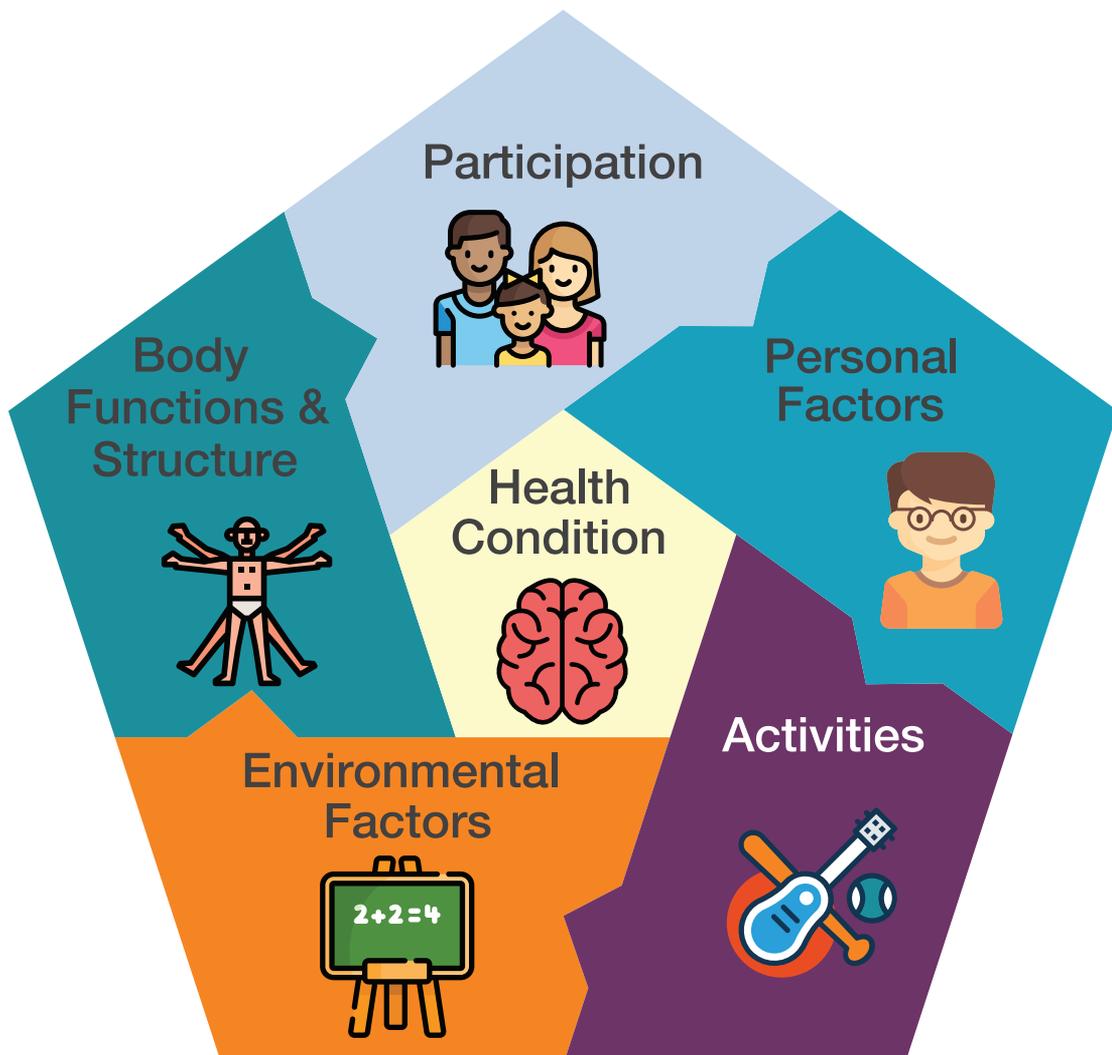


ICF

A Hands-on Approach for Clinicians and Families



Edited by **Olaf Kraus de Camargo,**
Liane Simon, Gabriel M Ronen
and **Peter L Rosenbaum**

