Exploring the tension between written and enacted policy: Provincial legislation, policies and programs that affect Canadian parents of children with a neurodevelopmental disorder

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Abstract
This study is part of a larger research project that sought to explore the experiences of parents of children and youth with a neurodevelopmental disorder (NDD) and examine how parent, child, social and environmental factors influence both parent and child well-being. This study was undertaken to situate findings from this larger study within the context of existing provincial legislation, policies, programs and resources currently available to Canadian parents of children and youth with a NDD. Findings highlight the push-pull involved in the work of policy makers and frontline program staff as they navigate tensions between written and enacted legislation, policy, and programs at different levels of jurisdiction. Interviews revealed diverse or unclear definitions of what constitutes a NDD; fragmented methods for monitoring the number of children with NDDs and the type, quality and quantity of services accessed within and across jurisdictions; discrepancies in funding allocation (urban vs. rural; on reserve vs. off reserve); and finally a diversity of service delivery models across provinces that reflect differing perceptions of the role of parents of children with a NDD.

Context
Children and youth with NDDs require a range of diverse services and supports as they grow and develop: from education to health to community and social services. In order for families to gain access to the care and supports they need for their child, they must maneuver within the various levels of service provision entities within their province. In Canada, the support policies and programs available to these families vary from province to province. This study aimed to explore the processes of policy and program development, implementation and evaluation as experienced by both policy makers and front-line program staff and implications of these for parents/caregivers of children with a NDD.

Research Questions
• What income support, respite and case management programs support children with neurodevelopmental disorders and their families?
• What processes are associated with the implementation of these programs across three Canadian provinces?
• What policies at relevant levels of jurisdiction, inform the delivery of these programs; how do they act as barriers/ facilitators to the implementation of these programs?

Methods
METHODOLOGICAL APPROACH
• Interpretive description was chosen based on its usefulness in exploring critical problems within an applied practice context (Thorne, 2008)
• Interpretive description seeks to inductively describe and begin to offer interpretive explanations of phenomena

RECRUITMENT & SAMPLE
• Three Canadian provinces were selected as sites of data collection
• A sample of 14 participants were purposively selected based on their experience working at either the ministerial level in program and policy development or in agencies or in centres providing direct service or program delivery

Data Collection
• Data was collected and analyzed from semi-structured telephone interviews with participants and from relevant federal and provincial government publications.
• Interview questions focused on income support, respite services and case management as well as the legislation and policies that affect provincial service provision

DATA ANALYSIS
• Evolving and iterative analytic process that moved from broad or open coding to the identification of tentative patterns and groupings and finally to the identification of significant relationships and contextual meaning.

Results

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<th>Key Themes</th>
<th>Description</th>
<th>Participant Quotes</th>
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<td>Silos of care &amp; 'exceptional cases'</td>
<td>• Participants identified that “silos of care” exist across ministerial and regional jurisdictions and impede system navigation • initiatives to enhance cross-ministerial information-sharing and collaboration emerge out of the need to meet the needs of ‘exceptional cases’</td>
<td>“Because our services are so spread… it is challenging for parents to know what is available and who to get it from … there are many different doors you can knock on…”</td>
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<td>Parent as Expert or Professional as Expert? A Continuum of Service Delivery Models</td>
<td>• There is a continuum of service delivery models that range from single point of entry, agency-based case management models to parent-driven case management models • A single model may not necessarily ‘fit’ the needs of all parents</td>
<td>“… it is a mish mash and … it depends how you define case management… in some cases, like when the parents find the right agency and goes to that agency there is a case manager.”</td>
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<td>Eligibility vs. Access to Services: Building Flexibility into Government-funded Services and Supports</td>
<td>• Universal access is expressed differently across regions as provinces rely on their flexibility and creativity to meet the unique needs of their communities • This flexibility has both significant benefits and drawbacks and highlights the need to capture and share both regional best practices and challenges</td>
<td>“The agencies would get the money and… decide how they want to spend it on their particular services…These agencies are around for a long time so… we certainly have financial accountability… I believe a fair amount of discretion about how you spend the money so they might put more money into… whatever they think is needed and have their own criteria.”</td>
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<td>The 'Inputs and Outputs' of Funding: What about Outcomes?</td>
<td>• Funding is determined by a basic input-output formula that does not acknowledge outcomes and does not require the reciprocal exchange of information between jurisdictions</td>
<td>“We collect outputs but very rarely do we collect outcomes.”</td>
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<td>On the Frontlines: The Push-Pull between Written &amp; Enacted Policy</td>
<td>• Participants described a clash between written policy and the everyday service delivery practices of those who work within health and social service agencies e.g. policies aimed at reducing wait times conflict with case management and continuity of care practices</td>
<td>“It seems all nice and good but it’s not always that easy ‘in the field’…”</td>
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<td>When Needs-based Services Compete with 'Sexy' Diagnoses</td>
<td>• Provinces generally adhered to a non-categorical approach to service delivery • However, certain diagnoses receive specialized funding for the development of diagnosis-specific programs</td>
<td>“Our government, a while ago, decided they were going to cure autism and they put together a very resourceful intensive program… very quickly there were long lines around the block … but in our total environment they are probably getting… a lot of the money that would go to kids in a general way.”</td>
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Conclusion
Opportunities need to be created for policy makers to share best practices across provincial boundaries

Acknowledgments
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