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Developing a Canadian framework for social determinants of health and well-being among children with neurodisabilities and their families: an ecosocial perspective

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ABSTRACT

Purpose: Social Determinants of Health is a conceptual framework typically used to understand patterns of health and ill-health at the population level. Its applicability to children and youth who already have a health condition, in this case, a neurodisability, is not well understood, particularly when the “health” component of that framework is extended to include more pluralistic notions of well-being. The purpose of this study was to address this challenge and to develop an ecosocial framework that is conceptually integrative and meaningful to children and youth with neurodisabilities and their families.

Methods: Drawing on a critical literature review, a conceptual analysis approach, and a secondary analysis of a compendium of 36 social determinants of health models, we critically analysed how these models map onto the context of childhood neurodisability and identified key conceptual and empirical challenges. The emerging framework was further validated through iterative stakeholder consultation with parents, self-advocates, researchers, practitioners, community leaders, and decision-makers.

Results: The review and consultation process generated The Canadian Framework for Social Determinants of Health and Well-being among Children with Neurodisabilities and their Families. This new framework consists of two hemispheres encompassing explanatory (or observational) and action-oriented (or transformational) components relating to social determinants of health and well-being and living a daily life of quality in childhood neurodisability.

Conclusion: The proposed framework provides a roadmap for practitioners, policy-makers, and researchers as well as activists, families, and communities, to reflect on both social determinants and social change processes that shape the health, well-being, and everyday lives of children and youth with neurodisabilities and their families.

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► IMPLICATIONS FOR REHABILITATION

- Social Determinants of Health provides a conceptual framework for understanding the social causes and consequences of health and ill-health at the population level.
- In childhood neurodisability, however, it is important to consider pluralistic notions of “well-being” and living a daily “life of quality” that may relate, but are not limited, to health.
- The Canadian Framework for Social Determinants of Health and Well-being among Children with Neurodisabilities and their Families comprises an *explanatory hemisphere* of social determinants, factors, and contingencies, and an *action-oriented hemisphere* that identifies different forms and levels of mobilization that can guide rehabilitation practice to achieve social change in the lives of children, youth, and their families.
- Using an ecosocial perspective, this framework provides a roadmap for future research and policy development that is relevant to children and families as well as to current perspectives in rehabilitation, social and health justice, and childhood, disability, and neurodiversity rights.

Introduction

Social determinants of health is a conceptual framework that has typically been used to better understand factors that influence the presence/absence of disease and health conditions in the general population. Children and youth who have a

neurodisability associated with diagnoses such as autism spectrum disorder, cerebral palsy, or global developmental delay, already have a “health condition.” Therefore, one way of thinking about how social determinants of health applies to this population is to consider it from a “causes of ill-health” perspective, where consideration is given to the correlation of social factors,

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such as poverty, with rates of neurodisability [1]. Alternatively, a “consequences of ill-health” perspective would have us examine how neurodisabilities may be considered as a determinant of other physical health conditions such as obesity or oral health issues [2].

Yet in both cases, existing frameworks have failed to capture what is at the heart of what matters to children and youth living with a neurodisability and to their families, namely child and family well-being and the right to lead one’s life in non-normative, neurodiverse terms [3,4]. When the “health” component of a social determinants of health framework is defined more broadly than the presence or absence of disease (or certain health conditions), and when pluralistic notions of well-being are considered, this framework can be conceptualized and reimagined in terms that are more ecological, inclusive, and relevant to these children and their families. This perspective shifts the focus of the social determinants of health debate away from a normative model of medical “health conditions” toward a social ecological model of health and well-being that is pursuant of children’s, disability, and neurodiversity rights [5,6].

The purpose of this paper is to explore how existing social determinants of health frameworks might apply to children and youth with neurodisabilities and their families and to conceptually develop a framework in a way that is meaningful to them and other stakeholders in the field. To this end, we begin our paper by exploring the definition, scope and challenges posed by the key concepts of social determinants of health, well-being, and living a life of quality in the specific context of childhood neurodisability. Next, we describe the project rationale and research aims as well as the methods used, which included a secondary review of an existing compendium of social determinants of health frameworks ($n=36$) published by the Canadian Council on the Social Determinants of Health in 2015 [7]. This compendium included frameworks whose scope was both local and international. We also drew on a critical review of the literature and a concept analysis approach to reflect on and synthesize different features of these frameworks. Our aim was to gauge the potential for, and challenges raised by, the application of existing constructs and frameworks (e.g., social determinants of health, well-being, and life quality) to childhood neurodisability. In our results, we posit a novel framework that is conceptually integrative and ecosocial in its approach as it charts the dynamic interplay of neurobiological, developmental, social, environmental, and multi-systemic processes influencing the health, well-being, and daily lives of children and youth with neurodisabilities and their families. We conclude with a discussion of how our proposed conceptualization contributes to advancing knowledge about social determinants of health and well-being in this context and consider the implications for future programs of research and rehabilitation practice, as well as advocacy and policy development.

Social determinants of health, well-being, and living a daily life of quality: key concepts and their challenges in childhood neurodisability

Children and youth with neurodisabilities represent between 8 and 9% of the general population of children in Canada [8,9]. We use the term “neurodisability” as it is a more inclusive and less categorical term than “neurodevelopmental disorders”: it goes beyond any particular neurodevelopmental diagnosis, capturing a broader group of children and youth who present with congenital or acquired long-term conditions that are attributed to

neurodevelopmental disorders and/or impairments of the neuromuscular system. These impairments create functional limitations that vary in severity and complexity spanning the areas of movement, cognition, hearing and vision, communication, emotion, and behavior [10]. This non-categorical approach has been endorsed as an alternative to studying children with individual diagnoses since at least the mid 1980s [11,12] and has been used successfully in a program of research on childhood neurodisability documenting, among other elements, caregiver health [13] and parenting experiences [14]. Its underlying assumption is that children with specific types of impairments (e.g., motor or intellectual impairments) and their families share similar experiences, challenges and needs [15], regardless of diagnosis.

