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PERSPECTIVES IN REHABILITATION

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Perspectives in childhood-onset disabilities: integrating 21st-Century concepts to expand our horizons

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ABSTRACT

Purpose: A powerful aphorism states: "If I hadn't believed it, I wouldn't have seen it!" This challenging notion reminds us how strongly we are influenced by prevailing ideas, and how we interpret things according to current fashions and teachings.

Materials and methods: In this paper we present and discuss contemporary perspectives concerning childhood-onset disability and the evolving nature of how people are thinking and acting. We illustrate these ideas by reminding readers of how we have all traditionally been trained and acculturated to think about many dimensions of neurodevelopmental disability ("What?"); reflect on the impact of these ways of thinking in terms of what we have conventionally "seen" and done ("So What?"); and contrast those traditions with contemporary concepts that we believe or know impact the field ("Now What?").

Results: Many of the concepts discussed here will be familiar to readers. In taking this analytically critical perspective we aim to illustrate that by weaving these individual threads together we are able to create a coherent fabric that can serve children with childhood-onset NDD, their families, service providers, the community, and policy-makers. We do not purport to offer a comprehensive view of the whole field.

Conclusions: We encourage readers to consider the integration of these new ways of thinking and acting in our still-evolving field of "childhood-onset disability".

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IMPLICATIONS FOR REHABILITATION

- 21st-century thinking about childhood-onset neurodisability builds on WHO's ICF framework for health, expanding well beyond traditional primary biomedical foci on diagnosis and management and toward a focus on functioning and belonging.
- New emphases put family at the centre, attending to family voices and prioritizing family wellbeing as targets for intervention equal to a focus on the child.
- There is strong emerging evidence to support the value and impact of these broader approaches on overall family functioning and wellbeing.
- These developments are primarily conceptual rather than technical: they emphasize child and family development, parenting, promotion of functioning, and a life-course approach from the start of intervention.

Introduction

There is an important reconceptualization underway in the field of "childhood-onset disability". These conditions are usually neurologically based; are commonly referred to as "neurodevelopmental disabilities" (NDDs); and have traditionally been discussed in terms of specific diagnoses and "managed" as distinct entities ("categories"). Decades after the concept of "non-categorical" thinking was first posited by Pless and Pinkerton [1], and supported by the work of Ruth Stein and her colleagues [2–4], there is a broad recognition of the commonalities among these disparate conditions, coupled with the value of shared perspectives and approaches to them.

Without any implied criticism of the pioneers of our field (e.g., Ronald Mac Keith, Ronald Illingworth, Kenneth Holt in the UK; Arnold Gesell, Berry Brazelton, Arnold Capute in the US), this paper makes an analytically critical effort to bring together multiple related but distinct concepts that the authors argue are cross-cutting themes that apply to all NDDs—and indeed to all childhood-onset chronic health conditions. Some of the ideas offered here are innovative, while others are being re-emphasized, developed, and integrated in new ways. As will be reported in this paper, the value of presenting these concepts in this integrated manner has been validated in the ENVISAGE-Families program discussed below.These concepts include:

1. EXPANDED IDEAS ABOUT "HEALTH". The World Health Organization's International Classification of Functioning, Disability and Health framework [5] and its animation with the "F-words for child development" [6] can guide how

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we think, what we do, and why. There is also an exciting reconceptualization of "health" in the context of modern thinking [7].

2. DEVELOPMENT. This universal force—a process of Being, Becoming and Belonging [8]—impacts all children and families. The corollary idea is the imperative to promote FUNCTIONING, however it is accomplished, in order to enable development and belonging.
3. PARENTS and the FAMILY UNIT. "Family" is the essential environment in which children typically grow up [9]. We propose that, expanding beyond "child," "family" (however defined) [10] should be identified as the focus of interest in all areas of "child health".
4. PARENTING. We posit that parenting is "a dance led by the child," and as such should warrant discussion in our field where children with developmental impairments often cannot "dance" easily, and where "parenting" often implies application of therapies by parents [11].
5. LIFE-COURSE PERSPECTIVES. It is essential to look beyond the childhood years, and traditional child-directed "therapies," to promote healthy development across the life course [12].

It will be apparent to readers that most of these ideas are complementary and interrelated rather than discrete. We discuss them individually to highlight intrinsic aspects of each concept without intending either to prioritize one over another or to assume that they are independent. They are in reality "transactional"—constantly influencing each other over time. Thus, in each section we may refer to other concepts that make up the fabric of this approach to childhood-onset NDD—being family-centred and holistic, promoting functioning and development, and taking a life-course view.

The structure of the paper follows a consistent pattern, addressing three related questions:

- *WHAT* has been our traditional thinking related to each of these themes—what were we acculturated to "believe"? This will outline our field's past points of departure to illustrate what we mean by each of the major themes, showing where we have come from conceptually.
- *SO WHAT?* How have these ideas influenced how we have been thinking and acting, and why does this matter?
- *NOW WHAT?* We present and illustrate contemporary ideas in the field to contrast these new approaches with traditional ways of thinking and acting. What are the implications for the field? How can we use these ideas? What do we gain, and what do we give up? This focus illustrates how these ideas can be used with families and in offering services.

This paper has been created by clinician-researchers and academic educators engaged fulltime in the study of childhood-onset disability and its translation into clinical practice. Our aim is to address questions frequently raised by colleagues, learners, parents and policy makers about our teaching, our research directions, and the approaches we advocate. It is our hope that this essay will be read and assessed in that light.

THEME one: contemporary ideas about "health"

WHAT has been our traditional thinking about childhood-onset disability?

Conventional thinking in the field of childhood NDD has been grounded in sound biomedically-based clinical approaches drawn from acute care medicine. These include (i) doing tests and investigations to make a specific diagnosis, before (ii) applying the best evidence-based treatments for that diagnosis, and then (iii) assessing the impact of interventions on the person's symptoms and functioning. This remains an essential clinical paradigm in most areas of health care.

By analogy, our field is usually referred to as "paediatric rehabilitation". Just as we have drawn on important approaches from acute-care medicine, so have we imported into child health ideas that are essential in adult "rehab". We have done this without acknowledging that re-habilitation seeks to support people's *return* to prior functioning, whereas children with early-onset NDDs often have never displayed "neurotypical" development. In the absence of a past history of "usual function" the default target in childhood-onset disability has been "normal function"—an odd and often unrealistic "ableist" goal.

So WHAT? How has the field of NDD been influenced by these ideas?

In traditional biomedical thinking about NDDs, the "problems" have been considered to exist within the person with the impairments (in our field, the child). Interventions have therefore been aimed at addressing the impairments ("fixing" where possible) to promote "normal" functioning. Insofar as the child and their impairments have been the focus of concern in "management," we have provided families with well-intentioned "early interventions" *for their children*. These approaches have usually paid less attention to the impact of the NDD on child and family development than we believe is warranted.

