

Value for Who? Value-Based Healthcare for Children and Families



COMMENTARY

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ABSTRACT

If the goal of “value-based healthcare” (VBHC) is to promote health, the shift towards health promotion as fostering resilience of individuals through supportive systems and environments is grounded in the importance of providing value or outcomes that matter to all patients. VBHC puts patients at the centre of healthcare, but critical questions include which patients and what services? Here we explore the importance of life-course considerations of a resilience-based definition of health and consider the role of a broader horizontal and vertical system and individual level integration to attain VBHC for children and families.

Value for Who?

Youth health in Canada lags behind that of other industrialized nations. The UNICEF Innocenti Report Card ranks Canada at 25th out of 41 countries for children’s health and well-being (UNICEF 2018). Canada is falling short in tackling current threats (e.g., youth mental health, childhood obesity, youth suicide and substance use epidemics [Hollis

2018]) as well as future threats; improving child health improves adult outcomes. Given that well-being outcomes for children are best measured over the long term, current system level emphasis on short-term financial returns on investments in health is partly to blame (Wong et al. 2018). Attracting the attention of payers and policy makers to invest in innovative approaches for funding

for children’s healthcare has been difficult – the 2019 Federal Election saw Children’s Healthcare Canada focused on “getting kids back on the radar” (Children’s Healthcare Canada 2019). Canada’s 25th place ranking by UNICEF is in relation to sustainable development goals and rooted in inequity of income for Canadian children (measured via the impact of tax credits, transfers, benefits and service provided) (Phipps, 1999). This is despite strong evidence indicating the value of investing in programs and supports for early childhood services, particularly for disadvantaged children (Heckman and Masterov 2007).

Critical to this ranking is the reality that child health outcomes are influenced by programs outside the traditional health services delivery system in Canada. While universality is a major value underpinning healthcare, Canadian social policy remains a “patchwork” of social housing and family, disability, unemployment, welfare and early childhood benefits and services (Boychuk 1998). Though spending on social services does not equate directly to action upon the social determinants of health, it does represent non-health spending that should have an impact on health outcomes. Social policy in Canada can impact health in two complementary ways: by reducing poverty (e.g. welfare payments for families and disability supports) and reducing social inequalities (e.g. public education, subsidized university tuition, subsidized quality daycare, free and accessible medical care).

Work by Bradley and colleagues highlights that health outcomes are influenced by the total amount spent on both health and social programs (Bradley and Taylor 2013; Bradley et al. 2016; Bradley et al. 2011). Building on this work and a relatively long tradition of comparative public policy in Canada (Bennett 1996; Imbeau et al., 2000; Montpetit 2008), we examined whether

social to health spending ratios in Canadian provinces are correlated with population health measures (potentially avoidable mortality, infant mortality and life expectancy (Dutton et al. 2018). Our analysis posits that better health outcomes in Canada might not just be a result of spending on health services (the focus for most health spending analysis) or direct social assistance programs (the focus for Bradley and colleagues), but rather a result of an encompassing approach to the common welfare. Ultimately, findings from our analysis indicate that social to health spending ratios have a negative correlation with potentially avoidable mortality and a positive correlation with life expectancy, suggesting that population-level health outcomes could benefit from a reallocation of government dollars from health to social spending, even if total government spending were left unchanged (Dutton et al. 2018).

However, more costly adult health needs often eclipse child-specific needs. For youth aged one to 14, per-capita average spending on health was \$1,539 in 2016 in Canada; the equivalent for those aged 65 and older was \$11,301 (CIHI 2018). Social spending on younger generations under the age of 45 in Canada hasn’t kept up with economic growth. Canadian governments spend \$33,321 to \$40,152 per senior compared to \$10,406 to \$11,614 per person under age 45 (Kershaw and Anderson 2016). Isolating this estimate for children is impaired by the way Canadian provinces collect expenditure data.

Child-Specific Value Considerations

The move toward value-based payment for services presents a *critical* opportunity to consider the value of all services that impact health, particularly those in social services designed to improve children’s short- and long-term health and well-being outcomes (Wong et al. 2018). A value-based healthcare (VBHC) system requires a special focus on

quality and outcome measurement for child health programs; issues for children are not identical to those for adults. Specifically, the unique characteristics of child health are often referred to as the “four D’s”: development, dependency, different epidemiology and demographics (Beal et al. 2004). Guided by frameworks for evaluating quality care (Donabedian 2005), these characteristics must be reflected in child health delivery systems (AHRQ 2012). To achieve these, we need to recognize these systems span multiple ministries and start “measuring what matters”: cross-ministry service use.

At the systems level, linkage of provincial administrative data provides a more practical representation of the range of programs and public systems that assist children and families in achieving and maintaining better health. Understanding the interaction of service delivery across ministries (impacting the social determinants of health with domains such as economic security, housing, family stability, child development and education) is a critical step toward better understanding services and supports spanning health and social service sectors (Fischer et al. 2019). This data linkage ranges from being non-existent to under development across provinces and alignment of this data and linkage with federal tax measures is an important immediate direction. Harmonization of reporting of expenditure and service use data would strengthen the policy application (Kneebone and Wilkins 2016).