For the purpose of this paper, we propose to extend that medical definition of neurodisability to include interactions between existing impairments and various environments and barriers that “hinder full and effective participation [of persons with neurodisabilities] in society on an equal basis with others” following the United Nations Convention on the Rights of Persons with Disabilities [16] and the International Classification of Functioning, Disability and Health of the World Health Organization [17]. Our extended, non-categorical definition of neurodisability implies that a child or young person with such condition not only has an underlying neurological impairment, which may fit into a “disease” category or medical “diagnosis,” but is also a person with a “disability” and with a diverse set of needs and rights, as well as aspirations and capabilities, that warrant a pluralistic and social ecological (or ecosocial) perspective beyond disease [18,19]. Posited in the social and health sciences literature, this perspective represents a contextually sensitive approach to health and well-being that focuses not only on its neurobiological *variables* and social *determinants* but also on interactive *dynamics* and *processes* across domains (e.g., biosocial, developmental, socio-environmental) and at different levels of the ecosystem (i.e., family, community, public policy) [20–23].

One of the key advantages of using this ecosocial approach, alongside an extended, non-categorical definition of neurodisability, is that it allows us to critically engage with the social determinants of health and well-being in a manner that is (i) *inclusive* of a broader range of neurological conditions and neurodevelopmental disabilities (i.e., counting those that are less prevalent and even rare) and (ii) contextually and conceptually *relevant* to children and youth with neurodisabilities and their families—by taking their experiences and common needs into account while recognizing the diversity of their aspirations, capabilities, and identities (e.g., being “neurodivergent” as opposed to a neurotypical person). This consideration adopts a person-in-environment perspective and acknowledges the meaningful inclusion of disability and neurodiversity rights as central to this population [24,25].

Developing an inclusive and integrated framework for understanding the role of social determinants of health and well-being in the context of childhood neurodisability starts with a set of key questions about what is meant by “health,” what counts as a “social determinant,” and what is the relationship between these terms and other existing constructs such as “well-being” and “life quality.” The World Health Organization constitution of 1946 defines health as a “state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” [26, p. 1]. In 2001, the World Health Organization adopted the International Classification of Functioning, Disability and Health [17]. Its Child and Youth Version, published in 2007, was designed to take into account the characteristics of the developing child and the influence of her/his/their surrounding environment [27].

These latter two documents extended our understanding of health by situating it in a dynamic process that not only focuses on *functioning* (i.e., interaction between, or individual components of body functions and structures, engagement in activities and participation), but also on *disability* (i.e., impairments, activity limitations, and participation restrictions). Personal and contextual factors interact with the health condition to inform level of function/disability. Contextual factors are most closely aligned with “social determinants” and act as barriers or facilitators of function/disability (e.g., geographic location, access to recreational activities, level of social support, and access to health care). The International Classification of Functioning, Disability and Health further differentiates “health-related states” from “health conditions,” with the latter referring to primary and secondary (or comorbid) conditions, and the former referring to various domains of function [28] such as seeing, speaking, and remembering [27] that are associated with well-being. Some have referred to “well-being” as “contentment, satisfaction, or happiness derived from ‘optimal functioning’ [which need not imply] perfect function” [29, p. 70], whether this is physical or social. Given that this is a subjective (as opposed to a universal) concept, well-being also speaks to the idea of daily living conditions and living well relative to one’s own aspirations, everyday experiences, and the fulfilment of various needs [3,29].

Social determinants refer, in turn, to living conditions (e.g., where one lives, learns, works, plays and ages) that can shape the health of a population [30]. Existing typologies and models of social determinants of health draw on educational, socioeconomic, psychosocial, and community/societal factors [31] that influence patterns of health and the unequal distribution of ill-health at the population level [32]. From these models and recent studies on how acquired disability affects social determinants of health [19], it is difficult to ascertain how and to what extent this conceptualization applies to (and resonates with) specific groups who already have a prior condition that alters their health, development, and everyday life as well as the lives of their families. If we were to use presence/absence of a health condition as the central construct, our main focus would be on causes, levels and consequences of ill-health [33]. Although valuable in some contexts, this focus does little to address the diversity of social determinants of health, well-being, and their interplay in the lives of those who have a neurodisability. Furthermore, existing frameworks that define health in terms of “outcomes” and “statuses” tend to assume the centrality of ill-health as the main construct of interest. In the context of childhood neurodisability, however, a more plural and neurodiverse [3,25] understanding of the social determinants of health and well-being and of the conditions for living “a daily life of quality” [34–36] is pivotal as these tend to be subsumed under normative (and often neurotypical) definitions of health, ill-health, and health-related quality of life.