Biomedical perspectives are highly appropriate when someone who was previously well becomes unwell or impaired for any reason; we strive to "rule out" diagnostic options in order to arrive at a specific answer. However, these approaches have less immediate utility in the field of childhood-onset NDD. Conditions like cerebral palsy, autism spectrum disorders, and other NDDs vary widely in their biomedical features; they often defy specific biomedical characterization and require understanding and "developmental" supports and management that are rarely specific to a particular diagnosis. This can be accounted for by several factors. (i) NDDs are often phenotypic manifestations of a wide variety of disparate underlying biomedical impairments rather than being specific to a particular "diagnosis" or pathophysiology; hence it can be challenging to discern the exact biomedical nature of the condition. Furthermore, detecting biomedical variations such as a genetic difference or "abnormality" as might show on an MRI scan does not automatically "explain" the NDD or lead to specific treatment. (At the same time, it is well acknowledged that identifying underlying impairments often is very important in addressing families' needs for an explanation of their child's situation.) (ii) In most NDDs, interventions target aspects of *functioning*—the presenting manifestations of the condition—rather than the often elusive specific biomedical underpinnings of the functional impairments [13]. Furthermore, "treating" impairments such as spasticity in children with CP does not in itself lead to changes in functioning [14]. (iii) The frequent absence of specific biomedical diagnoses to which biomedical therapies can be directed is often regarded as a source of frustration, limitation, and futility in "treating" NDDs, at least using conventional biomedical thinking and interventions. Many clinical programs still require a medical "diagnosis" before starting interventions rather than looking at children's functioning and supporting development from the perspective of what they can do and what they would like to do next, while continuing to pursue a diagnosis.

NOW WHAT? What are contemporary ideas about health, and how are they being applied?

In 2001, with the input of adults with impairments, the World Health Organization (WHO) redeveloped and refined its original 1980 International Classification of Impairments, Disabilities and Handicaps [15]. The result was the creation in 2001 of a universal integrated framework for health—the WHO's International Classification of Functioning, Disability and Health, colloquially called the ICF [5]. In the ICF, no traditional elements of "health" are excluded; rather, the ICF provides an *expanded*, interconnected picture of the many complementary elements—biomedical, psychological, and social—that influence people's lives and health, integrated into a single multidimensional "rule in" framework (Figure 1).

In 2012 Canadian childhood disability researchers animated the ICF framework with the "F-words for Child Development" (Functioning, Fitness, Family, Fun, Friendships, and Future) [6]. Their goal was to encourage people to see the whole child with an NDD in the broader context of their life as a unique individual, their family, and their community (Figure 2). In contrast to approaches in adult rehabilitation, interventions for children with NDD aim to support and promote a child's (and family's) *development and functioning*, regardless of whether things are done in ways that are considered typical [16]. This way of thinking moves beyond the tyranny of "normal" [17–19], a confining idea and one that is often not realistic for children developing with NDDs. The early use of evidence-based interventions to enhance functioning is of course encouraged; in parallel, one can continue to pursue a diagnostic search to understand the specific nature of the NDD.

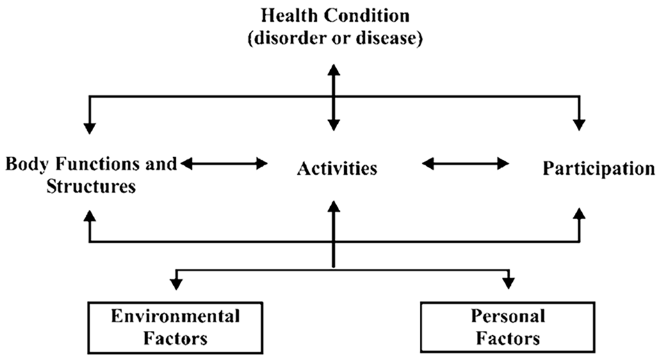
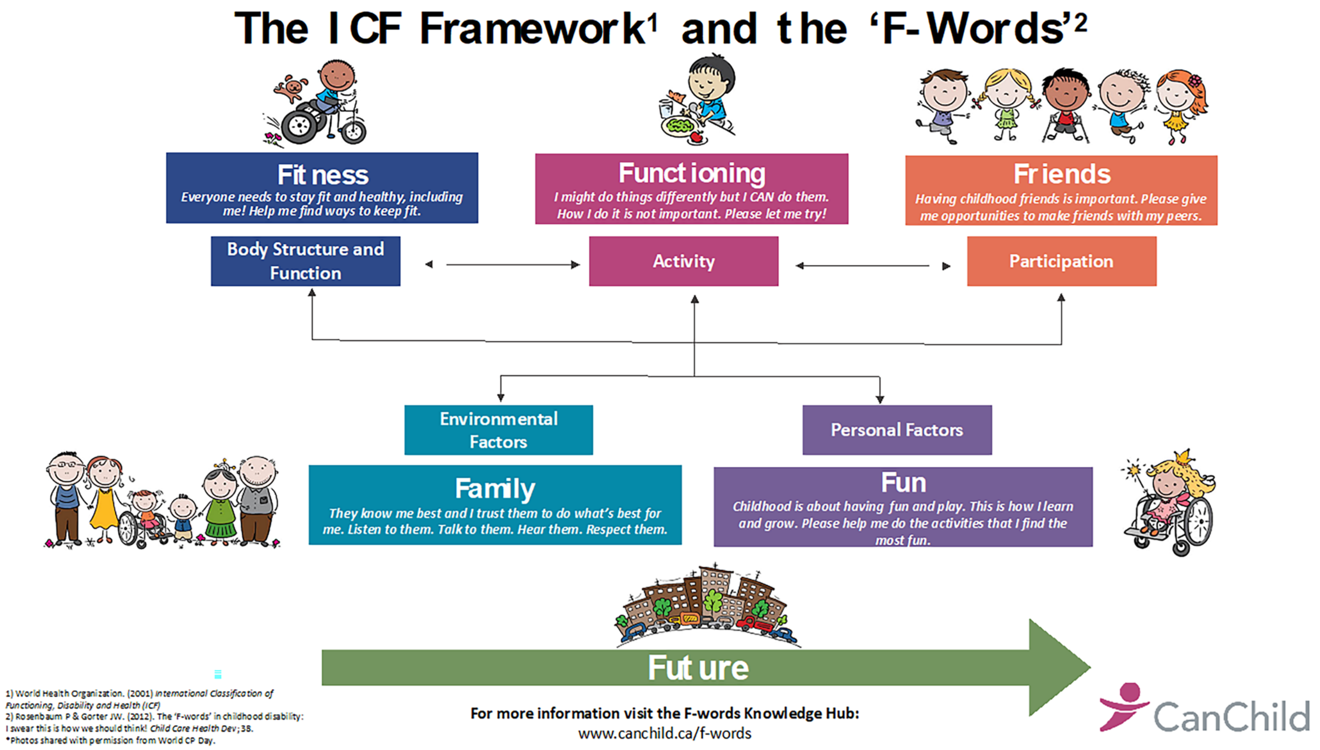


Figure 1. World health organization's ICF framework for health.
ICF schematic. Reprinted with permission from: the International Classification of Functioning, Disability and Health (ICF), World Health Organization, 2001.