Integrating Child Health Delivery Systems

“The true measure of a nation’s standing is how well it attends to its children and youth, including their health, safety, material security, education and socialization and their sense of being

loved, valued and included in their families and societies ...” (UNICEF 2007)

For many children, adolescents and young adults (youth hereafter) in Canada, the UNICEF aspiration is not yet a reality. Access to services for youth and their families/caregivers, particularly during transition periods, is a critical gap across all Canadian provinces (Clark et al. 2009). Fragmentation of service delivery across the life course is a modifiable barrier to the achievement of the UNICEF goals. Limited service utilization negatively impacts family health and quality of life (Abbott et al. 2005; Canada 1998; Dutton et al., 2018).

The Life Course Health Development model conceptualizes an individual’s health capacity based on experiences with supports and services (Giele and Elder Jr 1998; Halfon and Hochstein 2002). Transitions are associated with changes in environment and service provision (e.g., changing schools or moving from pediatric to adult services), and often associated with changing social roles. Transitions across the life course may represent risks to health capacity, and multidisciplinary services and systems across education, social services and health services impact these transitions for children and families. For example, supportive interactions with healthcare, social and education services can help youth with developmental disability navigate transitions (Frisch and Msall 2013; Gorter et al. 2014; Halfon et al. 2014; Siddiqi et al. 2007). Not receiving an early developmental disability diagnosis impacts access to developmental support services across ministries, as services often require a diagnosis (Campbell et al. 2014; Heckman 2012; Russell et al. 2019). Resources allocated to early childhood are believed to have a greater impact across the lifespan than later support (Heckman 2012). Similarly,

youth that perceive less support from their school during school transitions report more depressive symptoms (Gillan and Coughlan 2010).

In Canada, youth are supported through multiple publicly funded ministerial areas, including: healthcare, social and education services, which results in tensions regarding funding accountability between ministries and between community- and hospital-based services (Simon 2011). Despite repeated emphasis on issues of fragmented access and long waits for many critical support services for youth and their families (such as youth mental health services as highlighted by both Romanow and Kirby reports) (CIHI 2015; Simon 2011), ministries still have different priorities, mandates and approaches, fragmented by inconsistent policies, distinct eligibility criteria and a lack of data on service use provided across the continuum of care (Kuo et al. 2011; Quigley et al. 2014; Wiart et al. 2010). For example, a parent of a child with a disability classified as medically complex or “severe” in the education system would need to be referred to multiple specialist clinics in the health system, apply for special education supports, apply for disability supports provincially and apply for the disability tax credit federally. Each program has different eligibility criteria and processes, often long wait lists and some require reapplication yearly (Cohen et al. 2011). Access to services is an issue. An estimated 20-30% of families who are eligible for programs are utilizing them often due to confusion, complexity, lack of awareness and out-of-pocket costs required (Dunn and Zwicker 2018; Russell et al. 2020).

VBHC must evolve to include a broad systems level approach that takes into account the vast literature pointing to critical periods, sensitive periods, social determinants and accumulations of risks and protective factors that health, education and social policy can impact (Pratt and Frost 2016). Policy

makers must “reach across traditional divides, define shared goals, align their strategies and – in essence – share control over their programs” (Adalsteinn et al. 2010). Inter-governmental (federal, provincial/territorial) and inter-ministry/sector collaboration on measurement, data sharing, funding and accountability is a required step to achieve the level of integration required across chronological interfaces of care (maternal, infant, child, adolescent) and acuity levels (health promotion, primary, tertiary care).

Operationalizing a life-course strategy at a provincial and federal level must move from theory to measurement of operationalizing, implementing and evaluating such a strategy. Core considerations must include equity, resource alignment, impact on intergenerational wellness and current scientific understanding of life-course health (Callahan et al. 2015). Practical steps for implementing a life-course approach could include: aligning with existing monitoring frameworks, leveraging commonly used measures and data collection methods (including linked administrative data) and promotion (and public funding) of longitudinal datasets to support health information producers and researchers in developing interdisciplinary longitudinal studies across the lifespan (Jacob et al. 2019). For example, UNICEF recently developed indices for use in Canada (UNICEF 2019). Alternatively, the LifeCourse Metrics Project in the US identified indicators for assessing the core features related to a life-course approach. These indicators were selected in part for the practicality of use in pre-existing data across states and are currently being adopted in multiple states to track health across the life course and inform policy decisions (Callahan et al. 2015). Canada is desperately lacking quality longitudinal data in children, with no longitudinal surveys focused on children active at Statistics Canada

(UNICEF 2019), emphasizing the need for indicators such as these for use in linked administrative data.