Chapter 9

The ICF from the parent perspective

Jennifer Johannesen

My experience as a parent to a child with multiple severe disabilities lasted just a few short years; my son Owen died in 2010, at the age of 12. His early death was both surprising and wholly predictable – while he was in the midst of a particularly healthy spell, we had always known his life-long physical and developmental challenges would likely mean a shorter-than-average life. As Owen’s full-time caregiver, I knew the amount of work required to simply keep him alive, never mind *also* trying to provide a good quality of life for him, as well as his younger brother, Angus (who is typically developing). I felt immensely grateful to the Canadian healthcare system as well as to our team of skilled and compassionate health professionals. At the same time, particularly as my experience and confidence grew, I became increasingly attuned to absurdities, redundancies, and confusing narratives that lived alongside the good care and technical excellence. Since Owen’s death, I have been attempting to make sense of these contradictions by reflecting on our experiences and imagining new ways forward – including, as outlined in this book, considering use of the ICF in clinical practice.

Owen had what I think of as ‘conventional’ medical treatment – we were primarily focused on his physical health and considered his functioning in terms of ‘normal’ stages of development. Indeed, we had the good fortune to be treated by clinicians who were also caring, inquisitive and observant. Their biomedical approach was tempered by their maturity and experience, and, dare I say, by their humanity. It was their diagnostic and technical capabilities *combined with* their creative and sensitive approaches to figuring out how to help our family that made for enriching and successful interventions.

We also experienced the opposite end of the clinical encounter spectrum. My son's various diagnoses included profound hearing loss, spastic quadriplegic cerebral palsy, and dystonia. He was also non-ambulatory and G-tube fed. His requirement for supportive equipment and devices seemed endless, which meant we encountered many specialists whose skills were closer to those of engineers than physicians. For these types of specialists, our lives and contexts mattered only so far as they related to the use of a particular apparatus or that would be impacted directly by a particular intervention. There was little inquiry into the many minor and major intersections of Owen's or our family's life activities and experiences that may have been tangentially impacted.

Regardless of the type of encounter we experienced, there was little interprofessional communication. I was the conduit through which details of Owen's health and development were reported to others. Because I couldn't possibly know exactly which details would be important to which health professionals, I am quite sure my ability to relay pertinent and accurate information was less than perfect.

Reflecting on the biomedical paradigm

I learned about the ICF long after my son's death, but immediately saw how it might have improved some of our healthcare experiences. It offers a much-needed paradigm shift in terms of how clinicians see our disabled children, by including individual and family context, priorities, and goals as part of the health record. In addition, when the ICF concepts are well used, members of the healthcare team collaborate, aligning their care towards shared goals. I can imagine that use of the ICF in clinical practice will help healthcare teams better understand the perspectives of the individual and family.

Parents may also come to see their own situation and experiences in a different light. Parents may learn that adherence to a rigid trajectory of 'normal' development may impede discovery of opportunities for connection, fun, and access to social and public spaces. For example, a focus on developing walking as the sole means for a child to get around may delay or indeed impede the use of a wheelchair, which can provide independence and access to activities.

We had an experience that illustrates this. As a 2-year-old, Owen was still very much functioning as an infant – he was fully physically dependent and had little functional movement. I had saved up a pressing question for several months and finally worked up the nerve to ask Owen's neurologist, 'Will he ever walk?' The neurologist seemed to have anticipated the question. 'Well,' she said, 'typical child development follows a certain path. First, a child might lift his head, then look around, then decide he wants to get something and so figures out how to crawl. And so on.' I understood where she was going, even as my heart sunk – Owen hadn't yet even lifted his head. She continued to explain that we should look for developmental achievements in sequence so we

Section C

don't get ahead of ourselves. I remember thinking it was a kind way to say no. I left our meeting with a renewed focus to work on head control.

When Owen died at the age of 12, he still couldn't hold up his head despite the many years of therapy. At some point I had indeed moved on and stopped focusing so much on this one particular 'skill', and with the help of his occupational therapists, trialled many different pieces of equipment to support sitting, standing, and walking. In his various therapies, there were several times he was clearly 'walking' (albeit with full body support), and although for Owen these efforts did not amount to functional ambulation, I was proud nonetheless. Upon reflection, I can see that our neurologist's well-intentioned explanation may have set me down a path that held me back from exploring other ways of 'walking' using assistive devices.