The global embrace and uptake of the ICF and especially of the "F-words for Child Development" [20,21] illustrates that, in the field of childhood-onset disability, these ideas have captured the imagination of parents, service providers, clinical programs, researchers, and policy-makers. They have gained considerable currency with parents, service providers, and researchers around the world, as judged by the downloads (>82,000) and citations (over 700) of the original paper and the myriad translations of the concepts [21]. There is a rich "tool box" of free resources (https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability/f-words-tools) that can be used by children and families to present a fuller picture of the child and family, as well as their strengths, priorities and values across the domains of the ICF [22] (see www.canchild.ca/f-words). This way of presenting a child and family helps everyone who works with the child—be they extended family, service providers, teachers—to see beyond the impairments and recognize the child as a whole person, with their own story, strengths, identity and preferences (See Figure 3).

By considering both a child's "capacity" (best abilities) and "usual performance" we are encouraged to try to identify what may be creating a gap between these manifestations of functioning and to narrow that gap [23]. The ICF/F-words way of thinking



1) World Health Organization. (2001) *International Classification of Functioning, Disability and Health (ICF)*
2) Rosenbaum P & Gorter JW. (2012). The 'F-words' in childhood disability: I swear this is how we should think! *Child Care Health Dev*; 38.
*Photos shared with permission from World CP Day.

Figure 2. CanChild's F-Words for child development.

Figure 3. Illustrating one use of the F-words profile: Six-year old boy with level IV CP.

gives people "permission" to offer interventions that might be helpful anywhere and everywhere in the framework: think of mobility aids such as a walker or powered chair, an "environmental" intervention, to enable a child's mobility and by extension to expand their horizons without either prioritizing or neglecting interventions for the impairments at the level of "body structure and function". Thus, while applying the best of evidence-based biomedical interventions (e.g., therapies, medications, bracing, surgeries, etc.), the ICF concepts broaden the nature and scope of interventions. and enable us to think beyond the "What" to the "So What?" of interventions and what they offer children and families in terms of enhancing participation and quality of life [24].

As one evidence of the policy impact of these concepts, the Canadian Province of Ontario's Ministry of Children, Community and Social Services has incorporated the F-words as a key principle in their publicly-funded services [25] (see also https://www.ontario.ca/document/smartstart-hubs-guidelines), and supported CanChild Centre for Childhood Disability Research, creators of the F-words, to develop a series of free F-words training modules for families and service providers [26] (available at: https://canchild-fwords.ca/).

The ICF and F-words in no way prescribe what goals should be addressed or what interventions are to be done or avoided. They simply provide a broad contextual and conceptual framework onto which a child's and family's strengths, concerns, and future thinking can be aggregated by the child and family, with their service providers as a basis for exploring and planning shared approaches to support and enhance child-and-family-identified development. Insofar as the F-words provide a common language across NDDs, countries, and service providers, people may wish to apply them to their clinical work, program development, and education of child health professionals.

Take-away messages from this expanded way of thinking about "Health"

- Recognize that health is multifaceted and multidetermined.
- Take a "rule in" approach to a child's (and family's) profile; avoid reductionist thinking.
- Learn, and apply, concepts promoted by WHO's ICF and brought to life with the F-words

Theme 2: Development and functioning as a universal force for children and families

WHAT has been our training and thinking about child development?

In pediatrics the dominant approach to assessing child development has usually involved tracking milestones—typically related to aspects of motor, communicative, cognitive, and adaptive skills. The skills listed do not usually include social dimensions of functioning such as transactional relationships, engagement in play, exploration of close and far contexts; rather, they focus predominantly on what the child can or cannot *do*, with almost no identification of the contextual elements that drive development. Parents of children with NDDs search the Internet for information on when children without impairments "should" walk/talk/sleep through the night/be toilet trained… the list is long and the sources of information are varied and often inconsistent and [27–29].

So WHAT? How does this affect what we see, think and do?

Even when they have had *formal* training in or exposure to "child development"—and that is not a common experience for pediatricians—service providers are usually preoccupied with assessing the developmental progress of children with NDDs against normative standards. One implication of the use of the markers of "typical development" with children with NDDs is that as time goes on the gap often seems to widen between the progress of a child with NDD and impaired development, and the expected norm-based performance of many skills. This is almost always an artifact of the way we approach assessing development against age-based norms, rather than evidence of regression. We focus on the child's limitations instead of celebrating their achievements and the changes in their being and belonging [11].

Implicit in the milestone approach to child development is the expectation not only of the quantitative *(timing)* aspect of milestones, but also of the qualitative component (*how* things will be accomplished, to which standard and in what order). Thus, deviations of either the "quantitative" or "qualitative" markers of a child's development can create additional concern for everyone. We may then fail to observe, value and celebrate elements of development that are not on "the checklist"—the development of personality and identity, of problem-solving, of relationships and sense of being and belonging to family and community—each of which is crucial to wellbeing and life quality.

NOW WHAT? What's new in our thinking?

Children learn by active experience! A basic concern in the field of childhood-onset disability is to understand and address the *impact—on child and family development*—of the condition that is creating the "disability" [30]. Thus, while offering the best current evidence-based interventions for impairments, the focus of our work must be on *promoting development and functioning*, however these are accomplished. Development is infinitely varied, and expectations based on strict "norms" can be confining and disheartening. For example, children showing variations of development and function, some of which may be considered "deviant" by usual standards may appear not to fit in and thus may experience restrictions in their opportunities for development and learning (e.g., within school and peer group, or participation in community activities). It is important to recognize that the milestones by which we assess development are averages, computed as means and standard deviations of observations from large (often western) populations, and are likely variable across the world related to culture and environment [31]. Thus, it is essential to accept that each individual child's progress in any dimension of development may vary considerably even within the "norms".

In our preoccupation with the current developmental "problem," it is too easy to forget the innate capacity of the young child to continue to learn and progress—in other words, to *develop*—even if they do so differently because of childhood-onset brain impairment and related "deprivation" of experience [32]. By starting with an assessment and interpretation of the developmental progress of any specific child with an impairment, and charting their individual achievements over time against set goals, we can gain a sense of that particular child's trajectory, and capture their individual developmental progress. This is analogous to how we think about physical growth: a child's initial weight, length and head circumference, plotted on centile curves, provide a perspective of this child's growth against sex- and age-base norms. On subsequent assessments of that child, however, we are evaluating their growth progress against themself: are they tracking consistently for *them*, as opposed to the means for the population? In this way, one can capture change and identify incremental progress using a more individualized lens.

How can this expanded perspective be applied in everyday practice? We must always ask: how does this condition affect a child's *being, belonging and becoming* [7] and what is needed in the environment around the child and family to support these three crucial elements? Developmental outcomes related to being, belonging and becoming are closely related to wellbeing, identity, confidence, connection to family and others, culture and community, and a child's sense that they contribute to the contexts in which they live, learn and play [7]. These are the internal developmental conditions in which other developmental milestones (e.g., those related to movement, object manipulation, reading, talking) can be nurtured.

