



Parenting a Child with a Neurodevelopmental Disorder

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Abstract

Purpose of Review Traditional thinking and focus in ‘childhood disability’ have been on the child with the impairment — with the imperative to make the right diagnosis and find the right treatments. The implicit if not direct expectation was that interventions should aim to ‘fix’ the problems. Professionals have led the processes of investigation and management planning, with parents expected to ‘comply’ with professionals’ recommendations. Much less attention has been paid to parents’ perspectives or their wellbeing.

Recent Findings In the past two decades, we have seen a sea change in our conceptualizations of childhood disability. The WHO’s framework for health (the International Classification of Functioning, Disability and Health (aka ICF)) and CanChild’s ‘F-words for Child Development’ inform modern thinking and action. We now recognize the family as the unit of interest, with parents’ voices an essential element of all aspects of management. The goals of intervention are built around the F-words ideas of function, family, fun, friendships, fitness and future.

Summary There has been world-wide uptake of the F-words concepts, with increasing evidence of the impact of these ideas on parents and professionals alike. There are important implications of these developments on the structure, processes and content of services for children with neurodevelopmental disorders, their families and the services designed to support them.

Keywords Childhood disability · Child and family development · ICF · F-words in child development · Family wellbeing

Introduction

In developing the ideas for this paper, we felt it would be useful for the reader to understanding the evolving basis of several new ways of thinking about childhood disability. To do this, we will introduce a number of the premises on which new thinking is based. This will allow us to discuss the clinical and research implications of parenting a child with a disability and to contrast these approaches with traditional thinking. We have integrated these themes and their direct applications by presenting three main concepts. Each comes with an explanation and is followed by what we see

to be implications for direct clinical services and relevant research opportunities.

Readers will also note how often the authors refer to the world around us, with examples and analogies drawn from everyday experience. This is done to emphasize the reality that childhood disability is not a separate domain from childhood and child development, nor is parenting children with impairments fundamentally different from parenting any other child. The same principles should apply, as we endeavour to illustrate here.

It is important that readers understand the perspectives that the authors bring to this paper. We are both ‘developmentalists’ — that is, health professionals with a longstanding engagement with children with neurodevelopmental impairments that do, or might, put the children’s development at risk. PR is a developmental paediatrician and health services researcher; MNP is a physiotherapist currently pursuing doctoral studies with PR. We work together academically and in clinical research. We have come to recognize, in all our work — be it teaching, research or clinical encounters — that it is essential to outline the assumptions that inform our work with families of children with any

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neurodevelopmental impairment. If the implications of these premises, in terms of recommended approaches, are clear to others, and if people find these ideas interesting, they will hopefully adopt the role of ‘knowledge broker’ to promote these ideas to others.

Premise 1: Children Live in a ‘Context’ of Family and Community

This may seem like a statement of the obvious: all children (including those with neurodevelopmental disabilities) must be seen and thought about in the context of *child-in-family-in-community*, and not as isolated ‘child cases’ [1••]. The reason to emphasize this self-evident truth is that our traditional biomedical focus has been on the child: we strive to make a diagnosis, find the right interventions (therapies and other treatments), prescribe these to parents and expect to find both ‘compliance’ from the family to carry out our well-intentioned advice and changes in the child’s progress. While we know that the child lives in a family, and is being raised by parents, traditional thinking is child-centric, often with little or no formal acknowledgement of the roles and needs of parents and families.

There is no doubt that parenting a child with disabilities can, and very often does, come with greater worry, increased stress levels, financial insecurity and many other physical, psychological or socio-economic challenges [2, 3, 4•, 5, 6•, 7, 8]. While parents experience the increased burden of caregiving for their children with disabilities, they have often said that they are just as ‘normal’ as any other family. It is not surprising that some parents of children with disabilities report that the child’s disability did not significantly impact their family functioning until they were expected to get involved in the ‘outside-the-family’ life. On the other hand, seeking the best (and often costly) services, advocating endlessly for their child with a host of community services (educational, recreational, social services, etc.), dealing with stigmatization and discrimination — these seem to many parents to be bigger issues than the disability itself. It is reasonable to consider that far too often the source of parents’ stresses and worries is not their ‘poor coping’, but the attitudes and attributes of the ‘outside’ world.