The Child and Youth Version of the International Classification of Functioning, Disability and Health, for example, depicts quality of life “as a composite, emergent and changing phenomenon of all aspects of functioning that may be impacted by a person’s health condition, other personal factors and environmental factors” [37, p. 208]. Within this modified version, importance is placed on the conceptual compatibility between “quality of life” and “health/disability” where the first construct refers to what people “feel” about their health condition and/or its impacts, from a subjective perspective, and the latter refers to “objective and exteriorised” signs [17]. Yet scholars in this field, such as Fayed and colleagues [38], have grappled with the conceptual differentiation between quality of life and health in the context of

measurement, and their results support how confounded these two concepts are. Similarly, Zekovic and Renwick [24] have identified multiple conceptual and measurement issues in their review of models and frameworks of quality of life for children and youth with developmental disabilities. Others have questioned the contextual sensitivity and the conceptual relevance of that notion of “quality of life” as it creates an artificial dichotomy between objective and subjective measures (or dimensions) of a person’s lived experience of a developmental disability [39]. In other words, the existing technical definition of “quality of life” may fail to capture what a person identifies as the necessary conditions for living a daily “life of quality” and the *plural qualities* of his/her own life.

While definitions of quality of life have been associated with experiences and understandings of disability and could be considered as an indicator of (or proxy for measuring) health in this context, they imply a differentiation between not only the objective and subjective measures but also the internal and external dimensions of living a life of quality. This seems problematic in practice and when mapped onto the context of neurodisability. In this context, experiences of living with a neurodisability are not necessarily external to but jointly produced with one’s sense of identity and the right to lead a life in non-neurotypical terms. Equally, the well-being of children and youth with neurodisabilities tends to be contingent on circumstances and environments that are largely determined by their families and caregivers [39] and, thus, cannot be adequately understood when framed in terms of social functioning or individual autonomy that are culturally normative [4].

Accounting for these contextual, relational, and ecosocial dimensions of neurodisability requires a more inclusive, relational, and pluralistic understanding of well-being, as well as a holistic view of what living a “life of quality” as a whole (and not only living “with” a disability) means for different people and for public policy development in this field [24,39]. Hence, the stakeholders involved in the development of our framework, as described next, did not speak to an absolute notion of “quality of life” but rather a relative notion of “life of quality” that is contingent on their own experiences of daily living and neurodisability.

Project rationale, research aims and methods

In the development of an integrated ecosocial framework for understanding social determinants of health and well-being in childhood neurodisability, we reviewed and critically examined a comprehensive compendium of existing frameworks published in 2015 by the Canadian Council on Social Determinants of Health [7]. This report identified 36 social determinants of health frameworks whose scope was local/provincial, national, and/or international and provided a deep examination of 7 of those frameworks for the Canadian context.

Existing frameworks and models of social determinants have been developed to identify factors that could lead to more equitable health outcomes and, in the case of children, healthy child development and well-being, with some frameworks proposing action orientations to address identified disparities. Yet these frameworks have largely disregarded those whose development, health, and lives have already been altered by a prior condition in multiple ways. To address this gap, we conducted a secondary analysis of the reviewed studies and frameworks in that compendium to identify key scholarship addressing social determinants of health. In our review, we identified considerable diversity and multiplicity among the social determinants of health literature as

it encompassed multiple levels of analysis and/or research focus ranging from individual level characteristics that could be described as *micro-determinants* (e.g., personal health practices and coping skills [40,41]) and *meso-level determinants* concerning specific sub-groups (e.g., gender and women's health [42–45]) to *macro-level determinants* at the various levels of the ecosystem (such as community and health system characteristics [46–48]). Only a few articles considered the applicability and relevance of social determinants of health models for populations with neurodisabilities [28,49,50], although these focused mainly on physical health outcomes among children specifically with autism spectrum disorders [2].

Neither this literature nor the aforementioned 36 social determinants of health frameworks reviewed by the Canadian Council provide a coherent conceptualization of social determinants that could capture a broader range of childhood neurodisabilities as they did not embrace a pluralistic definition of health and well-being beyond disease/diagnosis categories. Of further concern, environmental, institutional and/or structural factors seldom were incorporated into this literature, preventing researchers and stakeholders from drawing implications for practice, policy development and/or social change in the field of neurodisability. Accordingly, one of the aims of our project was to develop a social determinants of health and well-being framework that is relevant and specific to children and youth with neurodisabilities and their families (and caregivers). The second aim was to refine this conceptual framework through iterative development and a process of consultation and construct validation involving key stakeholders. The third and final aim of our project was to draw implications from our conceptualization to inform crosscutting, action-oriented strategies addressing social determinants of health and well-being in neurodisability at multiple levels and critically oriented toward social justice and social change; these strategies and actions can be undertaken by researchers, practitioners, advocates, and/or policymakers.

To address these aims, our study was guided by the following research questions:

1. What social determinants and other factors shape the health and well-being of children and youth with neurodisabilities and their families?
2. How do these social determinants and other factors interact?
3. What actors, strategies and/or processes contribute, at multiple levels (micro, meso, macro), to the health and well-being of children and youth with neurodisabilities and their families?

Methods

Development of the framework drew on a combination (and modified version) of two methodological approaches: (i) Jabareen's [51] eight-step technique for conceptual framework analysis and (ii) Walker and Avant's [52] eight-step procedures for concept analysis. These approaches guided the identification, categorization, and stakeholder validation of concepts that were relevant and instrumental to the development of our framework for social determinants of health and well-being in childhood neurodisability.

