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The 'F-words' in childhood disability: I swear this is how we should think!

P. Rosenbaum* and J. W. Gorter*†

**CanChild* Centre for Childhood Disability Research, McMaster University, Hamilton, ON, Canada, and
†NetChild Network for Childhood Disability Research, Utrecht, the Netherlands

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Correspondence:
Peter Rosenbaum, MD, FRCP(C), *CanChild* Centre for Childhood Disability Research, IAHS Building, McMaster University, 1400 Main Street West, Hamilton, ON, Canada L8S 1C7
E-mail: rosenbau@mcmaster.ca

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Abstract

The 21st century is witnessing a sea change in our thinking about 'disability'. Nowhere are these developments more apparent than in the field of childhood disability, where traditional biomedical concepts are being incorporated into – but expanded considerably by – new ways of formulating ideas about children, child development, social-ecological forces in the lives of children with chronic conditions and their families, and 'points of entry' for professionals to be helpful. In this paper, we have tried to package a set of ideas, grounded in the World Health Organization's International Classification of Functioning, Disability and Health (the ICF), into a series of what we have called 'F-words' in child neurodisability – function, family, fitness, fun, friends and future. We hope this will be an appealing way for people to incorporate these concepts into every aspect of clinical service, research and advocacy regarding disabled children and their families.

Introduction

Childhood disabilities are conditions that do, or are highly likely to, affect the trajectories of children's development into adulthood. Many have a neurological basis and are commonly referred to as 'neurodevelopmental' disabilities (or simply as 'neurodisabilities'). Additional impairments often include musculoskeletal conditions or genetic syndromes, and cognitive, behavioural and communication disorders, reflecting the complexity of most of these conditions.

The field of childhood disability (what we like to refer to as 'applied child development') is still in its infancy as an academic discipline. For this reason, traditional views of childhood disability have been influenced very strongly by approaches taught and practised in biomedicine, built to a large extent on the way health problems are managed in acute care medicine. Think, for example, of how we manage the sudden onset of acute chest pain: we take a history, examine the patient, 'rule out' competing possibilities in order to make the right (specific) diagnosis, find the right treatment, intervene and watch the evolution of the illness after treatment. In this way of thinking, we work towards 'fixing' (one of the 'F-words' traditionally used in childhood disability, as elsewhere). 'Fixing' refers to the expectation that the appropriate diagnosis will lead to the right interventions and that the underlying biomedical impairments will be ameliorated to the patient's advantage. Of course, in acute situations the time course of events is usually rapid and outcomes can often be assessed in days or weeks.

We believe that there are a number of significant limitations to the idea of 'fixing' in childhood disability. First, although we often forget this, in our field there is much less precision regarding many of the common 'diagnoses' we make. 'Cerebral palsy' (CP) and 'autism spectrum disorder' (ASD) appear to be specific terms, but in reality they describe a rather heterogeneous group of conditions that can impact on the development of children's function for a variety of biological reasons, with a very wide range of effects.

Second, the 'treatments' we have available may at times address signs and symptoms underlying biomedical aspects of the condition (as is the case, e.g. with botulinum toxin to

manage spasticity, or anticonvulsants for seizure disorders); however, given both the limited understanding and the complexity of the biomedical underpinnings of conditions like CP and ASD, and the paucity of specific 'treatments', we have very few opportunities to 'treat' biomedically to prevent or cure the conditions. Even for the treatment of something as obvious as muscle weakness in CP, we still have insufficient evidence to support or refute the efficacy of muscle-strengthening exercises in children with CP (Verschuren *et al*. 2011).

Third, even when it is possible to affect the biomedical 'impairments' of these conditions, there are often, at best, limited connections between changes in how the body works and the functional outcomes of those changes (Wright *et al*. 2007). Fourth, the course of development is usually rapid, while the effects of many of our treatments are relatively slow. Against the background of natural changes influenced by growth and development, it is challenging to detect causal connections between interventions and outcomes that can be attributed to those treatments.