I don't know if our neurologist was aware of the ICF. She was certainly kind and patient, and interested in our lives and experiences. Perhaps more than anyone she understood that we would always be assessing Owen outside the boundaries of typical development. Yet, her academic training, combined with old habits, ran deep – I suspect the impulse towards biomedical framing was very strong. In many cases, perhaps even in this case, a biomedical view may be appropriate. However, if there had been an explicit effort to bring together our specialists to help address my own questions and priorities, I may have received a different or more comprehensive answer to my question about walking, thus helping me imagine a different future. The ICF, with its emphasis on individual and family priorities and goals, combined with its encouragement for interprofessional dialogue and information sharing, makes it a robust patient-centric approach that can possibly offer fresh and productive directions for individuals and families.

Considering disability

Through the ICF lens, disability is considered not as a series of deficits within the person, but as a contemplation of the 'fit' between a person and their environment. When assessing an individual's needs from this perspective, we might more readily identify physical barriers that can be removed or adjusted, or better prepare social groups to include someone with particular communication needs. In other words, barriers and hindrances to accessing certain experiences can be located not exclusively in a person's diagnosis or physical limitation, but also in how we set up and maintain an environment to support that person with their specific constellation of characteristics. The ICF framework allows a healthcare team, including the individual and family, to examine how a person lives and interacts with their environment, which can give important clues as to what interventions can be helpful. This strikes me as a respectful and person-centred approach to supporting an individual's needs and goals – more so than simply diagnosing a 'problem' and trying to fix it with a medical intervention.

This idea of determining fit is, of course, something that all people contemplate, not only those with disabilities. One could say that *all* people in a community live on a spectrum of needs, wants, and priorities. Therefore, everyone has needs and everyone requires some kind of intervention or accommodation; this reframing of disability challenges our assumptions and biases about what constitutes *normal*, which can create opportunities for a constructive shift for individuals and families.

While positive messaging and attitudes may be helpful, parents and professionals alike should consider that euphemisms can be confusing and misleading and can run counter to how some individuals feel about their identities. For example, some disability advocates reject the term ‘differently abled’, as it potentially erases their disability identity, and still carries stigma as it is not a term commonly applied to everyone (ADA National Network 2015, Dunn & Andrews 2015). Indeed, use of the ICF does not mean we no longer discuss symptoms and diagnoses. In fact, traditional labels can be helpful as long as they are accurate and descriptive, and accompanied by contextual and function-based information as described in the ICF.

When considering language choice and how a child’s conditions and experiences are described, parents may wish to consider connecting with parents of older children and young adults, as well as adults with similar disabilities, to help broaden their own perspectives.

Decision-making

By the time Owen was 8 years old, I felt immensely overwhelmed with the types of decisions I was increasingly being asked to make. His ‘interior’ health, as I called it, was relatively stable. This meant his respiratory, circulatory, and digestive health all seemed to be functioning as expected. His spasticity and dystonia, on the other hand, were continuing to pose new and difficult challenges. I was concerned about his caregivers’ ability (including my own) to continue to care for him safely, given his unpredictable movements and growing size. He had reached the tolerance thresholds associated with his oral medications, so our only recourse was to consider more invasive approaches that would potentially address his symptoms more directly. He had already had one implanted device, an intrathecal baclofen pump, which was eventually removed due to malfunction. We were now being asked to consider an invasive surgery that involved another implant – deep brain stimulation.

I felt overwhelmed because I became increasingly uncertain about how I ought to go about making decisions. I was concerned especially with the responsibility of making irreversible medical decisions on behalf of someone else, whose own wishes and priorities I might never know. I felt this acutely even though Owen was my own son. As well, trying to distinguish between his needs and my own was especially difficult, given how

Section C

intertwined our lives were. Our health professionals were sympathetic and of course informative – I never doubted their advice and guidance from a biomedical perspective. However, when it came to this level of nuanced and deeply personal contemplation, it seemed to fall outside the scope of what they were able or felt willing to provide. Eventually I consulted a bioethicist in our local children’s rehabilitation hospital, after which I concluded that even though I may make imperfect decisions, the responsibility to do so was indeed, appropriately, mine.

I share this story to illustrate the complexities and challenges some parents experience when making decisions, especially those that are emotionally fraught. Use of the ICF may create both opportunities and challenges for health professionals to support individuals and families while making difficult decisions, as well as navigating inner or interpersonal conflict. Certainly, having pre-established priorities and goals may help with assessing factors in ways that contemplating purely biomedical factors do not. For example, a surgical intervention may indeed increase range of motion for a child’s hip, but the length of recovery time may compromise their ability to participate in a ‘priority’ activity, such as summer camp. Therefore, with this in mind, the family may choose a less invasive therapy, or may choose to delay surgery until after the preferred activity is completed.