An emphasis on being, belonging and becoming as the entry point for our efforts to support *development and functioning* means helping children to progress developmentally, however that is accomplished. Many parents, and sadly many professionals, express concerns about interventions that offer extra support for children to function independently. They worry that making things "too easy" for children will lead to dependency and stifle initiative to try harder; they believe that children need to learn and practice "normal" functioning. To address this hesitancy, consider the parent or therapist who does not want a two-year-old with limited independent mobility to have a walker, but who has happily provided their older typically-developing child with training wheels to help that child learn to ride a bicycle, and where the training wheel "intervention" has often only been needed for a short time. We like to tease these adults by asking why it is okay for the older child to have a "walker" while the child with an impairment cannot have "training wheels"? Like training wheels, the walker empowers the child's independent mobility, something that may otherwise be very limited. Mobility leads to exploration and huge opportunities for learning—just think of being able to "liberate" the activity and learning capacity of a developing two-year-old!

Our intervention efforts, and our counseling to families, must be directed at *enabling* children to have experiences of success by providing just-right challenges that build the child's sense of self—their confidence and competence—while often astonishing parents and others with what children *can* do if given the opportunities and the right supports. Providing opportunities for children to engage in everyday learning experiences—doing the things they love, with the people they love, in the places they love, harnesses their strengths and preferences and contributes to their being, becoming and belonging. This approach to promoting development and functioning contrasts with well-intentioned but naïve beliefs in many schools of therapy that things have to be done "nicely" and "normally" from the outset, and that doing them "wrong," or with too much support, will lead to long-term problems [32].

Take-away messages from this expanded way of thinking about development

- Development in children is enhanced by experience-based learning. Promoting functioning is essential.
- Development is infinitely varied, and strict milestone-based markers disadvantage many children.
- Children with childhood-onset impairments still develop in their own ways: our challenge is to recognize, support and promote that development.

Theme three: Parents and family—the essential environment in which children grow up

WHAT has influenced our thinking about "family" in the context of NDD?

In the field of childhood-onset disability, as elsewhere, family, however constituted [10], is recognized as the human environment in which children grow and develop [9]. Parents/caregivers in particular are assumed to be the people to whom our advice about interventions and "management" will be provided, with the expectation that they will heed and apply our advice.

However, in most areas of child health the *child* is traditionally regarded as the "patient". The child's developmental or behavioral challenges are seen as the "presenting complaint," brought by parents and families seeking help, advice, support. Thus, with good intentions, we counsel parents about the child, and then offer programs of "early intervention" directed almost entirely at promoting the *child's* development. These programs are meant to be carried out by parents, whose "compliance" and engagement with us we then judge [11].

So WHAT? Why might this matter?

In this way of thinking, if parents appear not to take and follow through with our advice it is easy to apply pejorative labels to people we deem to be "non-compliant," "difficult," or "resistant," or whose questioning of us is evidence of "non-acceptance" of the reality of their child's predicament [33–35]. This traditional approach is, in effect, top-down pressure in which service providers promote our experience and expertise and expect parents to 'comply'.

Now What? How can this expanded perspective be applied in everyday practice?

Children with childhood-onset developmental or behavioral difficulties, like all children with health issues, never seek help on their own! They are always brought to services by adults who have the role of parents and caregivers—be they biological family, extended family, surrogate/foster family, or kinship groups. Thus, it is the adult members of the "family" to whom we offer our assessments, interpretations, counseling, and recommendations for interventions. This statement of the obvious leads to the conclusion that it is—and certainly in our view should be—the *family* (and in some cultures the kinship group) who are our "collaborative partners" or, in conventional medical jargon, the "patient".

There is considerable clinical and epidemiological evidence of the impact on the wellbeing of parents raising children with NDDs and other chronic health conditions [36–38]. This in turn challenges us to address the needs of parents beyond the technical aspects of our recommendations for child-directed interventions. We need to ask about, listen for, and attend to the knowledge parents bring about the broader context of their child's development, including their own needs for practical and psychological support to build confidence and capacity to make decisions that fit with their values and goals for the child and family in their community. The needs and contributions of other children in the family of the child with NDD should also be understood and never be ignored or taken for granted [39–41].

There are several implications of this perspective. The first is that, as the world's experts on their child, with thousands of hours of observation and experience with the child's functioning in myriad situations, parents must be listened to actively, and trusted for their insights. A wise parent remarked: "You have textbooks, we have story books!" [42].

The second implication is that we need to engage respectfully with parents as collaborative partners in their child's care, offering and practicing "family-centred" services [43]. This means that the voices and values of the family should be actively sought and factored into any and all recommendations to address their child's (and family's) concerns and goals for the future. Another insightful parent observed: "I want our lived experience treated as valid evidence."

Third, we need to create programs and supports directed to all parents to help *them* understand and be able to apply new ideas such as those offered in this paper [44]. Evidence from a Canadian-Australian program co-created and co-delivered by parents, service providers and researchers (including the authors)—what one parent called "early intervention for parents"—shows clearly that ideas like these have a powerful measurable impact on parents' sense of empowerment, confidence and competence in parenting their children with NDDs [45–47].

Note as well the implications of expecting parents to take on the role of "therapist" [11]. This requires resources of time and energy *additional* to their already full plate, and for many parents this is not a role they seek. They want to "parent," and to have value placed on the importance of them as *parents*—arguably their most important role—and not as *therapists*! Furthermore, the emphasis on "therapies" continually refocuses parents on their child's impairments and limitations, as well as implying that their efforts are never "enough," because their child still needs therapy! We believe that the expanded focus on parents being promoted here supports the essential need for programs and approaches that actively include parents and caregivers as well as children, especially in the early years.

Take-away messages from this expanded way of thinking about parents and family

- Parents are central to all children's lives—their development and wellbeing—and should be considered the focus of all our work in developmental disability.
- Parents raising children with NDDs and other chronic conditions experience much higher rates of physical and mental health impairments than parents of typically-developing children.
- Family-centred services provide a framework for collaborative efforts that enable parents/families and service providers to co-create, tailor, and modify ways to support child (and family) development.

Theme four: parenting – a dance led by the children

WHAT has guided our thinking about parenting?

Parenting has traditionally been thought of as a top-down process: parents "parented" and children developed. When children were developing well and behaving appropriately, parents were complimented, based on the assumption that their methods were effective and they were "good parents".

So What? Is that wrong?

The sad corollary of the top-down view of parenting is that when children struggled in any sphere of their development, it was easy to assume that parents were responsible—i.e., they were parenting inadequately—and then to blame and judge them. The twentieth century's most egregious illustration of this problem was Bettelheim's notion of "psychogenesis"—the theory that placed the origins of autism in the toxic familial environments that denied the basic emotional needs of babies unlucky enough to be born into them [48]. This idea illustrates poignantly the aphorism with which this paper opened, namely that our prior beliefs condition what issues we see and how we interpret them. As a psychoanalytically-oriented developmental psychologist, Bettelheim was referred, and assessed, young children (mainly boys) with odd behaviors and delayed or aberrant development, displaying signs of what we now call "autism spectrum disorder" (ASD); they were usually accompanied by apparently disaffected and emotionally distant mothers (Bettelheim called them “refrigerator” mothers). His interpretation concluded, in effect, “No wonder the child is behaving like this—look at the mother!” Blaming parents (usually mothers) was a pervasive approach to interpreting impaired child development and behavior, and as noted above, created untold heartache and distress for thousands of parents.