Patient and Family-Centred Multidisciplinary Care

“I understand that the system needs to focus on fiscal needs. But I wish they could look at the bigger picture. Their fiscal needs will be met ... by addressing parental mental health, by providing adequate child care, by understanding that the time and focus I need to care for my child takes away from my ability to achieve my potential.” (Parent of child with NDD and medical complexity)

For many families of children and youth, accessing community services is confusing and complex. Despite Canada’s commitment to supporting children and individuals with disabilities, through ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD) (Miller et al. 2013) and the UN Convention on the Rights of the Child (CRC) (Canadian Coalition for the Rights of Children 2019), the primary responsibility for coordination of the patchwork of children’s services lies with families (Zwicker et al. 2017). As a result, caregivers of youth disability or medical complexity face disparities such as higher financial costs and reduced work hours (Stabile and Allin 2012) (ranging from \$3,000 to \$25,000 additional costs per year) (CIHI 2015; Dudley and Emery 2014; Petrou et al. 2013), lower quality of life (Boyle et al. 1994; Lamsal et al. 2018; Lamsal and Zwicker 2017; Reichman et al. 2008) and higher rates of poverty compared to other caregivers (Zwicker et al. 2017). These families report challenges to accessing appropriate services, often resorting to higher cost acute care

services like emergency rooms to react to crises resulting in higher costs for the healthcare system (CAPHC Complex Care Community of Practice 2018; Havercamp and Scott 2015; Trollor 2014). An estimated two thirds of these visits are attributed to an inability to access services in the community, due to fragmentation of services and system deficiencies (CAPHC Complex Care Community of Practice 2018; Sacchetti et al. 2000; Slonim et al. 2003). Caregivers also contend with significantly higher levels of stress, feelings of isolation and frustration and physical and mental health issues (Brehaut et al. 2009; Hodgetts et al. 2013; Hodgetts et al. 2015; Miodrag and Hodapp 2010; Woodman et al. 2014) due to their lack of access to services (Green 2007).

Children depend on caregivers for much of their well-being and providers need to consider approaches that support the family unit. To achieve this, physicians and health system providers need to play a bigger role in our present system or coordinators can be brought on to fill this role. In our interviews with families across Canada, the role of supportive primary care providers or anyone else who could play a connecting or coordinating role (ranging from a social worker to an accountant) was one of the biggest factors in ability to access services across education, social and health sectors.

Care coordination has been demonstrated by synthesis level evidence to improve health and social outcomes, patient and staff satisfaction and improve health system savings for vulnerable “high system user” populations (Hong, Siegel, & Ferris, 2014; Hudon et al. 2016; Kumar and Klein 2013; Moe et al. 2017; Soril et al. 2015; Stokes et al. 2015) or populations with chronic conditions (Kastner et al. 2018; Reynolds et al. 2018; Sheinfeld Gorin et al. 2013). For youth, coordination must go beyond medical case management,

by including social and educational support services to optimize outcomes outlined in a patient-centred care plan, and emphasizing collaborative working relationships across service sectors (Burke and Alverson 2010; Kuo et al. 2018).

Development of appropriate processes to support this type of coordination and multidisciplinary value-based care is critical. Facilitators include team-based care principles such as the use of patient panels for each clinician, family partnerships and continuous quality improvement processes (McAllister et al. 2013; Wagner et al. 2014). A flexible adaptable care coordination system that can address the lived experience of children and families throughout developmental trajectories and across social determinants of health is another facilitator (Kuo and Houtrow 2016). Alternative payment models or bundled payment approaches independent of in-person patient encounters linked to patient panel size, quality metrics, shared savings or proactive health planning are promising directions.

Reforming payment approaches to be linked to quality metrics requires accurate predictions of cost and projected resource use (Farmer et al. 2016). Critical is the use of patient-reported outcome measures that are important to children and their families. Health-related quality of life instruments are often used to estimate the quality component of interventions, particularly for cost-utility approaches to evaluation (Drummond et al. 2015). Measures used in adult health often have not been validated among populations of children with chronic health conditions. For example, a scoping review of the use of preference-based health-related quality of life instruments in children with a developmental disability found a dearth of studies using these instruments (Lamsal et al. 2019). Generally, the quality of outcome data in this and other chronic health conditions in children is

lacking, and this should be considered before guiding policy and care decisions. Similarly, measurement of outcomes for caregivers (such as caregiver quality of life) and family impacts is critical in assessing quality.

Conclusion

Donabedian's "law of diminishing returns" of healthcare suggests that, after a tipping point, greater resource allocation leads to limited improvement in outcomes (Donabedian 1990). Finding this tipping point when using a resilience-based definition of health is the challenge for VBHC for children and families; presently, the Canadian average per capita spending on health services is three times more than on social spending (Dutton et al. 2018). This article argues that improving child and family health requires tackling the social determinants of health with the aim of providing "freedom to lead lives they have reason to value" (Marmot 2006a). Fundamentally, this shift requires a systems approach to policy – not just individual approaches to behaviours – highlighting the role of supportive systems, environments and policies in enabling health (Shilton et al. 2011). While this is true for all demographics, child-specific considerations lead to three core policy recommendations:

- 1) Measure what matters: Data are needed to understand the full scope of service delivery and utilization for children and families across ministries. Linkage of administrative data is an immediate and feasible step that allows governments to see how children and families access services across ministries, beyond the ministry of health. Political will remains one of the greatest barriers to immediate action in some provinces.

- 2) VBHC approaches must incorporate a life-course perspective, considering equity, resource alignment, impact on intergenerational wellness and current

scientific understanding of life-course health. Development and implementation of indicators of health using this life-course approach is an important practical step that can be done using existing data.