Implications for Parents and Professionals

In today’s work in the field of childhood disability, we are increasingly recognizing family as the unit of interest. The first and most obvious fact is that children never independently seek help for their development or behaviour! Professionals form clinical relationships with parents about their child, who, in terms of classic clinical practice, might be thought of as the ‘presenting complaint’ about which

parents seek advice and support. Insofar as even the most skilled service providers can offer, at best, perspectives and recommended interventions, it is parents who are our real ‘clients’. It is parents and families who raise their children and who, we hope, will understand and apply our recommended interventions. For these reasons, professionals must develop respectful trusting relationships with families as the ‘context’ — the milieu — in which children will grow and develop.

For health and social care professionals, it is therefore essential that services be offered in ways that are ‘family-centred’ [9••, 10••, 11•, 12•, 13•, 14, 15]. Beyond the motherhood implications that this phrase might evoke, there are well-defined principles to guide the delivery of services in this manner [9••]. There is also considerable research evidence to demonstrate that parents who report experiencing ‘better’ family-centredness of services also report better satisfaction and mental health outcomes, as well as less stress in dealing with their child’s services [10••]. It will be obvious that this will be important for the children of these families. It also means that supporting parents with appropriate information about their child, ideas to promote development and sensitivity to the parents’ and family’s predicament, are every bit as important as specific therapies for the child.

Premise 2: The Centrality of ‘Development’ in ‘Developmental Disability’ and Its Importance for Parenting

Childhood neurodevelopmental conditions like cerebral palsy and autism spectrum disorder — often collectively called ‘disabilities’ — are not ‘diseases’ as such (though there is always a more or less well-identified neurobiological underpinning of these phenotypic conditions). Rather they are conditions that do, or are likely to, affect the trajectory of a child’s (and a family’s) development. The term ‘neurodevelopmental’ contains the word ‘developmental’ — but the ‘disability’ element immediately distracts people’s attention. As noted, traditional biomedical thinking has focused almost exclusively on the ‘disability’ and not nearly enough on the ‘developmental’ aspects of the child’s and family’s lives. In contrast, modern ideas about the role of ‘therapies, interventions, treatments, etc.’ do — or certainly should — address the ways that they enhance child (and family) development [16•].

The new emphasis of our thinking must therefore be to recognize that children with neurodevelopmental conditions are children first — ever-changing and constantly in the processes of ‘being, becoming and belonging’. This means that in offering any intervention, we must consider whether and how our advice is designed to enhance children’s development. Equally important, but less well recognized, is that

parents and families are also changing and developing, so our intervention advice must consider that reality as well.

Implications for Parents and Professionals

A corollary of the focus on development is the reality that ‘parenting is a dance led by an ever-changing child’ [16•]. If we think about it, every parent will acknowledge that all parenting is a kaleidoscopic, transactional experience, dependent upon what each child brings to each step of each ‘dance’! To understand this idea, think about how each of our own children is unique and different, and how we apply our parenting values in specific ways for each of them. Parents of twins can attest to this reality, because while they have two children at the same age and stage, they are always ‘dancing’ with each of their twins in ways that are unique to that child.

When children are developing ‘well’, it is easy for parents to feel that they are doing a good job. On the other hand, if a child struggles with developmental or behavioural challenges, it is often assumed (by parents and professionals alike) that this is somehow a failure on the part of the parents. The classic, and frankly very destructive, assumption that ‘refrigerator mothers’ caused autism should be an object lesson for all health and social care professionals regarding how narrow deterministic thinking can lead to great suffering [17]. On the other hand, when the constantly evolving child — with their changing capacities, interests and experiences — is appreciated to be leading the dance, parenting becomes both less formulaic and far more interesting!

Premise 3: New Thinking About ‘Disability’ and New Frameworks

Traditional thinking about the idea of ‘disability’ involved a number of ideas, assumptions and myths [1••]. These ideas, and their conceptual underpinnings, are addressed briefly here in order to provide a context for newer thinking.