Stage 1: Location and identification of key social determinants of health frameworks

This stage followed phases 1–3 of Jabareen's concept analysis technique [47] for building a conceptual framework that consisted of mapping selected data sources (phase 1), extensive reading

and categorizing of selected data (phase 2), and identifying and naming concepts (phase 3). These three phases also coincide with Walker and Avant's first four procedures for concept analysis that include selecting a concept of interest and identifying the various uses of the concept and its key attributes with a view of enhancing theoretical understanding as well as practical applications of a given concept (in this case, the concept of social determinants of health and of well-being). Hence, this stage involved a secondary review of the 36 social determinants of health frameworks identified in the compendium of the Canadian Council on Social Determinants of Health [7]. Drawing from the reference list, publications representing (or associated with) each of the frameworks were retrieved for further examination and categorization. Two research assistants (AB and RZ) independently read and generated a narrative description of each framework (i.e., a summary) that identified its key social determinants. A structure for data extraction was generated that allowed for the categorization of each framework according to their (a) scope and source, (b) focus or orientation (e.g., population-based, policy development, decision-making), (c) purpose or type of model (i.e., explanatory, interactive, and/or action-oriented), and (d) key concepts and features of the model (see [Supplementary Table 1](#)).

Stage 2: Integration, critical analysis and reconstruction of social determinants of health and well-being in childhood neurodisability

Drawing on phase 4 of Jabareen's conceptual framework analysis technique, we proceeded to deconstruct and categorize the concepts [51]. In order to achieve this, the reviewers (AB and RZ) and their supervisors (LL and DN) drew on aforementioned narrative descriptions of each framework and reviewed these for (e) strengths and limitations, ascertaining the conceptual and consequential validity of each framework for children and youth with neurodisabilities and their families. Doing so facilitated the integration of key concepts and social determinants across models allowing for a process of synthesis, deconstruction, and resynthesis, which generally corresponded to phases 5 and 6 of Jabareen's conceptual framework analysis technique. This technique was more suitable and aligned with our research aims than stages 5–8 of Walker and Avant's method for concept analysis as the latter drew on a more causal and linear (as opposed to a processual and iterative) approach to concept analysis. The research team audio-recorded their discussions, procedural notes were taken, and the first iteration of the framework for social determinants of health and well-being in childhood neurodisability was generated.

Stage 3: Validation of the framework and iterative consultation with stakeholders

In this final stage, we invoked phases 7 and 8 of Jabareen's analysis technique to validate and iteratively refine our emerging framework with a broad community of stakeholders. From the period of March 2016 and May 2019, the framework was presented to a group of stakeholders ($n=55$) and refined through a series of iterative consultations ($n=13$), which included their review, feedback, and collective debate among parents ($n=8$), self-advocates ($n=6$), researchers ($n=8$), representatives of community organizations and decision-makers ($n=8$), and practitioners ($n=25$) in the field of childhood neurodisability. These stakeholders were recruited from a national network of researchers, attendees at a national brain health conference, through service agencies, and word-of-mouth invitations; they were selected based on their lived experience, expertise, and potential interest in an evolving model on social determinants of health. Thirteen

iterations were conducted to ensure that the process was inclusive of various stakeholder perspectives. The diversity and quantity of stakeholder groups represented helped to guard against the potential emergence of a single perspective that would disproportionately shape and thus bias the synthesis [53].

These stakeholder consultations elicited reflections about who should be at the centre of the model (i.e., individual, parent, child or family), the recategorization and refinement of concepts (i.e., kinship, the importance of community, culture, lifespan perspectives), and the inclusion and reformulation of multiple intervening factors (i.e., relevance and meaningfulness, safety, and technology). This iterative process required the team to expand the secondary review of the literature beyond the 36 frameworks included in the aforementioned compendium and other related publications cited therein. To this end, the team conducted a critical and targeted review of relevant literature focusing on key publications (and theoretical foundations) underlying (i) social determinants of health, social justice, and social change, (ii) well-being and quality of life/life quality, and (iii) childhood and neuro-disability/diversity studies as well as rights-based frameworks intersecting these domains.

Results

In our secondary analysis of the Canadian compendium of social determinants of health, we found a group of frameworks that were more *explanatory* and identified factors that constituted a typology of determinants that contribute to the health of a population [54–56]. Conversely, other frameworks were more *exploratory* in the identification of constituent factors and processes and of their dynamic interactions [57–59]. Among the latter, we identified a sub-group of studies that also included an action-oriented companion framework or a set of actionable steps and strategies that need to be undertaken to improve health and/or well-being

in a population and that are critically oriented towards social change [60]. By combining this secondary analysis of existing frameworks with a critical review of the literature, conceptual analysis, and iterative stakeholder consultation, we developed the “Canadian Framework for Social Determinants of Health and Well-being among Children with Neurodisabilities and their Families.” The proposed framework offers an ecological understanding of how social determinants and other factors interact to shape the health/well-being of children and youth with neurodisabilities and their families, as well as an outline of strategies, processes, and conditions for achieving (or living) a daily life of quality in this context (see Figure 1, below).

In the resulting framework, we focused on developing a model that maintains at its core pluralistic notions of health, well-being and living a “life of quality” for children and youth with neurodisabilities and their families given that their everyday lives and experiences are often intertwined. This approach draws upon frameworks that focus on both the individual [58,61] and the broader population [60,62–64]. In doing so, our approach also addresses a gap in existing models such that those models fail to highlight the central importance of: (i) the health and well-being of specific members of the family or the family unit as a whole, (ii) how health and well-being can be interactive within the individual-caregiver dyad (e.g., child with a neurodisability and their parent), and (iii) how the interactive relationships may be dynamic, particularly as roles and responsibilities shift over time.