In this simple story, we can see how a fuller consideration of biopsychosocial factors may help the individual and family arrive at an agreeable decision. However, in this example, there may be other concerns that are not accounted for in the ICF model. For example, the parents may disagree on whether an intervention is needed at all; or, the child may be fearful and insistent that he or she doesn’t want any more surgeries.

These are complex issues that use of the ICF is not meant to address. However, given that use of the ICF may invite discussion about much more than physical health, it may reveal areas where consensus is difficult to achieve or where tensions already exist, whether between family members or among other members of the healthcare team. Because of this, use of the ICF in clinical practice should be undertaken as a means to *support* meaningful and robust dialogue, not *replace* it.

Does the ICF fit all families?

Owen was deaf and nonverbal, non-ambulatory, G-tube fed, highly spastic and dystonic, and had no clear language-based communication system. He could not indicate his preferences, let alone act on them. He could indeed express approval or disapproval through vocalisation, crying and laughing, and facial expression. He also could communicate pain and pleasure through those same means, as well as physical reaction. To some extent, those who knew him well could discern some of his preferences, some of the time. Regardless, Owen had no ability to place himself in or remove himself

from situations. He could not make requests, nor could he communicate decisions. All Owen's activities, situations, locations, and positions were not only determined by me, but also *performed* by me (or a designated caregiver). Unless an experience was (1) passive (e.g. he was sitting or lying down), and (2) tactile (e.g. feeling the wind on his face or water on his hands) or visual (e.g. watching a movie or seeing birds flying overhead), Owen required a facilitator to literally move him to and through an activity. Whether intentional or not, he was often cued as to what an appropriate reaction looks like – he would mimic his facilitator's facial expression, then be assumed to be feeling the associated emotions. Given this, to what extent could we really discern Owen's own goals and priorities, which are key components in using the ICF?

Through the ICF lens, one might place a parental relationship in the realm of 'environmental factors'. In Owen's case, this seems insufficient – even absurd. It would be very difficult to separate where he ended, and I began. Certainly, his physical body was his own as were his bodily functions (e.g. swallowing, elimination, perspiration) – I did not control these aspects. However, his baseline physical health and functioning could only be maintained by my constant intervention. For example, because Owen couldn't reposition himself voluntarily, I would arrange his arms and legs for what seemed to be more comfortable positioning. I would decide each night which side he was going to sleep on. As well, I decided which direction he should face and how long he would hold certain positions. Almost every aspect of his experience of simply *being* was dictated by my decisions and actions.

So, in this context, what should we make of ideas such as 'participation' and 'functioning'? Although we didn't use the ICF as proposed in this book, we did have therapists and other health professionals who would describe and assess Owen using similar ideas and language. When I read through reports – even those to which I contributed or where my own words were recorded – I could see that none captured the reality of Owen's complete dependence or the degree to which I *manufactured*, in a sense, his experiences. For example, when I interpreted Owen's response to a thing as 'positive', we would simply do more of that thing. That thing, then, by virtue of repetition, became his 'favourite', and was documented as such. In short, I would string together a series of attributions until they formed a logical and satisfying narrative. This presents interesting problems, then, in terms of using the ICF as a means to help individuals and families report on subjective experiences such as 'participation' and 'functioning'. One challenge is that it may be difficult to determine whose goals and priorities are being recorded. A second challenge is that, despite best efforts, it may be difficult to determine who is actually doing the participating and functioning.

A third and possibly more concerning challenge arises when a category doesn't quite fit how the individual or family might describe their own experiences, and parents in particular may feel they have to come up with 'good answers' regardless. In our case,

Section C

given the nature of Owen's severe disabilities, I would never have thought to describe Owen as 'participating' or 'functioning'. These would have been ideas suggested by a teacher or a therapist. When asked to describe Owen using similar categories (e.g. 'social skills'), I found creative ways to give an answer without outright lying. In fact, I would have felt I wasn't doing my job as his mother if I couldn't produce what I thought would be sufficient answers for each category presented.

This poses two interesting potential problems.