The first assumption was that the ‘problem’ (disability) lies within the person. Indeed, in many cultures, the additional implication of this idea was that some variation of fate, karma or divine judgement about the child and/or the family had contributed to this situation. From a strictly biomedical perspective, this meant that considerable effort was expended by professionals to find the right diagnosis — often involving a lot of time to pursue a range tests and assessments. The belief was (and still is) that the more precise the diagnosis, the more specific and targeted the intervention could be. This ‘diagnosis-to-treatment’ paradigm is certainly very appropriate in certain circumstances, most notably in acute-onset conditions. As an example, think of an adult with sudden chest pain, and the potential to offer life-saving treatments based on pinpointing the correct

specific diagnosis. On the other hand, while a specific diagnosis and formulation have an important place in neurodisability, as outlined below, the reality is that virtually none of our developmental interventions in childhood disability is diagnosis-specific [18•]. Thus, there is little reason to defer offering interventions, including providing parents advice and guidance for their child’s developmental issues, while the diagnostic search goes on. Both efforts can be done in parallel.

A second assumption about ‘disability’ was that the goal of our interventions is to fix the neurodisability — to which end our therapies and interventions have traditionally been directed [1••]. Realistically, this is at best an aspirational goal: in truth, in medicine we do not ‘fix’ much at all (perhaps with the exception of simple fractures). A related notion in childhood disability intervention is that we are doing childhood ‘rehabilitation’. Again, this is an idea imported, with good intentions, from adult health care, whereby after an adult experiences some function-limiting event, we strive to help them return to their former selves (‘rehabilitating’ to ‘return to function’). In children, the focus needs to be on promoting functioning in ways that are developmentally appropriate, rather than to return to a functional state that has not yet appeared!

This leads directly to the third assumption — that it is important to promote ‘normal’ function for children with impairments. The idea of ‘normal’ is, in our opinion, at best naïve and at worst confining and frankly silly. ‘Normal’ is based on ‘typical’ patterns of child development — *when* (milestones) and *how* (the ‘usual’ ways) children develop. This idea builds on the notion of ‘average’ times when things happen (for example, milestones) but fails completely to recognize the wide variation around these averages and hence creates worries when things are ‘outside the norm’ (literally, from Latin, ‘ab’ (away from) normal).

Together, these three assumptions can create a tyranny for families (and for professionals as well). In the next section, we present current thinking that addresses and moves well beyond these ideas.

Implications for Parents and Professionals

Conditions that impact a child’s neurodevelopmental status arise for a wide variety of identifiable reasons, and often with no recognized ‘cause’. To the extent that it is possible to identify a clear ‘explanation’ of the child’s condition, parents can know and hopefully understand both what ‘it’ is and what ‘it’ is not. For many people, the things they worry about are often ‘worse’ than what their child’s specific issues turn out to be. As one parent remarked many years ago: ‘It is better to know the worst than to not know’. Another said: ‘When you know the truth, then you can act’.

But in our opinion, the ‘truth’ should be a ‘formulation’ of the implications of the child’s impairment, in part because a diagnostic label by itself tells us nothing about the child as a developing being!

This speaks to the value of being able to explain, as clearly as possible, both what is happening and what it might mean for ‘this’ child and ‘this’ family at ‘this’ stage of development. It is essential that we individualize all our counselling to the specific situation. A parent captured the complementarity of parental and professional perspectives this way: ‘You have textbooks, we have story books!’ [19•]. Needless to say, we should always speak the truth — though there is an important difference between telling the truth and unloading everything we know all at once when parents are not ready to ask and hear. Counselling must be an ongoing process that evolves with, among other factors, the child’s continuing issues of health and development (including progress or lack thereof), the family’s emerging understanding of their issues and their knowledge, their readiness to hear what’s next (based on their questions to the people who work with them), and when new information becomes available.