The good news is that in the 21st century there are important new ideas about health and childhood disability that are helping us to expand our thinking. International health experts recently published a discussion paper about the limitations of the current World Health Organization (WHO) definition of health and proposed a new, more dynamic and empowering definition: 'health is the ability to adapt and to self manage' (Huber *et al*. 2011). Informed by our own 'development', the evolution of the field, endless discussion with colleagues and over two decades' of childhood disability research at *CanChild* and more recently *NetChild*, we have formulated these ideas as a set of six 'F-words', presented in a way that people will hopefully find both fun and memorable. Our purpose is to encourage people in the childhood disability field to apply these concepts in their work with children with disabilities and their families.

Background to the F-words: the International Classification of Functioning, Health and Disabilities (ICF) 2001

In 2001, the World Health Organization (2001) published a set of ideas about how we might think about health. These ideas, refining the WHO's original (World Health Organization 1980) International Classification of Impairment, Disability and Handicap (ICIDH), are meant to apply to all of us, and not just to people with 'disabilities'. The ICF provides both a detailed classification of aspects of people's health and function, and a pictorial framework that brings these ideas together. In this sense, we see it as a 'rule-in' approach, in contrast to the way acute issues are assessed. The ICF was published a decade ago, and represents the work of professionals and health consumers from around the world, but is still not as widely known and applied in clinical service, education and research as we believe it should be (Cerniauskaite *et al*. 2011). Figure 1 shows the framework, on which the rest of this paper will be built.

As can be seen, the ICF framework connects a number of ideas about health and health conditions to each other in an interesting way. Note that the concepts in the six boxes are all generic issues, and that none is specific to any disease or

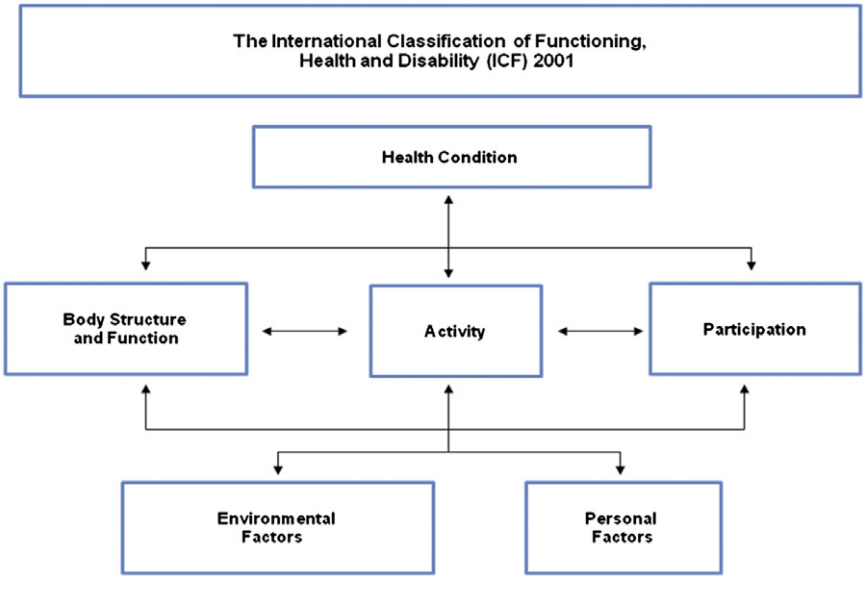

Figure 1. The International Classification of Functioning, Health and Disabilities framework.

condition. Note as well that these ideas are interconnected without any hierarchy of implied importance. Having the health condition ('diagnosis') at the top traditionally directed our thinking towards the biomedical, whereas the ICF clearly presents the opportunity to consider all health issues within a broader social-ecological context that could be considered to turn the framework 'upside down'. This suggests that, within this 'dynamic system', changes in any area of the framework may potentially have influences elsewhere in the system. These ideas are elaborated below with an illustration of the connectedness of these concepts.

By taking a journey along the ICF 'trail', we can see how people are now beginning to think about disability. We hope to illustrate that by embedding the 'F-words' into relevant components of the framework, we open up possibilities for thought and action that should benefit children, parents, families and professionals.

The first 'F-word': function

Function refers to what people do. Synonyms include 'role', 'job', 'occupation', 'task', etc.; for children, 'play' is their 'work'. In the ICF, we see functioning as belonging in both the ICF category 'Activity', which in WHO terms refers to 'execution of a task or action by an individual', and the ICF category 'Participation', defined in the WHO-ICF as 'involvement in life situations'. Most people who work in the field of childhood disability would of course argue that their efforts in counselling, treatment and management are all aimed at promoting and improving function. So one might ask: Is this different from before, and if so in what ways? We believe the answer is clearly yes: the emphasis we see in modern disability work represents an important advance on earlier thinking.