There are two hemispheres to the framework. The left hemisphere represents the explanatory processes associated with social determinants of health and conditions for living a life of quality for the child and family, while the right hemisphere represents action-oriented processes that redress social determinants of health and well-being across family, community, and policy contexts in order to achieve social justice and to foster social change. Each hemisphere continually shapes the other through a

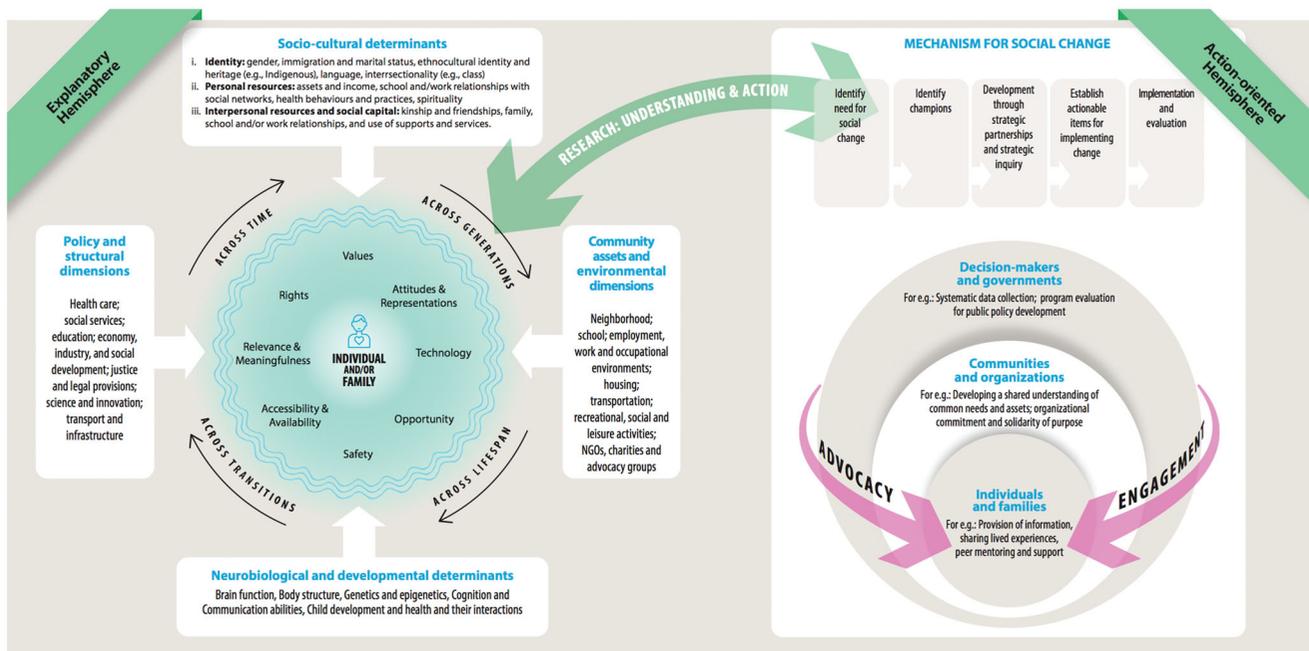


Figure 1. The Canadian Framework for Social Determinants of Health and Well-being among Children with Neurodisabilities and their Families: An Ecosocial Perspective.

research-action process that acts as a catalyst, thereby linking components in the two hemispheres. Specific components of each hemisphere are outlined below:

I. **Explanatory or observational hemisphere (social determinants of health and well-being in childhood neurodisability)**

- The *child and/or family* are the focus of the left hemisphere. There was no consensus among stakeholders about whether the child or the family should be at the centre of the model. Stakeholders agreed that the two are inextricably linked such that prioritizing one over the other seemed irresolvable. In this case, “family” refers to the biological, adoptive or social family, whichever is most relevant.
- Four main sets of *determinants* were identified: (1) socio-cultural determinants, (2) policy and structural dimensions, (3) community assets and environmental dimensions, and (4) neurobiological and developmental dimensions.
 1. *Socio-cultural determinants* refer to factors that describe a person’s identity characteristics (e.g., immigration and marital status, gender, ethnocultural and Indigenous identity, language); their personal resources (e.g., assets and income, health behaviors and practices, spirituality); and their interpersonal resources and social capital (i.e., kinship and friendships, family environment, education/employment, work and occupational environments, access to supports and services).
 2. *Policy and structural dimensions* refer to policies, programs, and legal provisions guiding public services and supports (health care, social services, education, economy, justice, housing, science, transport and infrastructure), which does not preclude other programs in the private and plural sectors.
 3. *Community assets and environmental dimensions* refer to the characteristics and capacities of the communities in which persons with a neurodisability and/or their families are embedded, including the environments they inhabit (e.g., transportation; housing; school; social and outdoor activities; NGOs, charities and advocacy groups).
 4. *Neurobiological and developmental determinants* refer to interactive genetic (and epigenetic), functional, and developmental processes related to brain and child development as well as physical and mental health.

In addition to the four main sets of determinants, two sets of intervening factors (or moderators) are embedded between the person and/or family and the four main sets of determinants. The first set contains constructs that explain both for whom, and how any particular determinant plays a role in individual and/or family life quality. These include: (a) *rights* – the extent to which the United Nations Conventions’ rights are adhered to in the communities to which the person/family belong; (b) *values* – values and principles (e.g., beneficence) that guide the lives of persons with a neurodisability and their families; (c) *attitudes and representations* – beliefs and understandings that persons with a neurodisability, their families, and others hold about the determinant; (d) *relevance and meaningfulness* – the significance of a determinant for the person/family at that point in their life; (e) *accessibility and availability* – how and whether a determinant/resource is

obtainable and accessible; (f) *safety* – the degree to which a determinant can pose a potential harm to the person/family; (g) *opportunity* – the extent to which a person/family is able to take advantage of the determinant; and (h) *technology* – access to devices and aids to facilitate the determinant/support. For example, the role played by a determinant varies based on how meaningful and relevant that determinant is for the person/family, and how it is accessed and/or supported.