New ideas about ‘disability’ are in many ways formulations of concepts that have been with us for decades but are now taking root in child health care. Some of these concepts have appeared in fields parallel to health care (e.g. developmental or social psychology) and hence are not as well recognized as they should have been. An important example is Bronfenbrenner’s ecological systems theory framework of child-in-family-in-community [20••]. In the field of health, the World Health Organization’s framework for health was published in 2001 within the International Classification of Functioning, Disability and Health (known by the nickname

ICF) [21••] (see Fig. 1). This universal framework of integrated, interconnected parts expands beyond the traditional reductionist diagnosis-based (‘rule out’) view of disability to a holistic biopsychosocial framework (‘rule in’). It allows our thinking to be inclusionary, in order to bring in relevant elements within the person, their human environment, the myriad external influences on them, and so on. Most importantly, it focuses on what people ‘can’ do, providing a strengths-based approach rather than one built on deficits. Such a view may help families (and providers) to target interventions to those issues identified by families to be important to them at this stage of their development.

In 2012, CanChild Centre for Childhood Disability Research published a whimsical paper that offered an operationalization of the ICF framework — the ‘F-words in Childhood Disability’ [1••], now renamed as the ‘F-words for Child Development’ (see Fig. 2). The emphases in this way of thinking — now widely shared and applied internationally by families as well as professions — are outlined briefly here to illustrate the ways that these ‘F-words’ address the myths and constraints associated with traditional thinking about childhood disability. The website www.CanChild.ca/f-words offers a broad range of free downloadable F-words-related resources — many created by parents and colleagues and generously shared with CanChild.

Functioning: The ICF’s ‘activity’ is reformulated as ‘functioning’, which refers to ‘doing things’, without regard to doing them ‘nicely’, ‘normally’ or as fast as others. All children need the opportunity to experience things themselves, integrating their self-initiated efforts with the sensory, behavioural and social feedback associated with those efforts. Research shows that making opportunities available

Fig. 1 The International Classification of Functioning, Health and Disabilities framework

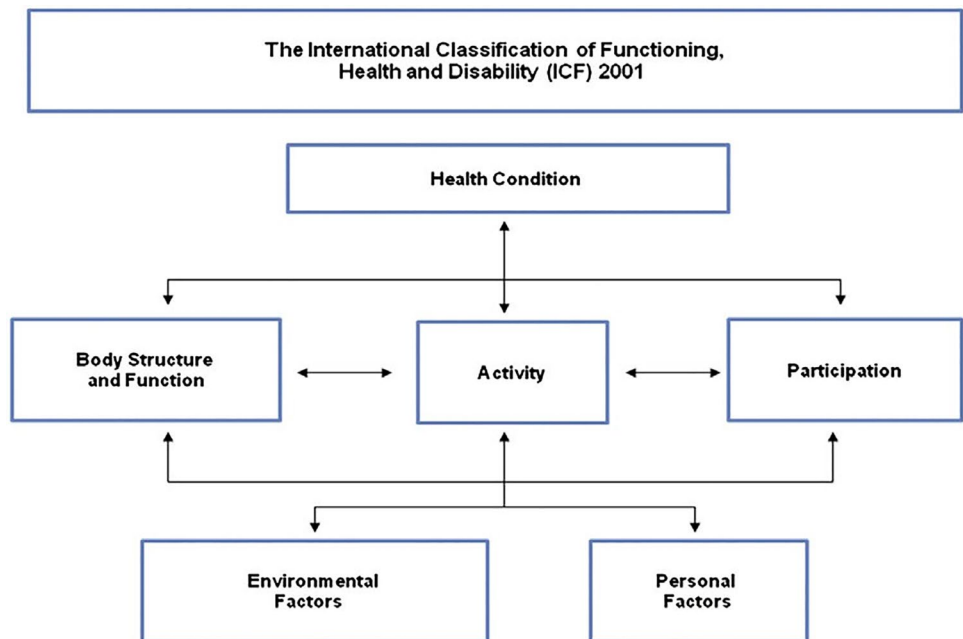
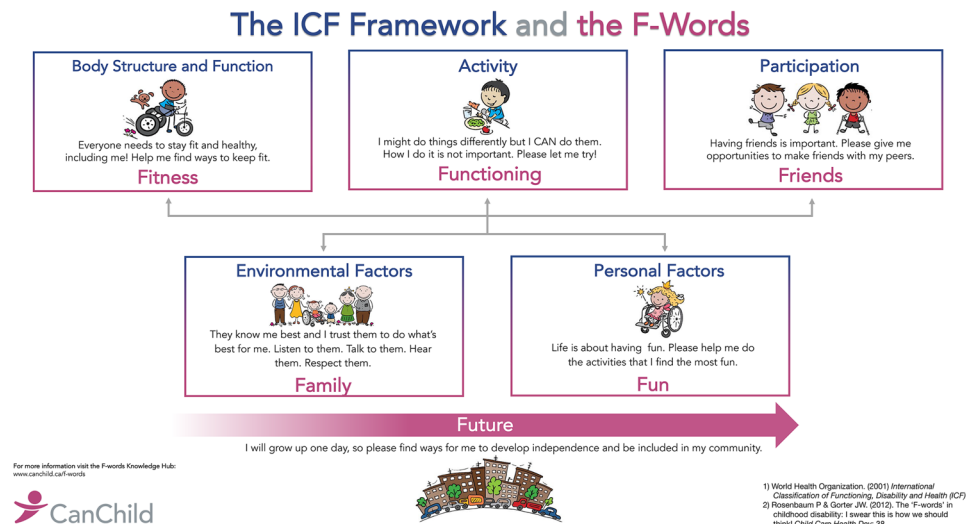