First, we used to believe that all our efforts needed to focus on 'impairments' in body function or structure, such as a significant deviation or loss at a biomedical level. The ICF refers to 'body functions (as) the physiological functions of body systems (including psychological functions)' and 'body structures (as) anatomical parts of the body, such as organs, limbs, and their components'. Thus, we have traditionally put much of our clinical effort into 'treatment' of impairments, and assumed that improvements in body structure and function would make a child better and thus would lead to functional gains. Unfortunately, this does not seem automatically to be the case (Wright *et al*. 2007), likely because any aspect of function is influenced by a myriad of factors (Chiarello *et al*. 2011), of which impairments are but one (even when they are 'treatable').

Second, we used to believe that from a very young age children's everyday activities – for example, walking or talking – had to be done 'normally', and we used typical ('normal') development as our standard. We agree that the idea of normality (what most people do) can be useful as a guide to function but it certainly need not be the *only* way that things are done. Consider, for example, how many well-functioning people are left-handed, or wear glasses, or only use a computer because their handwriting is slow or messy. We have likely inhibited children's development by stopping them doing things considered to be outside the normal – literally 'abnormally'. One need only think of preventing children with CP from pulling to stand and walking in a crouch gait, or expecting children to communicate only with spoken language. We have traditionally worried that such behaviour would lead to the development of bad habits, and prevent 'normal' acquisition of skills and function. This approach may have sacrificed developmental progress in activities and participation on the altar of 'normality' (Gibson *et al*. 2011).

In considering other perspectives on function, two related concepts inherent in the ICF should be discussed. 'Capacity' is what we can do at our best, while 'performance' is what we ordinarily do. There is research indicating that capacity and performance are distinct constructs (Holsbeeke *et al*. 2009) and those data support the idea that a gap exists between the two. This is seen, for example, in mobility in school-aged children with CP, and can lead to a question, framed in ICF terms, about what to focus on in therapy: capacity or performance (Tieman *et al*. 2004; Smits *et al*. 2010).

Performance improves with practice, and hence our primary emphasis in counselling and intervention should be on promoting activity. This approach is consistent with developmental realities: children *first* learn to do things in their own way, and *then* (maybe) develop good skills in those activities. Picture a typical toddler learning to cruise and walk, first holding onto the furniture, and how that early 'developmental' gait progresses quickly over the second year of life. Children with unilateral spastic CP (hemiplegia) with a Gross Motor Function Classification System functional level of I or II, indicating they are independent on at least level surfaces without walking aids, are characterized by a wide spectrum of phenotypic variation in their gait patterns (Dobson *et al*. 2011). Note that *how* things are done is not initially considered important. Thinking in this way hopefully moves us towards 'achievement' of the activity and away from the tyranny of 'normal' as the only goal.

It is also important to recognize that children with disabilities can often be 'deprived' of experience. This may occur secondary to their functional challenges, and also because they have

limited chances to *practise* skill development over and over unless the environment facilitates such possibilities (as might be done, e.g. through the provision of technical aids such as powered mobility; Butler 1986). To date, the perspectives and experiences of parents and children about *their* values and beliefs remain largely absent. We are excited to read a recent study in which children's and parents' beliefs about the value of walking were investigated, and to see how these beliefs inform rehabilitation choices and perceptions of 'success' (Gibson *et al.* 2011). Gibson and her colleagues found that the children under study are affected by normative ideas about walking as a moral good. This may contribute to parental feelings of angst and doubt, and negative self-identities for children; for this reason, we feel strongly that it is important to encourage the development and practice of function without regard to how 'nicely' it is achieved.

The second 'F-word': family

Family represents the essential 'environment' of all children. In ICF terms, parents are the central 'contextual factor' in their children's lives. One might well ask, 'Isn't this already obvious?' The answer, in many respects, is a mix of yes and no!