The *second set* of intervening factors surrounding that circle, whose boundaries are depicted as permeable (rather than static), add a spatio-temporal component to the framework. Hence the relative role that any determinant plays in individual and/or family life quality will vary *over time* and *across context/spaces* (i.e., socio-cultural, geographic) and will be informed and potentially mediated/moderated by age (e.g., adolescence vs. middle age vs. old age) and by significant transitions over the life course (e.g., pre-school to school age; marriage to separation/divorce).

II. **Action-oriented or Transformational Hemisphere (Actions and Strategies Needed to Improve Conditions for Living a Life of Quality)**

The action-oriented and transformational hemisphere highlights the strategies and the advocacy and engagement activities directed toward social change at the individual and family level, the community level, and the broader macro-systemic level. Within this hemisphere, the mechanism for social change characterizes actions and concrete steps that can be undertaken to achieve social change with the aim of improving the living conditions of children and youth with neurodisabilities and their families. This mechanism relies on an iterative and reflexive process of understanding, action, and evaluation that enables families, communities, and relevant stakeholders to engage with one another meaningfully, to deploy knowledge and research to advocate for neurodisability rights and needs, and to intervene more capably at different levels of the ecosystem [65,66].

1. *Individual and Family Level* advocacy and engagement refers to activities that persons with a neurodisability and their families can engage in that render visible changes needed to achieve a life of quality. As individuals participate in actions that make their needs better known, discordance between supports and services that already exist and what is truly needed can be identified and addressed. In this way, informational and emotional support can be increased, thereby potentially easing social exclusion and isolation that otherwise may be imposed by pressing demands, barriers to access, and a lack of adequate support. It is acknowledged that isolated stories of individual and family experiences may be ignored, but organized and thoughtful advocacy that identifies pressing issues and seeks solutions to those issues, is more likely to garner attention of the public and of society.
2. *Organizations and Community Level* advocacy and engagement involves breaking down siloes that exist between government, non-government, and private sector organizations involved in providing resources and support to children and youth with neurodisabilities and their families. This can be accomplished by bringing key stakeholders together to identify the extent to which they share mutual concerns, needs and interests, have a solidarity of purpose, and can make organizational commitments to pursue common goals through a collective community impact process [67]. A

concerted effort by community organizations is needed as the collective voice can be influential in drawing societal attention and nurturing service and community change processes.

3. *Decision-making and Government Level* advocacy and engagement addresses siloes that exist between systems involved in establishing policies, programs, and financial resources allocated to deliver those programs at a macro level (whether municipal, provincial or federal). This can be achieved through systematic data collection, stakeholder, and decision-maker engagement across sectors (e.g., education, health, social services, justice, housing), and program evaluation that informs public policy development [68,69].
 - The Mechanism for Social Change:
4. *Identify the Need for Social Change.* Frustration and even exasperation with the status quo is most often the starting point for social change. A collective understanding of the problems or challenges can be achieved through community dialogue and ongoing, mutual engagement of various stakeholders and decision-makers across sectors and levels of the ecosystem (i.e., individual and family, community, systems) as is highlighted by the role of community conversations in the context of disability [70]. Not only does this process break down siloes and increase collaboration, it also lays the foundation for building relationships of trust among key actors and advocates both within and across systems.
5. *Identify Champions and Backbone Support.* Leaders, partners, and “champions” [61, 71] for social change tend to be embedded in different levels of the ecosystem. The creation of a steering committee comprised of those champions can assist in galvanizing synergies and resources for moving forward. Such a committee must be adequately supported by their respective organizations (e.g., backbone support, infrastructure), with clear terms of reference, and endorsement that findings and recommendations will be considered for implementation.
6. *Develop a commitment to strategic partnership/relationships through a strategic inquiry process.* A strategic inquiry process [72] requires a candid exchange and a mapping of individuals who are key to the process, issues they can address, and actions that can be taken toward social change. This process requires deployment of resources and a shared agreement on which issues will be prioritized in moving forward together. Organizations may be at different levels of readiness and may have different priorities and agendas at stake and so may seek to protect what they have built. Strategic partnerships require the valorisation of and investment in recognizing what is working well, critical reflection on what could be done differently, and ongoing commitment (e.g., personal, institutional, financial) to trust this process and develop collective solutions for the benefit of children and youth with neurodisabilities and their families.
7. *Establish actionable items for implementing change.* Moving to action is complex, yet it seems advisable to start with actionable items that are most likely to generate gain (i.e., seek “low hanging fruit”) while fostering intersectoral cooperation and action [48]. This entails developing a plan for implementation toward goals that are more easily attainable in order that anticipated and realized change is visible and meaningful.
8. *Evaluate and refine.* Action solely for the sake of “change” is not sufficient and in fact may be counter-productive.

Building a culture of critical reflection and an evaluation plan that provides adequate feedback to those involved is essential to constructive public policy and systems, to frontline staff and practice, and research funding prioritization [68,69].