Fig. 2 The F-words for child development



for children with impairments to enable them to ‘do’, in whatever way they can, is associated with better development than traditional approaches that constrain ‘abnormal’ functioning [22••]. In our day-to-day world, people may be left-handed, wear glasses, or use a hearing aid to enhance function. We accept those variations as long as they ‘work’ — so why are we traditionally so strict with children with impairments who are supposed to do things in specific ‘typical’ ways?

An example we like to use with both parents and professional colleagues concerns the value of a walker to enable children with mobility limitations to learn and practice independent mobility. When people balk at this idea (‘We want her to learn to walk normally and not be dependent on a device’), we tease people about how their other kids have used training wheels when learning to ride a two-wheeler — but abandoned them when they had learned the skill — without becoming ‘dependent’ on them! This inconsistency is often eye-opening.

Family: As noted above, this is the central and essential ‘environment’ of children and is highlighted in the F-words framework to emphasize this idea, lest it be simply taken for granted and then ignored.

Fun: This ‘personal factor’ should be obvious to everyone who works with children and is, we believe, essential for children whose development is in some way challenged or at risk. When we hear, directly from the child themselves, what is fun for them, we can build our ideas about intervention around those activities. In the same way as ‘parenting is a dance’, professionals need to learn to ‘dance’ with children (and families) and adapt to the children’s preferred interests so that they can help them achieve their goals as efficiently and easily as possible. Children are far more likely to want to pursue and work at what they like (and what might at the same time be ‘therapeutic’) than when we impose therapies.

A useful analogy is illustrated by parents of typical children expecting them to love piano or violin lessons, when this is rarely the child’s choice or their passion!

Friendships: The ICF concept of ‘participation’ (engagement in life in ways that are meaningful to that person) is embodied in the idea of friendships. This is done in order to emphasize the powerful role of peers in children’s social development. Parents often speak sadly about the challenges that their children with disabilities experience in making friends. This may be due, in part, to functional challenges, but it is likely also related to limited social opportunities. Insofar as participation is a fundamentally important element in people’s lives (powerfully illustrated as this paper is being written during the COVID-19 lockdown!), exposure to opportunities — especially in activities that are fun for children, as discussed above — is one way to increase possibilities for friendships built around common interests.

Fitness: Children with disabilities are less fit than their peers (and typically developing children in Canada are generally less fit that we would like)! Building this F-word onto the ICF’s ‘body structures and functions’ is designed to remind people that whatever therapies we recommend to address issues in body structure and function, there must always be consideration of the question ‘Why’ this intervention is being prescribed. We need to think well beyond the efforts to ‘fix’ and ‘normalize’ and see our efforts as being directed at bigger, broader purposes related to activity and engagement in efforts to, among other goals, enhance both physical and mental fitness and wellbeing.