First, it highlights just how deeply all parties are socialised within the biomedical paradigm; not only the healthcare team members but also the individuals and families. Just as professionals are trained in accepted norms and practices, so too are parents. This is evidenced by my own need to develop a narrative according to what I thought was expected of Owen, as well as of myself as his parent. This means that, if it's the health professionals that 'use' the ICF with the individual and family merely answering questions or otherwise providing data for the professionals' use, it will be more difficult for people to see its relevance to individuals and families. Use of the ICF as described in this book will likely have more impact and will ultimately feel more satisfying for individuals and families if it is deployed for team collaboration, not patient interrogation. Ideally, individuals and families will take it up as a means to lead and manage their own interaction with the healthcare system. This does not mean that families are left on their own, nor does it mean they dictate the terms of their care. Rather, it means they feel empowered, for example, to take initiative, to explore creative ideas, to experiment within agreed boundaries, and to probe and question professional recommendations openly.

Of course, it may take time for all parties to feel comfortable with this shift from a biomedical paradigm, where the health professional traditionally dictates or leads interactions from a biomedical perspective. In the ICF approach, the focus is less about 'who is in charge' and more about what – and whose – needs, goals, and priorities take centre stage. These terms should be negotiated and continually reassessed by the whole care team, including the individual and family.

A second problem may arise when individuals and families inadvertently reorient their perspectives to fit the categories presented by the tool, as people may assume those categories are comprehensive and definitive. The risk is that the healthcare team may miss out on important clues and information that are integral to the person for whom they are providing care. To be clear, *any* tool is likely to present its own normative stance. In this case, using the ICF in clinical practice might discourage individuals and families from sharing their experiences through the lens of their own paradigm, which might not fit the stated ICF categories. This challenge may not easily be addressable, as underlying counter-narratives such as these do not tend to readily reveal themselves. As well, parties may have an interest in demonstrating or understanding a situation

in a particular way – perhaps to preserve their role as ‘expert’, which may have been my own unconscious motivation as well. In addition, it may simply be asking too much of any healthcare team member to unpack and decipher such emotional and inner complexities. To some extent, it is reasonable, and respectful, to take at face value how an individual or family may choose to represent themselves. On the other hand, a healthcare team member – particularly one who is trusted by the family – may find opportunity to engage in an exploratory dialogue about such matters.

This issue applies not just to severe disability, but could also apply to situations experienced by people from other cultures, languages, and socio-economic realities, to name a few. On a popular blog hosted by Holland Bloorview Kids Rehab Hospital in Toronto, Jaqui Getfield describes moving to Canada from Jamaica with her twin boys, both of whom are diagnosed with Autism Spectrum Disorder (Getfield 2013). She compares Jamaican and Canadian parenting, noting that ‘Jamaican mothers do not carry on incessant ... chatter with children who themselves can’t speak’ and that it’s unheard of for working mothers to conduct ‘pretend play’ sessions and arrange play dates. She notes, that, in Jamaica, adults ‘are not expected to be integrally involved in unstructured free play’. These and other parenting differences made it difficult for her to adapt to the expectations of her son’s health professionals. Of particular note is Ms. Getfield’s observation about eye contact – in some communities, she says, eye contact from children is considered disrespectful and confrontational. Until she arrived in Canada she did not appreciate the ‘cultural importance of eye contact as a means of communication’ to Canadians. Her sons’ lack of eye contact at two years old, therefore, was much less concerning to her than it seemed to be to the health professionals.

Ms. Getfield’s experience highlights how easy it might be for healthcare teams to miss important cultural differences and interpretations if a tool deployed to support information-gathering does not allow for other ways of understanding a person’s condition or situation. In this account, we might surmise that indeed her sons’ lack of eye contact warranted further investigation – we should also, then, appreciate that normative expectations in Canada may be different than elsewhere. Individuals and families from immigrant, marginalised, or otherwise under-served communities may feel they need to adapt to the normative paradigm presented through a given tool, thereby pushing aside or suppressing their own perspectives.

Although use of the ICF in clinical practice is a more robust and dynamic way of capturing a person’s life situation, it nonetheless asserts culturally normative ideas of how one ought to categorise and describe needs, priorities, and experiences. People are indeed free to accept, reject, or adapt its terms. However, if a health professional presents the framework to a family *even just as a point of discussion*, the act itself is suggestive of a ‘right way’ to think about things. As mentioned above,

Section C

I would not have thought of ‘participation’ as a way to describe Owen’s activities. Yet, how could one introduce the language of ICF into our care without requiring me to orient my thinking towards ‘participation’ as a basis for evaluation? Even if I were to reject it as a relevant category for our family, my sense would be that we were deviating from a proposed ‘standard’. The issue I raise here is that all frameworks, including the ICF, have a *point of view* and should not be mistaken for being neutral, even if highly flexible.