Beginning in the early 1970s two streams of thinking emerged. First, Arnold Sameroff [49] and others began to articulate the notion of “transactionality” in parent-child relationships. As expressed clearly by Sameroff, the world around the child impacts the child in myriad ways, and changes them; the “changed” child then interacts back on the (animate, e.g., parent) environment and creates new interactions in this constant and ever-changing relationship across space and time. Both parent and child are changed! We choose to refer to this as an illustration of “Parenting is a dance led by the (constantly changing) child.”

The second important development at this time was the work of Professor Michael Rutter and his colleagues at the Maudsley Hospital in London [50]. They had been studying children with autism and recognized that ASD was a childhood-onset neurodisability, with considerable neurodevelopmental impairment and complexity that was present from a very young age. Armed with this major evidence, it was now easy to turn the causal aphorism on its head and say: “No wonder the parents are like this (i.e., puzzled, apparently disaffected and ineffectual)—look at the child!”

Sadly, there remain today far too many threads of this older top-down view of parenting as promoted by Bettelheim, with its attendant negative impacts on parents.

NOW WHAT? What’s new? How can this expanded perspective on parenting be applied in everyday practice?

Current understanding of child development includes our awareness of the uniqueness of each child. This is well—and usually amusingly—illustrated by asking parents of twins and triplets how their children are *different*. The response is often an eye-roll and a smile, followed by an insightful account of the individuality of the children, even identical twins! One mother, when asked whether she loved her twins equally, indignantly responded “Yes”, as if being accused of favoring one. When she was then asked whether she treated them the same, she responded “Yes – uh, No!” and laughed heartily. She was able to acknowledge that she danced differently – distinctly – with each twin.

The reason for focusing on parenting in the context of NDDs is that our traditional emphasis with parents has been to offer advice to address children’s impairments, with the assumption that this will lead to improved functioning—a wish that is seldom fully realized [14]. Furthermore, parenting children with developmental disabilities is a complex process with children who may not be able to “dance” easily, so mis-steps may happen as children and parents learn to dance effectively with each other [51]. One minute they are doing the Viennese Waltz and then next minute they find themselves in the moshpit.

However, the scope of our interactions with parents much less often includes discussions of “parenting” the child as a child, asking about achievements and typical developmental issues not apparently associated with the impairment [17]. We may therefore be missing opportunities to understand how the child is progressing across the many domains of development and their “being, becoming and belonging” beyond the impairments on which we are focusing. We may not ask how parents are interpreting what their child is doing and how they are doing it, another illustration of how the opening aphorism impacts parents as well as service providers.

We believe that we should routinely take opportunities to learn about all aspects of a child’s development, to counsel parents about things of concern to them, and to celebrate and reinforce the things that are going well. This provides openings to illustrate our wide-ranging interest in both child development and parenting, and to hear about successes as well as concerns. An experienced parent of her youngest child with cerebral palsy (then aged 3 or 4 years), was asked how he was getting on. She replied: “He’s getting into a lot of mischief—that’s good, isn’t it?” She understood child development!

Like health professionals, parents have been acculturated by the health care system to focus on problems, so they easily assume that is all that we want to hear about. An approach to our conversations with families that is fun and disarming is to ask them: “What do you want to boast about? What is going well? What are we celebrating?” Insofar as our traditional history-taking in the context of NDDs focuses on problems, concerns, and limitations parents usually pause briefly and are then delighted to talk about their child as a person and to celebrate even small achievements. Asking about and listening for celebrations of other children in the family, and the relationships between siblings, friends or pets, is an important part of this conversation. In so doing, they and we once again expand the scope of our interest. And note that this idea is consistent with our promotion of the F-words concepts and tools as a way to understand the individual with the impairment, and not just to see the child as a “case” of NDD.

In talking with parents about the concept of transactionality, it is worth asking parents, right from the start, how they know what’s on their child’s mind. Some parents of infants, or of children who are significantly functionally challenged, are confused by this question, because their child is “too young” or “cannot talk”. Asking how they know their child is hungry, or tired, or happy almost always leads to an “aha” moment—parents become actively aware of these cues and signals but had not recognized them as examples of their child’s “communication”. Following up with questions like “What do you do when you see (whatever signal the child sends)?” helps parents see that even simple dances can be (have been!) learned, though perhaps not appreciated as “dances” till now.

Take-away messages from this expanded way of thinking about parenting

- Parents of children with childhood-onset NDDs often need help, support and insight to reinforce their “parenting” roles and values beyond applying therapies.
- Thus, in addition to parents and service providers seeing impairments and developmental challenges, everyone needs to recognize opportunities to help parents see, and to “parent,” their whole child within the context of their family and community.
- This broader focus on child (and family) development is analogous to the broadened focus on health discussed in Theme One.

Theme five: life-course perspectives

What has influenced our thinking about developmental trajectories?

As outlined elsewhere in this paper, our traditional focus in childhood-onset NDD has been on therapies to address and, wherever possible, remediate the impairments to enhance child functioning. We devote less effort to thinking and talking about how children's everyday skills, acquired in the early years (e.g., dressing, feeding, toileting, playing, having chores around the house) support children's development of being, becoming and belonging, which in turn scaffold and support ongoing development toward ever-increasing autonomy, individuation and self-determination into adulthood.

So what?

When children are dependent on adult help, parents may be required to do more of the tasks than would be necessary for a typically developing child who actively seeks independence. This in turn may limit the opportunities for a child with NDD to problem solve their own challenges, learn and build their own plans and scaffolds toward further independence. It is often more expeditious for parents to dress their children and get them ready for school than (in this example) to find the extra time for the child to have the opportunity to try and work it out for themselves with strategic questioning and guided discovery from the supporting adult. Given that this is the Monday-to-Friday routine it takes a lot of insight and commitment on everyone's part to have a different approach on weekends; thus, without anyone meaning for this to happen, learned dependency can easily develop. An approach such as that promoted by CO-OP [52] could prove useful. (This is an example of how we can support "parenting" of children with childhood-onset NDDs.)

One might wonder whether these ideas apply to children with significant life-long functional impairments. Even under circumstances of limited independent functioning, children are still part of their family and are still in a state of being, becoming and belonging. It is essential to give them opportunities to develop their own identity, express their individuality, and as much as possible to make choices and develop life skills. An F-words-based "profile" of the child can provide insights into strengths, preferences, connections and aspirations.