Future: This F-word was added to the ICF framework because time is not included in the WHO’s concept. The aim was to remind people of the changing, developing child (and family). It is also included to cue people to the longer-term as well as the immediate future and to ask at all times how any of our recommendations and efforts with children and

families are meant to impact the child's 'being, belonging and becoming'.

As noted, these ideas have had considerable impact around the world in over 30 languages and appear to resonate with parents and professionals working in this field. Among other purposes, they are meant to bring the ICF ideas to life and to address the myths, misconceptions and dated thinking that have limited progress in the field of childhood disability.

What Does All This Mean for Service Providers?

The ideas presented in this paper represent a different — we believe a fresh and expanded — perspective on old issues. A metaphor might capture the way in which modern thinking and actions can be thought about. Imagine attending an opera with a famous diva as the star attraction. The spotlight is on her every move and every note, and it may only be as one's eyes accommodate and the spotlight expands that one sees that there are other members of the cast on the stage, and perhaps a chorus. A further examination of the expanded scene reveals that events are unfolding in a forest, or a castle, or a tomb! In other words, in addition to the leading role, there are other players and a context to the story. Not only does this wider lens not detract from the diva, it helps people recognize how well she is managing her plight: her role is enriched by these many contextual details.

We use this idea to remind people that in addition to the traditional biomedical 'disability' elements of 'childhood disability', where the spotlight has always shone, we need to appreciate the rest of the scenario. Applying these concepts does not tell others what 'not' to do! Rather, we are challenging people to embrace a broader set of ideas and to consider at all times whether and how both traditional and innovative thinking and interventions address child (and family) development, functioning, child and family voices and strengths and the F-words/ICF concepts in which these ideas are embedded.

Work underway by the authors and our research colleagues in Canada and Australia is exploring these ideas with families. The program we are promoting and studying carefully (ENVISAGE for Families [ENabling VISions And Growing Expectations]) has been co-developed by parent leaders and university-based professionals and assessed by additional parents. The program is now being co-presented and piloted by parents and professionals in both countries. One of the next steps, already underway in mid-2021, is to offer this program to paediatric healthcare providers (ENVISAGE for service providers). There is already interest being generated by parent participants, who are sharing their excitement with their children's service providers, who are in turn asking for opportunities to learn these concepts.

Conclusion

We hope that the clinical implications of this expanded and refocused approach to childhood disability are both accessible and appealing to people. Our experience in teaching and promoting these ideas in scores of invited keynote lectures and workshops provides informal evidence that these ideas are taking root. More importantly, the embrace and promotion of these ideas around the world, especially by parents, is reassuring [23•, 24•].

What's next? There are myriad research opportunities to be explored. We need more evidence of the value and impact of the ideas advocated in this paper. Targets to be explored include whether implementation of these concepts enhances parent wellbeing and mental health. Do we see measurable improvements in the development of children with impairments whose parents adopt this way of promoting child development and functioning? Can service providers become comfortable to move beyond our classical biomedical thinking toward a holistic, strength-based approach that might require letting go of older ideas in favour of new ones?

In the next few years, we hope to have a solid research foundation to support the fact that what sound (to us!) like good ideas are also credible, applicable and evidence-based approaches to 'childhood disability'. We welcome colleagues who wish to join this journey.

Declarations

Conflict of Interest In this article, Peter Rosenbaum and Monika Novak-Pavlic present and discuss CanChild's F-words for Child Development and describe the CIHR-funded ENVISAGE study. Dr. Rosenbaum is the lead author of the original F-words paper that reported these concepts. All the F-words materials discussed in this paper are available for free on the authors' website: www.canchild.ca/f-words. ENVISAGE is a research study underway as this paper was being written, and there are no financial implications of this work. Peter Rosenbaum and Monika Novak-Pavlic declare no conflicts of interest relevant to this manuscript.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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- Of major importance

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