3) To increase VBHC for children and families, the systems level changes recommended must be integrated with patient-level coordination of services. This requires measuring quality of life outcomes that matter to children and families (including validated child measure and caregiver quality of life).

Marmot cautions us that failing to meet the fundamental human needs of autonomy, empowerment and human freedom is a potent cause of ill health (Marmot 2006b). If a nation is “measured” in the context of its support for children and youth (UNICEF 2007), Canada can do more to measure up.

References

- Abbott, D., R. Townsley and D. Watson. 2005. Multi-Agency Working in Services for Disabled Children: What Impact Does It Have on Professionals? *Health & Social Care in the Community* 13(2): 155–63. doi:10.1111/j.1365-2524.2005.00543.x.
- Adalsteinn, D., W. Katherine, K. Allen, U. Quach, E. Chiu and L. Bialystok. 2010. Turning the Social Determinants of Health to Our Advantage: Policy Fundamentals for a Better Approach to Children's Health. *Healthcare Quarterly* 14(Sp): 68–75. doi:10.12927/hcq.2010.21985.
- Agency for Healthcare Research and Quality (AHRQ). 2012. *Why Child Health Measures?* Retrieved December 15, 2019. <<https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/chtoolbx/why/index.html>>.
- Beal, A.C., J.P.T. Co, D. Dougherty, T. Jorsling, J. Kam and J. Perrin. 2004. Quality Measures for Children's Health Care. *Pediatrics* 113(1 Pt. 2): 199–209.
- Bennett, C. 1996. Comparative Policy Studies in Canada: What State? What Art. In L. Dobuzinskis, M. Howlett and D. Laycock (Ed.). *Policy Studies in Canada: The State of the Art* (pp. 299–316). Toronto, ON: University of Toronto Press.
- Boychuk, G.W. 1998. *Patchworks of Purpose: The Development of Provincial Social Assistance Regimes in Canada*. Montreal, QC: McGill-Queen's University Press.
- Boyle, C.A., P. Decoufle and M. Yeargin-Allsopp. 1994. Prevalence and Health Impact of Developmental Disabilities in US Children. *Pediatrics* 93(3): 399–403.
- Bradley, E.H., M. Canavan, E. Rogan, K. Talbert-Slagle, C.L. Ndumele, L. Taylor et al. 2016. Variation in Health Outcomes: The Role of Spending on Social Services, Public Health, and Health Care, 2000–09. *Health Aff (Millwood)* 35(5): 760–68. doi:10.1377/hlthaff.2015.0814.
- Bradley, E.H., B.R. Elkins, J. Herrin and B. Elbel. 2011. Health and Social Services Expenditures: Associations with Health Outcomes. *BMJ Qual Saf* 20(10): 826–31. doi:10.1136/bmjqs.2010.048363.
- Bradley, E. H. and L. Taylor. 2013. *The American Health Care Paradox: Why Spending More Is Getting Us Less*. New York, NY: PublicAffairs.
- Brehaut, J.C., D.E. Kohen, R.E. Garner, A.R. Miller, L.M. Lach, A.F. Klassen et al. 2009. Health Among Caregivers of Children with Health Problems: Findings From a Canadian Population-Based Study. *American Journal of Public Health* 99(7): 1254–1262. doi:10.2105/ajph.2007.129817.
- Burke, R.T. and B. Alverson. 2010. Impact of Children with Medically Complex Conditions. *Pediatrics* 126(4): 789–90. doi:10.1542/peds.2010-1885.
- Callahan, T., C. Stampfel, A. Cornell, H. Diop, D. Barnes-Josiah, D. Kane et al. 2015. From Theory to Measurement: Recommended State MCH Life Course Indicators. *Maternal and child health journal* 19(11): 2336–47. doi:10.1007/s10995-015-1767-1.
- Campbell, F., G. Conti, J.J. Heckman, S.H. Moon, R. Pinto, E. Pungello et al. 2014. Early Childhood Investments Substantially Boost Adult Health. *Science (New York, N.Y.)*, 343(6178), 1478–85. doi:10.1126/science.1248429.
- CAPHC Complex Care Community of Practice. 2018. *CAPHC Guideline for the Management of Medically Complex Children and Youth Through the Continuum of Care*. Retrieved Jan 3 2020. <https://ken.childrenshealthcarecanada.ca/xwiki/bin/download/Management+of+Medically+Complex+Children+and+Youth+Across+the+Continuum+of+Care/WebHome/CAPHC%20National%20Complex%20Care%20Guideline%202018_final.pdf>.