In child health, our 'patient' has always been the child, and at times parents have been tolerated but not engaged as well as they might be. Although things have changed in many ways, services have traditionally been very paternalistic, and professionals have often not explored families' issues and realities. This approach misses valuable opportunities to be helpful. For one thing, we know that parents' lives are 'complicated' with their extra concerns about their children with disabilities. There is evidence from both clinical and population-based research to show that parental physical and mental health is often challenged (Brehaut *et al.* 2004, 2009, 2011; Raina *et al.* 2005; Lach *et al.* 2009), and that having a child with CP in a family may lead to parents perceiving restrictions in family participation. These restrictions arise early in the life of a child with CP and may become more prominent as the child grows older (Rentinck *et al.* 2009). We also recognize that parents are frequently caught in a 'generational sandwich', being parents to their children, and (adult) children to their own parents! Grandparental voices, another contextual factor that is often in the background, can be powerful influences on the parents of children with whom we work, and these should be asked about and understood. Family-centred services provide the tools to address these concerns.

Research on family-centred services, undertaken with families as partners, has enabled us to see that engagement with parents, respect, continuity of care and informing people appropriately are key elements of service values by families (Rosenbaum 2004, 2011). We know that when services are more family-centred, parents report better satisfaction and mental health, and less stress in their dealings with providers. We have also learned that collaborating with parents to identify their goals can work to improve therapy outcomes effectively and efficiently (Ketelaar *et al.* 2001; Ostensjø *et al.* 2008; Øien *et al.* 2010; Darrah *et al.* 2011; Law *et al.* 2011). It has become apparent that it is not only the physical disability of children that contributes to parental stress. Maladaptive behaviour of children significantly contributes to parental stress scores and impacts attachment, the relationship with spouse, parental depression and, in particular, a sense of competence (Ketelaar *et al.* 2008). We therefore have to think of the various supports and resources for families as a whole, and help them to find the resources to make informed decisions.

The third 'F-word': fitness

The fitness of children with disabilities, a component of body structure and function in the ICF framework, has until recently been a neglected aspect of childhood disability. Research shows that children with disabilities and chronic illnesses are less 'fit' than other children, and less fit than they should be (van Brussel *et al.* 2011). This speaks to the need for an emphasis on a health-promoting orientation to disabled children's lives and not one that simply focuses on remediation of their 'disabilities'. Although we know that exercise programmes can be beneficial in children with disabilities, fitness training alone is not effective enough for them to stay physically active (Claassen *et al.* 2011). We need to understand what makes it easy or hard for children and adolescents with disabilities to become and to stay physically active. There is also a need for more and better recreational opportunities for all children, whether these are considered 'therapy' or not. Research by Colver and colleagues (Hammal *et al.* 2004; Fauconnier *et al.* 2009) shows the importance of environment, and of social and other policies that affect the lives of *all* children.

The fourth 'F-word': fun

Fun spans the ICF elements of 'personal factors' (What does/might this particular child enjoy doing?) and 'participation', which in ICF terms refers to 'involvement in (meaningful) life situations'. More colloquially, life is about 'doin' stuff!' One might well ask: Isn't this what childhood should be about? Unfortunately, there is good evidence that people with disabilities have lower rates of participation than their able-bodied

peers (Bult *et al.* 2010). This prompts the question: What can we do to increase and enhance the participation of young people with disabilities?

The answers are deceptively simple and straightforward. First, find out what *they* want to do! This can be accomplished informally by asking, and more formally with the Children's Assessment of Participation and Enjoyment (CAPE) measure, a tool developed and validated for this purpose (King *et al.* 2004). Note that activities may be formal (structured) or informal (free-range), and may be done on one's own or with others. Second, adapt those self-identified activities as needed, to allow children to pursue the things they want to do. Third, do not worry about expecting children to do things 'normally' (One need only think of the Paralympics to realize that disabled people can, with more or fewer adaptations, demonstrate remarkable feats of physical and psychological achievement. And indeed, there is now a 'disabled' young man from South Africa, missing the lower parts of both legs, who runs with the aid of prosthetic 'blades' against 'able-bodied' athletes at a world-class level!) Finally, use participatory activities to build children's confidence, competence, sense of achievement and capacity. It is the doing, rather than a superior level of accomplishment, that is most meaningful to most children.