As a society we take for granted the division of lives into childhood (infancy, toddlerhood, etc.), adolescence, and adulthood (again subdivided in various way for various reasons). Conceptually, age in years is a logical factor on which to focus the many aspects of people's lives that are most obviously related to age: total dependency in the very early years, emerging independence throughout childhood, becoming one's own person in the adolescent years, and so on toward full independence as an adult. Thinking in ages and stages may make conceptual and practical sense when applied to young people who are developing typically, and for their families, but these divisions often do not accommodate children growing up with childhood-onset NDDs or other chronic health conditions.

Consider the obvious example of the way the health system organizes and delivers care and services by age categories, almost always in distinct facilities. A pervasive metaphor expressed internationally by parents of older children with complicated lives is that at the age of 16 or 18 years (jurisdictions vary) the children outgrow the services and "fall off the cliff". The same reality hits young people regarding the educational systems they have attended and that have provided an important social context for their lives until they are suddenly "done".

It is also sobering to consider that there are roughly three times as many adults with NDDs as children! This is simply a statement of the obvious—these young people grow into the adult years and seem to get lost. They do not all suddenly become able-bodied or capable of complete independence; nor do they all die (though longevity is often compromised by preventable medical and functional issues related to, for example, feeding, respiratory health, limited mobility, bone health). Rather, young people with childhood-onset NDDs too easily disappear from the systems (health, education, recreation, etc.) with which they and their families have until now been involved. Although their issues may be phenotypically similar to those of adults requiring "rehabilitation" (e.g., following stroke, motor vehicle accident, the onset of multiple sclerosis, etc.) the life course of these emerging adults has been fundamentally different from the beginning; the world of adult services often is unaware of these realities and how to support the people experiencing them.

Now What? How can this expanded life course perspective be applied in everyday practice?

There is an emerging awareness of the impact of fragmentation of services by age—a reality that imposes many challenges on families and young people growing up with NDDs. Models of care and service in the childhood years strive to be family-centred, recognizing the centrality of families' roles and their positionality as the responsible adults in the lives of their infants and children. By contrast, in the world of "adult" care the (typical adult) "patient" is assumed to be an independent and sentient being, capable of expressing their needs, making sense of the advice they are offered, and managing their lives. For young people growing up with different life experiences associated with childhood-onset NDDs or other chronic health concerns these assumptions may be naïve and potentially dangerous. Thus, unless the "adult" systems are attuned and receptive to these possible differences, young people may struggle to access services for which their parents have been primarily responsible until now [53,54].

Across the world of childhood-onset disability there are exciting efforts underway to create "transition" programs to address the concerns outlined above [55–57]. There is a genuine understanding that an NDD is not "just a physical impairment" or "communication impairment" or "intellectual disability". People with childhood-onset NDDs experience both physical and mental health concerns in ways that are inter-related and require a holistic approach to ongoing service access and provision [58]. These approaches take various forms, but all are designed to support an effective and hopefully seamless move across the gaps created by age-based services. Ideas include anticipatory planning with parents and young people starting in the early adolescent years; engaging receptive adult-focused colleagues to learn about the issues of these "former children" and to create services for them; and holding shared clinics that demonstrate the "hand-over" from one part of the healthcare system to another by people who talk and work across the age breaks.

A major implication of these transition issues is the need to recognize the importance, for those who work with young people with childhood-onset impairments, of seeing and thinking about the adult years, and sharing that vision with parents [11,59–62]. Taking a life-course perspective is essential if we are to promote heathy development across the lifespan for young people with NDDs. This means that from the outset of our engagement with parents of young people with childhood-onset NDDs, we can offer parents perspectives of varying "futures": "How might promotion of the functioning and autonomy we are talking about today support your child tomorrow/next month/next year/as they move into adulthood?" By starting early and exploring with parents how they might find ways to scaffold their child's opportunities to develop their autonomy, take risks, be responsible for decisions and choices, explore new possibilities, and learn to "lead" (all, of course, examples of "parenting") we can help parents see beyond the immediate challenges and become more confident in this often uncomfortable space.

We need systematic studies that elicit the voices and perspectives of current and former children with childhood-onset NDDs. "What do/did we do well? What do/did we do poorly, or miss doing, that would have served you better now?" Equally, but distinct from the voices of the young people, we need to hear from older parents about what they were told then, what they know now, and what they would tell their younger selves – and us—about what is more and less important. There are clearly rich resources of experience and perspective to be explored, with the findings fed back to those who work with young children and can then use these learnings in all we do, and in many cases stop doing!

Two ideas are worth considering:

i. At the level of the health care system, there are tantalizing examples of specially trained family physicians with a career-long interest in "disability across the lifespan". Queen's University in Kingston Ontario Canada makes such opportunities available [63]. As primary care providers they have been trained to bring a holistic view of the person-and-their-health-needs to all their encounters. With appropriate supports of specialists in NDD, adult rehab, and related areas, these specially-trained general physicians may be best positioned to provide stable life-course continuity to families and people with NDD. This is a model that bears exploration.
ii. The second idea is probably more aspirational—namely, to create, implement and evaluate national childhood-onset disability programs founded on concepts like those offered here, funded by public resources as investments in the well-being of *families* raising young people with NDDs, and supporting the full development of these young people and their families. Australia's National Disability Insurance Scheme [64], while still a work in progress, may provide a strong example of how national governments are well placed to provide the kind of leadership being advocated in this paper.

Take-away messages from this expanded way of thinking about Life-Course Perspectives

- Childhood-onset NDDs are life-long conditions, so life-course perspectives on health, development, parenting and functioning are essential from the very early years of the child's life.
- While much remains to be developed across communities to create opportunities for young people with NDDs to take their place in society, exciting efforts are being created and evaluated to support this broader view of "NDD".

In conclusion

Contemporary ideas in the field of childhood-onset NDDs challenge traditional thinking, teaching, beliefs and practices. Emerging research evidence indicates that we can do better. In weaving together the concepts presented in this paper the authors believe that we can and should expand our understanding of the needs of children with NDDs, their families, and our professional opportunities to offer an integrated approach to child-in-family-in-community. We advocate for consistent, holistic practices and policies that celebrate child and family strengths; provide the best of our interventions within the broad WHO ICF framework for health; and move beyond the usually elusive goal of "fixing" toward promoting functioning, to enable the fullest being, becoming and belonging of children with NDDs and their families. We welcome the opportunity to share these ideas with colleagues and families.