- Canadian Coalition for the Rights of Children. 2019. *Monitoring Canada and the UNCRC*. Retrieved December 20, 2019. <<http://rightsofchildren.ca/monitoring/>>.
- Canadian Institute of Health Information (CIHI). 2015, May. *Care for Children and Youth Mental Disorders*. Retrieved January 3, 2020. <https://secure.cihi.ca/free_products/CIHI%20CYMH%20Final%20for%20pubs_EN_web.pdf>.
- Canadian Institute of Health Information (CIHI). 2018. *National Health Expenditure Trends*. Retrieved December 15, 2019. <https://secure.cihi.ca/free_products/NHEX-trends-narrative-report-2018-en-web.pdf>.
- Children's Healthcare Canada. 2019. Election 2019: Getting Kids Back on the Radar. Retrieved January 3, 2020. <<https://ken.childrenshealthcarecanada.ca/xwiki/bin/view/CAPHC+Presents%21/Election+2019%3A+Getting+Kids+Back+on+the+Radar>>.
- Clark, D., M. Clark and K. Seel. 2009. *Disability Policy in Alberta: An Initial Exploration of Transition Implications*: Calgary, AB: Institute for Nonprofit Studies.
- Council of Canadians with Disabilities. 1998. In Unison: A Canadian Approach to Disability Issues. Retrieved November 19, 2019. <<http://www.ccdonline.ca/en/socialpolicy/poverty-citizenship/income-security-reform/in-unison.>>
- Cohen, E., D.Z. Kuo, R. Agrawal, J.G. Berry, S.K. Bhagat, T.D. Simon et al. 2011. Children with Medical Complexity: An Emerging Population for Clinical and Research Initiatives. *Pediatrics* 127(3): 529–38. doi: 10.1542/peds.2010-0910.
- Donabedian, A. 1990. The Seven Pillars of Quality. *Arch Pathol Lab Med* 114(11): 1115–18.
- Donabedian, A. 2005. Evaluating the Quality of Medical Care. 1966. *Milbank Q* 83(4): 691–29. doi:10.1111/j.1468-0009.2005.00397.x.
- Drummond, M.F., M.J. Sculpher, K. Claxton, G.L. Stoddart and G.W. Torrance. 2015. *Methods for the Economic Evaluation of Health Care Programmes*. Oxford, Oxford: Oxford University Press.
- Dudley, C. and J.C.H. Emery. 2014. The Value of Caregiver Time: Costs of Support and Care for Individuals Living with Autism Spectrum Disorder. *SPP Research Papers* 7(1). Retrieved December 15, 2019. <<https://www.policyschool.ca/wp-content/uploads/2016/01/Emery-Autism-Costs.pdf>>.
- Dunn, S. and J. Zwicker. 2018. Why Is Uptake of the Disability Tax Credit Low in Canada? Exploring Possible Barriers to Access. *SPP Research Papers* 11(2). Retrieved December 15 2019. <<https://www.policyschool.ca/wp-content/uploads/2018/01/Disability-Tax-Credit-Dunn-Zwicker.pdf>>.
- Dutton, D.J., P.G. Forest, R.D. Kneebone and J.D. Zwicker. 2018. Effect of Provincial Spending on Social Services and Health Care on Health Outcomes in Canada: An Observational Longitudinal Study. *Canadian Medical Association Journal* 190(3): E66–E71. doi:10.1503/cmaj.170132.
- Farmer, S.A., J. Shalowitz, M. George, F. McStay, K. Patel, J. Perrin et al. 2016. Fully Capitated Payment Breakeven Rate for a Mid-Size Pediatric Practice. *Pediatrics* 138(2): e20154367. doi:10.1542/peds.2015-4367.
- Fischer, R.L., F.G.C. Richter, E. Anthony, N. Lalich and C. Coulton. 2019. Leveraging Administrative Data to Better Serve Children and Families. *Public Administration Review* 79(5): 675–83. doi:10.1111/puar.13047.
- Frisch, D. and M.E. Msall. 2013. Health, Functioning, And Participation Of Adolescents And Adults With Cerebral Palsy: A Review Of Outcomes Research. *Dev Disabil Res Rev*. 18(1): 84–94. doi: 10.1002/ddrr.1131.
- Giele, J.Z. and G.H. Elder Jr. 1998. *Methods Of Life Course Research: Qualitative And Quantitative Approaches*. Thousand Oaks, CA: SAGE Publications, Inc.
- Gillan, D. and B. Coughlan. 2010. Transition From Special Education Into Postschool Services For Young Adults With Intellectual disability: Irish parents' experience. *Journal of Policy and Practice in Intellectual Disabilities* 7(3): 196–03. doi:10.1111/j.1741-1130.2010.00265.x.
- Gorter, J.W., D. Stewart, M.W. Smith, G. King, M. Wright, T. Nguyen et al. 2014. Pathways Toward Positive Psychosocial Outcomes And Mental Health For Youth With Disabilities: A Knowledge Synthesis Of Developmental Trajectories. *Canadian Journal of Community Mental Health* 33(1): 45–61. doi:10.7870/cjcmh-2014-005.
- Green, S.E. 2007. “We’re Tired, Not Sad”: Benefits and Burdens of Mothering a Child with a Disability. *Social Science and Medicine* 64(1): 150–63. doi:10.1016/j.socscimed.2006.08.025.

