<th>Positive</th>
<th>Consistent</th>
<th>Hostile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community or social service professionals</td>
<td>$ns$</td>
<td>$ns$</td>
<td>$ns$</td>
</tr>
<tr>
<td>Health professionals</td>
<td>$ns$</td>
<td>$ns$</td>
<td>$ns$</td>
</tr>
<tr>
<td>Religious or spiritual leaders/communities</td>
<td>$ns$</td>
<td>$+$</td>
<td>$ns$</td>
</tr>
<tr>
<td>Books or magazines</td>
<td>$ns$</td>
<td>$ns$</td>
<td>$+$</td>
</tr>
</tbody>
</table>
Other questions we’d like to examine

- Trajectories (long-term patterns) of parenting, family function, marital satisfaction, and parents’ perceptions of social support
  - Are these patterns same/different for families with children with NDDs and/or behaviour problems?

- Testing conventional wisdom: Are parents of kids with significant health problems more likely to divorce than parents of healthy kids?
Multi-Method Clinical Study

- What social, family and child factors do mothers and fathers believe influence how they experience parenting/how they parent?
  - What social, family and child factors are associated with parenting of children with NDD? To what extent do these factors predict parenting?

- What aspects of parenting do mothers and fathers/parents believe make a difference in how well their child is doing on a day-to-day basis?
  - What is the relationship between parenting and child outcomes?
Multi-Method Clinical Study

- How do mothers and fathers, alone and together, experience parenting a child with a NDD?

- What are the resource needs of parents of children with NDD?
Multi-Method Clinical Study

- Selecting measures
- Consulting with the group about measures and interview questions
- What kinds of interview questions
# Multi-Method Clinical Study

## Needs and Supports in Fostering Child Outcomes

<table>
<thead>
<tr>
<th>Child Factors</th>
<th>Family Environment</th>
<th>Child Outcomes</th>
<th>Social Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Diagnostic factors: time since dx; type of dx</td>
<td>• Resources and Supports: Support and Services Questionnaire (NDD needs and services)*</td>
<td>• Mastery (Dimensions of Mastery Questionnaire) – 45 items</td>
<td>• Neighborhood Questionnaire (FastTrack) (neighborhood safety, social involvement, public involvement, engagement)</td>
</tr>
<tr>
<td>• Behavior and Functioning Behavior Problems: Strengths &amp; Difficulties Questionnaire ([SDQ]) – pro-social behavior, emotional problems, peer support, conduct hyperactivity* - 20 items</td>
<td>• Family Function: Family Assessment Devise (problem solving, communication, interaction, roles and responsiveness, support and mutuality) - 12-item*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Child Functioning – ABAS-II – need 6-15 year old version*</td>
<td>• Impact of Disability: Family Impact of Child Disability* - 20 items</td>
<td>• Mastery (Dimensions of Mastery Questionnaire) – 45 items</td>
<td></td>
</tr>
<tr>
<td>• Ask for clinical reports from parent</td>
<td></td>
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</tr>
</tbody>
</table>

## Child Outcomes
- Mastery (Dimensions of Mastery Questionnaire) – 45 items
- Integration/Participation (CAPE) – 55 items

## Parenting (Experienced, Enacted)
- Parenting as enacted: NLSCY Nurturing Subscale, Consistent Parenting Subscale, Positive Interaction Subscale, Ineffective Parenting Subscale – 5 items each
- Parent Protection Scale (protectiveness behaviors)
- Vicarious Futurity Scale (parenting as experienced)
- Parenting Morale Index (parenting as experienced – disability-related)

## Parent Factors
- Physical and Mental Health -SF-12*

## Family Environment
- Resources and Supports: Support and Services Questionnaire (NDD needs and services)*
- Family Function: Family Assessment Devise (problem solving, communication, interaction, roles and responsiveness, support and mutuality) - 12-item*
- Impact of Disability: Family Impact of Child Disability* - 20 items

## Social Environment
- Neighborhood Questionnaire (FastTrack) (neighborhood safety, social involvement, public involvement, engagement)
- Parent and Teacher Involvement Questionnaire – teacher form (do we need a consent form for teachers?) – does completing this imply consent?

## Demographics
- Child age; gender
- Parent age; gender; ethnicity
- Marital status; Family Constellation; # siblings (with and without NDD)
- Asset to liability ratio
- Parent education

## Couple Factors
- Relational Synchrony: Dyadic Adjustment Scale (relationship satisfaction)
- Parenting Synchrony: Parenting Alliance Measure (mutuality in parenting)*

## Child Factors
- Diagnostic factors: time since dx; type of dx
- Behavior and Functioning Behavior Problems: Strengths & Difficulties Questionnaire ([SDQ]) – pro-social behavior, emotional problems, peer support, conduct hyperactivity* - 20 items
- Child Functioning – ABAS-II – need 6-15 year old version*
- Ask for clinical reports from parent
Projected Implications

- **Policy**
  - Engagement of policy and institutional leaders in a process of reflection and action

- **Research**
  - Documenting the dissonance between policy and lived experience
  - Inequality in access to supports and services between mainstream and First Nations children with disabilities
  - Measurement development
  - Intervention studies
Projected Implications

Practice

- Differentiate between evidence-based knowledge and theoretical assumptions about parenting
- Know more about the extent to which parenting makes a difference to child well-being, which will inform assessment and intervention
- What kind of supports make a difference to how parents parent, which informs assessment and intervention
Thanks so much for your attentiveness and interest!