The fifth 'F-word': friends

Friends and friendships occupy the same ICF 'space' as 'fun' – namely 'personal factors' and 'participation'. Social development is an essential aspect of personhood, and we believe that considerable emphasis should be placed on facilitating this component of child development. It is the quality of relationships, rather than the number, that is important. Thus, as service providers we need to ask whether we include this dimension of children's development in discussing interventions – and if not, why not? We also need to consider what can be done to encourage, empower and enhance children's opportunities to develop and nurture meaningful peer connections. Being involved in peer group activities and opportunities for dating, rather than motor impairment or level of education, seems relevant for developing romantic relationships and sexual activity once children with CP reach adolescence and young adulthood (Wiegerink *et al.* 2010). Discussions with parents, right from the beginning of our relationship with them, should include counselling about this aspect of children's lives, and provide parents with ideas about how to address this.

So, how does the ICF help?

In Fig. 2, we have 'populated' the ICF framework with the first five 'F-words'. Consider the connections among these ideas. Imagine, for example, how an increase in a disabled child's self-identified meaningful participation might impact on the scope and intensity of their activities, and potentially lead to changes in body structure and function! In this scenario, engagement and participation (e.g. sport programmes in the community) – in activities meaningful and fun to a child (and family) – might have an important impact on activity (e.g. improved physical and social functioning) and on body

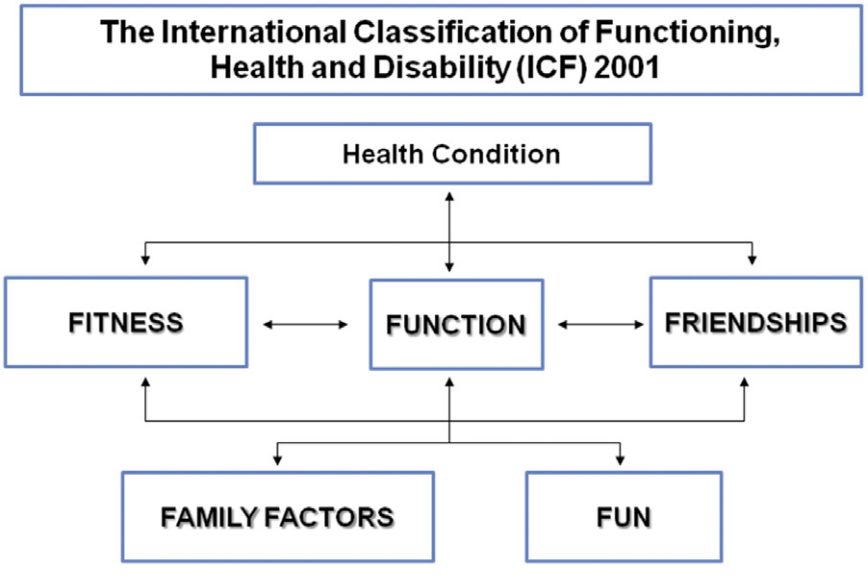

Figure 2. The International Classification of Functioning, Health and Disabilities framework: the interconnections among elements.

structure and function (e.g. fitness). The apparently 'backwards' direction of these connections certainly differs from traditional biomedical thinking – but it does work! This is how ICF thinking is making a difference!

Finally, the sixth 'F-word': future

This idea is included here to wrap the 'F-words' within the obvious but too often neglected idea that the future is what child 'development' is all about! All children, including disabled children, are in a constant state of 'becoming'. We believe that service providers need to think about the future – in a positive way – right from the start, and encourage parents to do so as well. This in no way implies that we should ignore the child's and family's present realities. Rather, we need to keep this horizon in view at all times. Addressing function, family, fitness, fun and friends will constantly remind us of what is important in the development of all children. We can ask parents and children with disabilities, at any time, about their expectations and dream for a future that is possible – and not decide for them what is impossible. These ideas present a challenge to professionals to acknowledge that 'modern' thinking provides many points of entry in our work with disabled children and their families.

Key messages

- The ICF provides a neutral framework for thinking about health as well as disability.
- We believe that applying the 'F-word' ideas presented in this paper at the clinical level should allow service providers to 'populate' the ICF framework with each individual's special issues – including their strengths – in order to personalize interventions.
- The authors encourage clinical and research colleagues to incorporate these concepts in all our work, and to evaluate whether good ideas actually make a difference!

Acknowledgement

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