- Halfon, N. and M. Hochstein. 2002. Life Course Health Development: An Integrated Framework for Developing Health, Policy, and Research. *Milbank Q* 80(3): 433–79. doi: 10.1111/1468-0009.00019.
- Halfon, N., K. Larson, M. Lu, E. Tullis and S. Russ. 2014. Lifecourse Health Development: Past, Present and Future. *Maternal and Child Health Journal* 18(2): 344–65. doi: 10.1007/s10995-013-1346-2.
- Havercamp, S.M. and H.M. Scott. 2015. National Health Surveillance of Adults with Disabilities, Adults with Intellectual and Developmental Disabilities, and Adults with No Disabilities. *Disability and Health Journal* 8(2): 165–72. doi: 10.1016/j.dhjo.2014.11.002.
- Heckman, J. J. and D.V. Masterov. 2007. The Productivity Argument for Investing in Young Children. *Review of Agricultural Economics* 29(3): 446–93. Retrieved December 15, 2019. <http://jenni.uchicago.edu/human-inequality/papers/Heckman_final_all_wp_2007-03-22c_jsb.pdf>.
- Heckman, J.J. 2012. *Invest in Early Childhood Development: Reduce Deficits, Strengthen the Economy*. Retrieved December 15, 2019. <https://heckmanequation.org/www/assets/2013/07/F_HeckmanDeficitPieceCUSTOM-Generic_052714-3-1.pdf>.
- Hodgetts, S., D. Nicholas, L. Zwaigenbaum and D. McConnell. 2013. Parents' and Professionals' Perceptions of Family-Centered Care for Children with Autism Spectrum Disorder Across Service Sectors. *Social Science & Medicine* 96:138–46. doi: org/10.1016/j.socscimed.2013.07.012.
- Hodgetts, S., L. Zwaigenbaum and D. Nicholas. 2015. Profile and Predictors of Service Needs for Families of Children With Autism Spectrum Disorders. *Autism* 19(6): 673–83. doi: 10.1177/1362361314543531.
- Hollis, A. 2018. *Economic Commentary on Raising Canada: A Case for Investing in Children*. Retrieved December 20, 2019. <<https://static1.squarespace.com/static/5669d2da9cadb69fb2f8d32e/t/5b f3b1f34d7a9c87e11108cc/1542697461156/Raising+Canada+Eco+Report+-+AH+PRF.pdf>>.
- Hong, C.S., A.L. Siegel and T.G. Ferris. 2014. Caring for High-Need, High-Cost Patients: What Makes for a Successful Care Management Program? *Commonwealth Fund* pub. 1764 Vol. 19.
- Hudon, C., M.C. Chouinard, M. Lambert, I. Dufour and C. Krieg. 2016. Effectiveness of Case Management Interventions for Frequent Users of Healthcare Services: A Scoping Review. *BMJ Open* 6(9): e012353. doi:10.1136/bmjopen-2016-012353.
- Imbeau, L.M., R. Landry, H. Milner, F. Pétry, J. Crête, P.G. Forest et al. 2000. Comparative Provincial Policy Analysis: A Research Agenda. *Canadian Journal of Political Science/Revue canadienne de science politique* 33(04): 779–04. Retrieved March 2, 2020. <www.jstor.org/stable/3232663>.
- Jacob, C.M., C. Cooper, J. Baird and M. Hanson. 2019. *What Quantitative and Qualitative Methods Have Been Developed to Measure the Implementation of a Life-Course Approach in Public Health Policies at the National Level?* Health Evidence Network Synthesis Report 63. Copenhagen, DK: World Health Organization. Retrieved December 19, 2019. <http://www.euro.who.int/__data/assets/pdf_file/0003/394275/9789289053938-eng.pdf?ua=1>.
- Kastner, M., R. Cardoso, Y. Lai, V. Treister, J.S. Hamid, L. Hayden et al. 2018. Effectiveness of Interventions for Managing Multiple High-Burden Chronic Diseases in Older Adults: A Systematic Review and Meta-Analysis. *CMAJ* 190(34): E1004-E1012. doi:10.1503/cmaj.171391.
- Kershaw, P. and L. Anderson. 2016. Measuring the Age Distribution in Canadian Social Spending. *Canadian Public Administration* 59(4): 556–79. doi:10.1111/capa.12193.
- Kneebone, R. and M. Wilkins. 2016. Canadian Provincial Government Budget Data, 1980/81 to 2013/14. *Canadian Public Policy* 42(1): 1–19. doi: 10.3138/cpp.2015-046.
- Kumar, G.S. and R. Klein. 2013. Effectiveness of Case Management Strategies in Reducing Emergency Department Visits in Frequent User Patient Populations: A Systematic Review. *J Emerg Med* 44(3): 717–729. doi:10.1016/j.jemermed.2012.08.035.
- Kuo, D.Z., E. Cohen, R. Agrawal, J.G. Berry and P.H. Casey. 2011. A National Profile of Caregiver Challenges Among More Medically Complex Children with Special Health Care Needs. *Archives of pediatrics & adolescent medicine* 165(11): 1020–26. doi: 10.1001/archpediatrics.2011.172.
- Kuo, D.Z. and A.J. Houtrow. 2016. Recognition and Management of Medical Complexity. *Pediatrics* 138(6): e2016-3021. doi:10.1542/peds.2016-3021.
- Kuo, D.Z., J.W. McAllister, L. Rossignol, R.M. Turchi and C.J. Stille. 2018. Care Coordination for Children with Medical Complexity: Whose Care is it, Anyway? *Pediatrics* 141(Suppl 3): S224–s232. doi:10.1542/peds.2017-1284G.
- Lamsal, R. and J.D. Zwicker. 2017. Economic Evaluation of Interventions for Children with Neurodevelopmental Disorders: Opportunities and Challenges. *Appl Health Econ Health Policy* 15(6): 763–72. doi: 10.1007/s40258-017-0343-9.