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References

[1] Pless IB, Pinkerton P. Chronic childhood disorders: promoting patterns of adjustment. London: Kimpton; 1975.
[2] Stein RE, Jessop DJ. A noncategorical approach to chronic childhood illness. Public Health Rep. 1982;97(4):354–362.
[3] Jessop DJ, Stein RE. Essential concepts in the care of children with chronic illness. Pediatr. 1988;15(1-2):5–12.
[4] Stein RE, Jessop DJ. What diagnosis does not tell: the case for a noncategorical approach to chronic illness in childhood. Soc Sci Med. 1989;29(6):769–778. doi:10.1016/0277-9536(89)90157-3.
[5] World Health Organization. International Classification of Functioning. Disability and Health (ICF). Geneva: World Health Organization; 2001.
[6] Rosenbaum PL, Gorter JW. The 'F-Words' in childhood disability: I swear this is how we should think! Child Care Health Dev. 2012;38(4):457–463. doi:10.1111/j.1365-2214.2011.01338.x.
[7] Bickenbach J, Rubinelli S, Baffone C, et al. The human functioning revolution: implications for health systems and sciences. Front Sci. 2023;1:512. doi:10.3389/fsci.2023.1118512.
[8] Commonwealth of Australia. Belonging, being and becoming. The early years learning framework for Australia. 2009. https://www.acecqa.gov.au/sites/default/files/2023-01/EYLF-2022-V2.0.pdf.
[9] Bronfenbrenner U . Ecology of the Family as a Context for Human Development: research Perspectives. In Adolescents and Their Families. Lerner RM, Castellino DR, editors. Routledge; 1999. 1st Edition. 1–21. eBook ISBN9781315827063.

[10] Dermott E, Fowler T. What is a family and why does it matter? Social Sciences. 2020;9(5):83. doi:10.3390/socsci9050083.

[11] Rosenbaum P. Beyond fixing: reconsidering assumptions about child-onset impairments. Dev Med Child Neurol. 2024;66(6):676. doi:10.1111/dmcn.15861.

[12] Palisano RJ, Di Rezze B, Stewart D, et al. Lifecourse health development of individuals with neurodevelopmental conditions. Dev Med Child Neurol. 2017;59(5):470–476. doi:10.1111/dmcn.13402.2017doi:10.1111/dmcn.134022017.

[13] Miller AR, Mâsse LC, Shen J, et al. Diagnostic status, functional status and complexity among Canadian children with neurodevelopmental disorders and disabilities: a population-based study. Disabil Rehabil. 2013;35(6):468–478. doi:10.3109/09638288.2012.699580.

[14] Wright FV, Rosenbaum PL, Goldsmith CH, et al. How do changes in body functions and structures, activity, and participation relate in children with cerebral palsy? Dev Med Child Neurol. 2008;50(4):283–289. doi:10.1111/j.1469-8749.2008.02037.x.

[15] World Health Organization. International Classification of Impairment. Disability and Handicap (ICIDH). Geneva: World Health Organization; 1980.

[16] D'Arcy E, Evans K, Afsharnejad B, et al. Assessing functioning for individuals with neurodevelopmental conditions: current clinical practice in Australia. Aust Occup Ther J. 2022;70(1):43–60. doi:10.1111/1440-1630.12834.

[17] Rosenbaum PL, Novak-Pavlic M. Parenting a child with neurodevelopmental. Curr Dev Disord Rep. 2021;8(4):212–218. doi:10.1007/s40474-021-00240-2.

[18] Miller AR, Rosenbaum PL. Perspectives on 'disease' and 'disability' in child health: the case of childhood neurodisability. Front Public Health. 2016;4:226. doi:10.3389/fpubh.2016.00226.

[19] Halfon N, Houtrow A, Larson K, et al. The changing landscape of disability in childhood. Future Child. 2012;22(1):13–42. doi:10.1353/foc.2012.0004.

[20] Soper AK, Cross A, Rosenbaum P, et al. Exploring the international uptake of the 'F-words in Childhood Disability': a citation analysis. Child Care Health Dev. 2019;45(4):473–490. doi:10.1111/cch.12680.

[21] Cross A, Rosenbaum P, Grahovac D, et al. A web-based knowledge translation resource for families and service providers (The "F-Words" in Childhood Disability Knowledge Hub): developmental and Pilot Evaluation Study. JMIR Rehabil Assist Technol. 2018;5(2):e10439. doi:10.2196/10439.

[22] [cited 2024 Mat 30]. Available from: https://canchild-fwords.ca/.

[23] Rosenbaum P. Editorial Advocating for children with impairments and their families: a proposed model. Dev Med Child Neurol. 2021;63(12):1364–1364. doi:10.1111/dmcn.15049.

[24] Madden RH, Bundy A. The ICF has made a difference to functioning and disability measurement and statistics. Disabil Rehabil. 2019;41(12):1450–1462. doi:10.1080/09638288.2018.1431812.

[25] Ontario Ministry of Children. Community and Social Services. Preschool Speech and Language and Children's Rehabilitation Services Guidelines. 2024. https://www.ontario.ca/document/preschool-speech-and-language-and-childrens-rehabilitation-services-guidelines.

[26] www.canchild.ca/f-words.

[27] Star Institute; [cited 2024 Mar 30]. Available from: 2024https://sensoryhealth.org/node/1856#:~:text=Note%20of%20Caution%3A%20Developmental%20milestones,account%20differences%20in%20neurology%20etc.

[28] Zubler JM, Wiggins LD, Macias MM, et al. Evidence-informed milestones for developmental surveillance tools. Pediatrics. 2022;149(3):e2021052138. doi:10.1542/peds.2021-052138.

[29] https://www.focusonthefamily.ca/content/social-and-emotional-milestones-in-child-development?utm_term=&utm_campaign=Focus+on+the+Family+-+Dynamic+Search+Ads+-+Canada&utm_source=adwords&utm_medium=ppc&hsa_ver=3&hsa_acc=4036375728&hsa_mt=&hsa_ad=617153507940&hsa_tgt=dsa-422618171263&hsa_net=adwords&hsa_grp=78929296969&hsa_kw=&hsa_cam=2065863790&hsa_src=g&gad_source=1&gclid=Cj0KCQjw8J6wBhDXARIsAPo7QA_p6fY8J3FWh8g6ApaNWyeoka7B5L9bgrHb0C1pvoljS9kwTiYRhAQaAmO2EALw_wcB.

[30] Rosenbaum P. Child development: the foundation of 'childhood disability'. Dev Med Child Neurol. 2023;65(12):1538–1538. doi:10.1111/dmcn.15738.

[31] Karasik LB, Robinson SR. Milestones or Millstones: how standard assessments mask cultural variation and misinform policies aimed at early childhood development. Policy Insights Behav Brain Sci. 2021;9(1):57–64. doi:10.1177/23727322211068546.

[32] Palmer FB, Shapiro BK, Wachtel RC, et al. The effects of physical therapy on cerebral palsy. A controlled trial in infants with spastic diplegia. N Engl J Med. 1988;318(13):803–808. doi:10.1056/NEJM198803313181302).

[33] Phoenix M, Rosenbaum P. Presenting the model of risk, disability and hard-to-reach families to inform early intervention services. Disabil Rehabil. 2017;41(2):244–249. doi:10.1080/09638288.2017.1385650. Epub 2017 Sep 29.

[34] Phoenix M, Jack SM, Rosenbaum PL, et al. Parents' attendance, participation and engagement in children's developmental rehabilitation services: part 1. Contextualizing the journey to child health and happiness. Disabil Rehabil. 2019;42(15):2141–2150. [Epub ahead of print] doi:10.1080/09638288.2018.1555617.