- *Research: understanding and action.* Acting as a catalyst, research is both informed by and mediates the relationship between the two hemispheres, that is, between the explanatory (or observational) components of social determinants of health and well-being and the action-oriented (or transformative) components, including the mechanism for social change. As Reason and Torbert put it, the purpose of this research and action-oriented inquiry is “to forge a more direct link between intellectual knowledge and moment-to-moment personal and social action, so that [it] contributes *directly* to the flourishing of human persons, their communities, and the ecosystems of which they are part” [73, p.6]. Strategies and methodologies will vary from context to context ranging from integrated knowledge mobilization and knowledge co-production [74,75] to participatory action-research and research interventions [66,76] with advocacy and community engagement components [61,69,70,77].

Discussion

An evolving and inclusive ecosocial framework has been constructed using an integrative approach to establish conceptual underpinnings and transformative processes that influence the health, well-being, and daily life quality of children and youth with neurodisabilities and their families. Within this framework, social determinants, well-being, and a living a daily “life of quality” are integral constructs. Historically, these constructs have been shaped by different disciplines and the trajectory of their development has not been linear. These variations, alongside semantic ambiguities surrounding rights-based notions of health and disability, have led to debates about how those concepts are (or ought to be) defined, operationalized, and researched [78,79]. Of particular importance in this context is a range of interrelated methodological, theoretical, and normative considerations as to how these various notions and constructs intersect with one another and the extent to which they are cogent with pluralistic notions of living a “life of quality” among children and youth with neurodisabilities and their families.

Through the iterative development of the Canadian Framework for Social Determinants of Health and Well-being among Children with Neurodisabilities and their Families, the pursuit (and enhancement) of well-being and the conditions for living a daily life of quality for persons with a neurodisability and their families was the focus rather than solely health. Stakeholders recognized that living a “life of quality” can have multiple dimensions similar to health; although when defined more broadly will include, for instance, environmental, relational, spiritual, and neurodiversity dimensions of well-being that differ from professional and normative definitions of “quality of life,” including health-related quality of life. These elements have been similarly identified in existing models [62,74,80]. Temporal aspects in the consideration of well-being and living a “life of quality” can be mediated and follow a developmental course relative to a lifespan approach [41,81,82]. The importance of temporal aspects, as well as geographic dimensions of social determinants of health [83], were endorsed by stakeholders who indicated that needs and priorities may change across place/region, time and in scope and/or

scale (e.g. changes in the complexity of special needs or in the availability of resources determined by availability of existing programs, public funding priorities, and governmental agendas).

The framework, as presented, encompasses four broad groups of determinants that shape the health, well-being, and lives of children and youth with a neurodisability and/or their family. Each group of determinants represents an array of factors that reflect and shape different aspects (e.g. social, community participation, and vocational) of one's life. These groups of determinants share similarities with other existing frameworks that illuminate the importance (and interplay) of biological, social, and environmental determinants [40,81,84] in shaping health and well-being. Contrary to many frameworks except two [61,85], the presented framework identifies public policy as both a structural determinant of and a means to improve the health and well-being of a given population [85,86]. Stakeholder reflections revealed how policy is created and influenced by many factors that, in turn, define, shape and promote/impede opportunities for children and youth with neurodisabilities and their families. For instance, policies may or may not be attentive to the influence of the built environments (e.g. issues of physical access, places of education, work, or leisure), psychosocial and professional environments (e.g. employment policies that facilitate the inclusion of young adults with neurodisabilities), or the natural environment (e.g. increase access to recreational activities and the outdoors including access to national parks). The need to continually and critically monitor policy across different sectors (e.g. health, social services, education, justice/rights, industry and government) [87,88], in order to understand its impact on children and youth with neurodisabilities and/or their families, was recognized by our stakeholders and integrated into the framework.

The result is a social ecological and conceptually integrative framework of social determinants of health and well-being in childhood neurodisability. This ecosocial framework embraces a dynamic understanding about what it means to live a life of quality with a neurodisability, which includes both contingencies and moderators that are situated between the person and family, mediating between biology and environment [40,81,89], and indicating an active interplay between individual and social dynamics and environments [59,84,90], such as supportive relationships within and across sectors of the community and society as a whole [60,61,80,87,91]. At the same time, our framework applies a pluralistic view of the pathways and diverse experiences of neurodisability as the relative importance and pertinence of individual components will vary from person to person and family to family, as well as across contexts/regions and over time [92]. These variations depend on critical junctions and transitions in the pathways of children and youth with neurodisabilities (e.g. at the point of diagnosis; entry into school; transition to emerging adulthood) and are contingent on the availability and accessibility of health and social care, family support, education and rehabilitation services, including unrestrictive (hence, potentially augmented) opportunities for participation in the community.

Given this need for advancement, our framework explicitly engages not only with the explanatory sphere of research, wherein it bridges the social sciences and the bio/neurosciences, but also with the sphere of action, advocacy, and engagement across sectors/systems of care and at different levels, ranging from family advocacy and community engagement to governmental policy and systems-level change [55,57,64,90,93,94]. Accordingly, our proposed framework adopts an interdisciplinary, intersectoral, and non-categorical approach to social determinants of health and well-being in childhood neurodisability while

offering a comprehensive strategy for addressing those determinants through action-oriented research and mechanisms for social (and systems) change at different levels of the ecosystem.

Limitations

There are some limitations to this secondary review of social determinants of health models and the conceptualization and iterative development of a new framework applicable to children and young people with neurodisabilities and their families. We view the proposed model as one that was developed with earnest intentions and as a work in progress.