- Lamsal, R., D.J. Dutton and J. Zwicker. 2018. Early Identification Of Neurodevelopmental Disorders Using the Ages and Stages Questionnaire (AQS-2). *BMC Pediatrics* 18(122). doi:10.1186/s12887-018-1105-z.
- Lamsal, R., B. Finlay, D.G.T. Whitehurst and J.D. Zwicker. 2019. Generic Preference-Based Health-Related Quality of Life in Children With Neurodevelopmental Disorders: A Scoping Review. *Dev Med Child Neurol* 62(2): 169-77. doi:10.1111/dmcn.14301.
- Marmot, M. 2006a. Health in an Unequal World. *The Lancet* 368(9552): 2081-094. doi.org/10.1016/S0140-6736(06)69746-8.
- Marmot, M. 2006b. Health in an Unequal World: Social Circumstances, Biology and Disease. *Clin Med (Lond)* 6(6): 559-72. doi:10.7861/clinmedicine.6-6-559.
- McAllister, J.W., W.C. Cooley, J. Van Cleave, A.A. Boudreau and K. Kuhlthau. 2013. Medical Home Transformation in Pediatric Primary Care – What Drives Change? *Ann Fam Med* 11(1). doi:10.1370/afm.1528.
- Miller, A.R., L.C. Mâsse, J. Shen, V. Schiariti and L. Roxborough. 2013. Diagnostic Status, Functional Status and Complexity Among Canadian Children with Neurodevelopmental Disorders and Disabilities: A Population-Based Study. *Disability and rehabilitation* 35(6): 468-78. doi: 10.3109/09638288.2012.699580
- Miodrag, N. and R.M. Hodapp. 2010. Chronic Stress and Health Among Parents of Children With Intellectual and Developmental Disabilities. *Current Opinion in Psychiatry* 23(5): 407-11. doi: 10.1097/YCO.0b013e32833a8796.
- Moe, J., S.W. Kirkland, E. Rawe, M.B. Ospina, B.Vandermeer, S. Campbell et al. 2017. Effectiveness of Interventions to Decrease Emergency Department Visits by Adult Frequent Users: A Systematic Review. *Acad Emerg Med* 24(1): 40-52. doi:10.1111/acem.13060.
- Montpetit, É. 2008. A Quantitative Analysis of the Comparative Turn in Canadian Political Science. L. White, R. Simeon, R. Vipond and J. Wallner (Ed.). *The Comparative Turn in Canadian Political Science* (pp. 17-40). Vancouver, BC: UBC Press.
- Petrou, S., S. Johnson, D. Wolke and N. Marlow. 2013. The Association Between Neurodevelopmental Disability and Economic Outcomes During Mid-Childhood. *Child: Care, Health and Development* 39(3): 345-57. doi:10.1111/j.1365-2214.2012.01368.x.
- Phipps, S. 1999. Economics and the Well-Being of Canadian Children. *The Canadian Journal of Economics / Revue canadienne d'économique* 32(5): 1135-63. doi:10.2307/136474.
- Pratt, B. and L. Frost. 2016, February 22. *The Life Course Approach to Health: A Rapid Review of the Literature* [White Paper]. World Health Organization. Retrieved December 15, 2019. <https://www.who.int/life-course/publications/life-course-approach-literature-review.pdf?ua=1>.
- Quigley, L., A. Lacombe-Duncan, S. Adams, C.M. Hepburn and E. Cohen, E. 2014. A Qualitative Analysis of Information Sharing for Children With Medical Complexity Within and Across Health Care Organizations. *BMC health services research* 14(1): 283. doi: 10.1186/1472-6963-14-283.
- Reichman, N.E., H. Corman and K. Noonan. 2008. Impact of Child Disability on the Family. *Maternal and Child Health Journal* 12(6): 679-83.
- Reynolds, R., S. Dennis, I. Hasan, J. Slewa, W. Chen, D. Tian et al. 2018. A Systematic Review of Chronic Disease Management Interventions in Primary Care. *BMC family practice* 19(1): 11. doi:10.1186/s12875-017-0692-3.
- Russell, M.J., S. Premji, S. McDonald, J.D. Zwicker and S. Tough. 2019, August 30. Health Care Service for Families with Children at Early Risk of Developmental Delay: An All Our Families Cohort Study. *Dev Med Child Neurol* 62(1). doi:10.1111/dmcn.14343.
- Russell, M., Y. Zhang, X. Cui, S. Tough and J. D., Zwicker. 2020. Administrative Data Analysis of Family Disability Service Use Among Families with Young Children with Disabilities. *Dev Med Child Neurol*. doi:10.1111/dmcn.14478
- Sacchetti, A., C. Sacchetti, C. Carraccio and M. Gerardi. 2000. The Potential for Errors in Children with Special Health Care Needs. *Acad Emerg Med* 7(11): 1330-3. doi: 10.1111/j.1553-2712.2000.tb00484.
- Sheinfeld Gorin, S., D. Haggstrom, K. Fairfield, P. Han, P. Krebs and S.B. Clauser. 2013. Cancer Care Coordination Systematic Review and Meta-Analysis: Twenty-Two Years of Empirical Studies. *Journal of Clinical Oncology* 31(15): 6536. doi:10.1200/jco.2013.31.15_suppl.6536.
- Shilton, T., M. Sparks, D. McQueen, M.C. Lamarre and S. Jackson. 2011. Proposal for New Definition of Health. *BMJ* 343: d5359. doi:10.1136/bmj.d5359.