[35] Phoenix M, Jack SM, Rosenbaum PL, et al. A grounded theory of parents' attendance, participation and engagement in children's developmental rehabilitation services: part 2. The journey to child health and happiness. Disabil Rehabil. 2019;42(15):2151–2160. doi:10.1080/09638288.2018.1555618.

[36] Brehaut JC, Kohen DE, Raina P, et al. The health of primary caregivers of children with cerebral palsy: how does it compare to other Canadian caregivers? Pediatrics. 2004;114(2):e182–e191. doi:10.1542/peds.114.2.e182.

[37] Lach LM, Kohen DE, Garner RE, et al. The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders. Disabil Rehabil. 2009;31(8):607–618. doi:10.1080/09638280802242163.

[38] Arim RG, Miller AR, Kohen DE, et al. Changes in the health of mothers of children with neurodevelopmental disabilities: an administrative data study. Res Dev Disabil. 2019;86:76–86. doi:10.1016/j.ridd.2018.12.007.

[39] Nguyen L, Jack SM, Davis H, et al. Being a sibling of a youth with a neurodisability: a qualitative study about the roles and responsibilities during the transition to adulthood. Child Care Health Dev. 2024;50(2):e13241. doi:10.1111/cch.13241.

[40] Nguyen L, Bootsma J, Ketelaar M, et al. Programs to prepare siblings for future roles to support their brother or sister with a neurodevelopmental disability: a scoping review. Curr Dev Disord Rep. 2023;10(1):47–79. doi:10.1007/s40474-023-00272-w.

[41] Nguyen L Davis H, Bellefeuille S, Havens J, et al. Canadian resources for siblings of youth with chronic health conditions to inform and support with healthcare management: a qualitative document analysis front. Rehabil. Sci. 2021;2:589. doi:10.3389/fresc.2021.724589.

[42] Rosenbaum P. 'You have textbooks; we have story books.' Disability as perceived by professionals and parents. Dev

Med Child Neurol. 2020;62(6):660–660. https://www.youtube.com/watch?v=E9NyZAUIqfA) doi:10.1111/dmcn.14491.

[43] Rosenbaum P, King S, Law M, et al. Family-centred services: a conceptual framework and research review. Phys Occupat Thera Pediatr. 1998;18(1):1–20. doi:10.1300/J006v18n01_01.

[44] Phoenix M, Reitzel M, Martens R, et al. Reconceptualizing the family to improve inclusion in childhood disability research and practice. Front Rehabil Sci. 2021;2:710580. doi:10.3389/fresc.2021.710580.

[45] Miller L, Nickson G, Pozniak K, et al. ENabling VISions and Growing Expectations (ENVISAGE): parent reviewers' perspectives of a co-designed program to support parents raising a child with an early onset neurodevelopmental disability. Res Dev Disabil. 2022;121:104150. doi:10.1016/j.ridd.2021.104150.

[46] Pozniak K, Cross A, Babic R, et al. Co-development of the ENVISAGE-families program for parents of children with disabilities: reflections on a parent-researcher partnership. Austral Occupat Ther J. 2022;1-9:11. doi:10.1111/1440-1630.12811.

[47] Miller L, Imms C, Cross A, et al. Impact of "early intervention" parent workshops on outcomes for caregivers of children with neurodisabilities: a mixed-methods study. Disabil Rehabil. 2023;45(23):3900–3911. Nov doi:10.1080/09638288.2022.2143579.

[48] Bettelheim B. The empty fortress: infantile autism and the birth of the self. New York: Free Press of Glencoe; 1967.

[49] Sameroff A. The transactional model. Sameroff A, editor. The transactional model of development: how children and contexts shape each other. American Psychological Association; 2009. pp. 3–21. doi:10.1037/11877-001.

[50] Rutter M. Autism research: lessons from the past and prospects for the future. J Autism Dev Disord. 2005;35(2):241–257. doi:10.1007/s10803-004-2003-9.

[51] Garner RE, Arim RG, Kohen DE, et al. Parenting children with neurodevelopmental disorders and/or behaviour problems. Child Care Health Dev. 2013;39(3):412–421. doi:10.1111/j.1365-2214.2011.01347.x.

[52] McEwen S, Polatajko H, Wolf T, et al. 2015. Executive C-OA. CO-OP Fidelity Checklist (Rev. ed.); [cited 2024 Aug 5]. Available from: http://www.ot.utoronto.ca/coop/research/coop_research/fidelity.html.

[53] Gorter JW, Stewart D, Woodbury-Smith M. Youth in transition: care, health and development. Child Care Health Dev. 2011;37(6):757–763. doi:10.1111/j.1365-2214.2011.01336.x.

[54] Gorter JW, Gibson BE. Independence in adulthood: ethical challenges in providing transitional care for young people with neurodevelopmental impairments. In: Rosenbaum P, Ronen G, Dan B, Racine E, Johannesen J, editor. Ethics in Childhood Neurodisability: cases, Principles and Clinical Practice. London: Mac Keith Press; 2016. Pp. 335–348.

[55] Toulany A, Gorter JW, Harrison M. A call for action: recommendations to improve transition to adult care for youth with complex health care needs. Paediatr Child Health. 2022;27(5):297–309. doi:10.1093/pch/pxac047.

[56] Doucet S, Splane J, Luke A, et al. Programmes to support paediatric to adult healthcare transitions for youth with complex care needs and their families: a scoping review. Child Care Health Dev. 2022;48(5):659–692. doi:10.1111/cch.12984.

[57] Gorter JW, Stewart D, Woodbury-Smith M, et al. Pathways toward positive psychosocial outcomes and mental health for youth with disabilities: a knowledge synthesis of developmental trajectories. Canad J Commun Mental Health. 2014;33(1):45–61. doi:10.7870/cjcmh-2014-005.

[58] CDC re mental health in people with developmental disabilities; 2024; [cited 2024 Mar 30]. Available from: https://www.cdc.gov/ncbddd/disabilityandhealth/features/mental-health-for-all.html.

[59] Culnane E, Loftus H, Peters R, et al. Enabling successful transition-Evaluation of a transition to adult care program for pediatric liver transplant recipients. Pediatr Transplant. 2022;26(3):e14213. doi:10.1111/petr.14213.

[60] Halfon N, Larson K, Lu M, et al. Lifecourse health development: past, present and future. Matern Child Health J. 2014;18(2):344–365. doi:10.1007/s10995-013-1346-2.

[61] Hanes JE, Hlyva O, Rosenbaum P, et al. Towards a better understanding of the lifelong health implications of cerebral palsy: exploring the lived experiences of young Canadians. Child Care Health Dev. 2019. 2019;45(5):613–622. Epub 2019 Jul 24 doi:10.1111/cch.12705.

[62] Palisano RJ, DiRezze B, Stewart D, et al. Promoting capacities for future adult roles and healthy living using a lifecourse health development approach. Disabil Rehabil. 2020;42(14):2002–2011. doi:10.1080/09638288.2018.1544670.

[63] https://meds.queensu.ca/academics/queens-lakeridge-health-md-family-medicine-program.

[64] https://www.ndis.gov.au/.