First, this model reflects insights emerging from our secondary review and synthesis of existing social determinants models and iterative stakeholder consultation. Although this iterative approach in developing the present framework can be viewed as robust and a strength, the synthesis [see [Supplementary table S1](#)] focused primarily on examining the concepts embedded in each social determinants of health model for their relevance to the population of interest, but was less systematic in addressing the processes of how each reviewed social determinants model was developed. Second, the concept analysis and iterative approach used in this study may enhance the trustworthiness of the framework that has emerged from this process as it relies heavily on previously published insights and validation *via* the experience and expertise of key stakeholders. However, we recognize that the model is dynamic; hence, would benefit from further application and iterative refinement through future research. Community-level adoption of the approach would add to the depth of understanding of its potential application and variants in practice as well as in community and policy uptake. Third, the broader application of the model is currently unknown, raising many questions meriting additional research, exploration, and possibly leading to its further refinement and elaboration. Questions may include how social change, as depicted by the model, can be prioritized, integrated, and evaluated and how funds and/or resources should be deployed. It is also worth noting that while the validation of this framework has largely been conducted from a child/family-oriented perspective, we recognize that it may have a wider application in other domains of health and well-being as well as across the lifespan, which would require further testing and validation work.

Despite its limitations, the development of the Canadian Framework for the Social Determinants of Health and Well-being among Children with Neurodisabilities and their Families offers a roadmap for a comprehensive strategy where communities of practice strive for proactive social change for improving the lives and well-being of persons with neurodisabilities and their families. This framework requires ongoing attention to the daily lives and abilities (rather than focusing only on the disabilities) of young people, families and community members, organizations and systems that come forward and commit to a process of critically and proactively addressing barriers to living a life of quality in the context of neurodisability.

Conclusion: implications for research, practice, and policy toward social change

Drawing on a critical literature review and a secondary analysis of a social determinants of health compendium, a conceptual analysis and development approach, and iterative stakeholder consultation, our aim was to understand whether and how a normative, population-based construct of social determinants of health mapped onto the lives and daily experiences of children

and youth with neurodisabilities and their families. This was no straightforward task, given the conceptual challenges surrounding these very constructs: “social determinants of health,” “well-being,” “quality of life,” and “neurodisability.” While resolving these challenges is beyond the scope of our paper, we sought to recognize them in our literature review and conceptual analysis and to elicit them further in the iterative development of a conceptual framework through a process of stakeholder consultation. This process shed light on a set of conditions for, and aspirations to, a daily “life of quality” in the context of neurodisability that are common to other social determinants of health frameworks (e.g. education, housing, employment, access to services, peer relations). Yet it also revealed the need for a distinctive and pluralistic understanding of what entails living a valued and meaningful life in non-neurotypical terms, which implies consideration for the views of children and youth with neurodisabilities and their families/caregivers who are collectively seen as “the best judges of the quality of their own lives” [39, p. 26].

The proposed Canadian Framework for the Social Determinants of Health and Well-being among Children with Neurodisabilities and their Families has significant implications for research, practice, and policy development that warrant additional validation work and further systematic inquiry in this field. *First*, it calls for a shift from the systematic use of health status and health outcomes to account for dimensions of well-being and life quality (e.g. in large-scale population surveys) and to the development of more granular instruments and research methodologies that can address the ecology of social processes and conditions for living a daily “life of quality.” This may involve devising socio-culturally appropriate measurement in collaboration with relevant stakeholders and affected groups/populations, including time/scale-sensitive instruments that allow for a clearer definition of both generic and group-specific constructs.

Second, our framework highlights the need for mutual engagement (e.g. across disciplines and sectors) and ongoing reflection on what is valorized as a social determinant of health, well-being, and a life of quality, by whom, and in what particular contexts and terms. Of particular importance in the context of neurodisability is to move beyond normative frameworks of social determinants of health at the population level and technical/professional definitions of quality of life (and health-related quality of life) towards more inclusive and pluralistic understandings of well-being and variant ways of being, of social determinants and capacities, and of moral agency and lived experiences of neurodisability. These understandings can be generated from the “bottom-up” through participatory research and in collaboration with children, youth, families, communities, and relevant stakeholders.

Third, our ecosocial framework comprises both explanatory elements of social determinants of health and well-being among children with neurodisabilities and their families (left hemisphere) and action-oriented elements of advocacy and community and public policy engagement at various levels of the ecosystem geared toward social change (right hemisphere). In doing so, the proposed framework seeks to capture the dynamic interplay between the two hemispheres in shaping the experiences and pathways of neurodisability. These pathways of experience and action are seen as (i) primarily mediated by the family, (ii) socially and politically determined, and (iii) variably distributed across geographic, societal, and discursive space and time and, therefore, embedded in an ecosocial crucible of interacting processes. In other words, social “determinants” of health and well-being will interact both with one another and with broader contextual

processes and contingencies (e.g., policy and public funding priorities and the availability and accessibility of services in different jurisdictions) that modulate individual pathways and family experiences of neurodisability over the lifespan.

In proactively addressing both practice and process, our ecosocial framework engages directly with structural and political implications of social determinants of health and well-being research and with notions of family/community advocacy offering a “case in point” for broader, contemporary debates on social justice, inclusion, diversity and citizenship in the field of disability, human rights, and global health and development. To the extent that it is conceptually integrative, socially inclusive, and actionable, the proposed framework for understanding social determinants of health and well-being in childhood neurodisability provides a roadmap for consideration in future research programs and strategies that can inform rehabilitation practice and policy development and, ultimately, social change.

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