- Siddiqi, A., L. Irwin and C. Hertzman. 2007. Total Environment Assessment Model for Early Child Development: Evidence Report for the World Health Organization's Commission on the Social Determinants of Health. Human Early Learning Partnership (HELP). Retrieved December 15, 2019. <https://www.who.int/social_determinants/resources/ecd_kn_evidence_report_2007.pdf>.
- Simon, D. 2011, May. The State of Child and Youth Mental Health in Canada: Past Problems and Future Fantasies. *Healthcare Quarterly* 14(Special Issue 2): 8–13. doi:10.12927/hcq.2011.22358.
- Slonim, A.D., B.J. LaFleur, W. Ahmed and J.G. Joseph. 2003. Hospital-Reported Medical Errors in Children. *Pediatrics* 111(3): 617–21. doi:10.1542/peds.111.3.617.
- Soril, L.J., L.E. Leggett, D.L. Lorenzetti, T.W. Noseworthy and F.M. Clement. 2015. Reducing Frequent Visits to the Emergency Department: A Systematic Review of Interventions. *PloS One* 10(4): e0123660. doi:10.1371/journal.pone.0123660.
- Stabile, M. and S. Allin. 2012. The Economic Costs of Childhood Disability. *Future Child* 22(1): 65–96. doi: 10.1353/foc.2012.0008.
- Stokes, J., M. Panagioti, R. Alam, K. Checkland, S. Cheraghi-Sohi and P. Bower. 2015. Effectiveness of Case Management for 'At Risk' Patients in Primary Care: A Systematic Review and Meta-Analysis. *PloS One* 10(7): e0132340. doi:10.1371/journal.pone.0132340.
- Trollor, J. 2014. Making Mental Health Services Accessible to People with an Intellectual Disability. *Aust N Z J Psychiatry* 48(5): 395–98. doi: 10.1177/0004867414531628.
- UNICEF. 2007. *Child Poverty in Perspective: An Overview of Child Well-Being in Rich Countries*. Retrieved December 19, 2019. <<https://www.unicef-irc.org/publications/445-child-poverty-in-perspective-an-overview-of-child-well-being-in-rich-countries.html>>.
- UNICEF. 2018. *UNICEF Innocenti Report Card*. Retrieved December 15, 2019. <<https://www.unicef-irc.org/publications/995-an-unfair-start-education-inequality-children.html>>.
- UNICEF. 2019. *Where Does Canada Stand? The Canadian Index of Child and Youth Well-being, 2019 Baseline Report*. Retrieved December 15, 2019. <https://oneyouth.unicef.ca/sites/default/files/2019-08/2019_Baseline_Report_Canadian_Index_of_Child_and_Youth_Well-being.pdf>.
- Wagner, E.H., R. Gupta and K. Coleman. 2014. Practice Transformation in the Safety Net Medical Home Initiative: A Qualitative Look. *Med Care*, 52(11 Suppl 4): S18–22. doi:10.1097/mlr.0000000000000196.
- Wiart, L., J. Church, J. Darrach, L. Ray, J. Magill-Evans and J. Andersen. 2010. Cross-Ministerial Collaboration Related to Paediatric Rehabilitation for Children with Disabilities and Their Families in One Canadian Province. *Health & Social Care in the Community* 18(4): 378–88. doi: 10.1111/j.1365-2524.2009.00909.x.
- Wong, C.A., J.M. Perrin and M. McClellan. 2018. Making the Case for Value-Based Payment Reform in Children's Health Care. *JAMA Pediatrics* 172(6): 513–14. doi:10.1001/jamapediatrics.2018.0129.
- Woodman, A.C., H.P. Mawdsley and P. Hauser-Cram. 2014. Parenting Stress and Child Behavior Problems within Families of Children with Developmental Disabilities: Transactional Relations across 15 Years. *Research in developmental disabilities* 36: 264–76. doi:10.1016/j.ridd.2014.10.011.
- Zwicker, J., A. Zaresani and J.C.H. Emery. 2017. Describing Heterogeneity of Unmet Needs Among Adults with a Developmental Disability: An Examination of the 2012 Canadian Survey on Disability. *Research in Developmental Disabilities*. 65: 1–11. doi:10.1016/j.ridd.2017.04.003.

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