Of course, no tool could, on its own, tease out the nuanced and complex biases described in Ms. Getfield’s account. As a result, as argued earlier here and elsewhere in this book, the tool should support, not replace, dialogue. Effective use of the ICF in clinical practice requires that clinicians be open to the ways that individuals and families in their care are conducting and experiencing their lives, even if the clinicians’ own perceptions or impulses are different. This helps to safeguard against potential pressure a family may feel to conform to the perceived ‘standards’ of the tool, or indeed, the clinician. Categories presented in the ICF should serve as *prompts* for all parties to align around the needs and priorities of the people involved, which may require adapting or refining the tool itself, the associated consultative processes, or the perspectives of the healthcare team members, to more accurately reflect a family’s life situation.

Back to basics

As described in the first two sections of this book, the ICF was not developed to be used in clinical practice to help individuals and families directly. It was first developed as a classification system by the World Health Organization, to more accurately reflect the functioning, needs and abilities of populations. For nations who might use the ICF at a federal policy level, it can help to determine current resource allocation requirements and also to anticipate future needs. But in order to do this effectively, the system needs data, which means it needs willing participants – clinicians and individuals alike – to use the associated instruments and contribute to ongoing data exchange activities. This framework needs to be implemented at ALL levels of healthcare, from international organisations, to federal health initiatives, to regional administrative bodies, all the way down to the clinic, and the home. A fully integrated system is required to support the two-way flow of communication that is vital to the entire analytical process. Individuals provide the data, the databases provide the statistics, the statistics (theoretically) inform funding decisions, which ultimately, should provide appropriate support and resources to communities and individuals.

It’s all a rather grand vision which, in its entirety, might not be one that individuals and families have the time or energy to concern themselves with. Instead, individuals and families would need to determine for themselves that this framework supports or

enhances the quality of their care, the nature of their family and care-provider relationships, and the ways in which they experience their activities and occupations. In other words, it needs to be meaningful to them in their everyday lives.

A common complaint among individuals and families is that their health professionals simply don't have enough time for them (Ogden et al. 2004). Modern healthcare, which is often under pressure to reduce costs, has failed to provide enough time and resources for health professionals to engage with their patients in a substantial way. At the same time the broader healthcare system, in Canada, is criticised for different reasons: it is perceived as administratively complex, and services are difficult to navigate (Grant 2017). For individuals and families, they may experience this in multiple ways. For example, they may feel there are too many specialists to keep track of, none of whom communicates with each other or has an overview of the 'big picture'. Families cannot provide or access centralised health records, and in fact must repeat their own story over and over again to different professionals. As well, they may feel their *experience* of their health is not well understood, despite all of the medical efforts to treat symptoms and conditions.

All of this, it seems, may be addressed by using the ICF in clinical practice. Individuals and families may feel their interests are more accurately captured in their health record. Health professionals may appreciate the collaboration and creativity of interprofessional dialogue. Subsequently, improvements in communication will hopefully lead to providing the most relevant and appropriate care for the individual, whether through medical interventions, environmental modifications, or supports of another kind. In one sense the ideas behind the use of the ICF seem novel. In another sense, they seem downright old-fashioned – perhaps the ICF approach represents a return to ideals of medicine that may have fallen away due to the biomedical institution's focus on efficiency and cost-savings.

Ways forward: Possible applications

The questions and considerations put forward in this chapter are complex and may not be resolved any time soon. These could best be thought of as ongoing queries that may come in and out of focus, as issues and opportunities arise through continued use and development of the ICF. I certainly do not suggest that considering these and other critical questions should delay or prevent clinicians, individuals, and families from working together to figure out how the ICF might support the individual and family.

The ICF approach does not necessarily need to be implemented as a permanent, exhaustive framework by which to assess everything, always. While none of these ideas has been tested or proven, I suggest a few ways one might consider integrating

Section C

ICF into clinical practice – either to ‘test the waters’ (potentially leading to a more robust implementation in the future) or as a selectively applied intervention at critical moments in the care journey of an individual and family. Although they are listed separately, one might imagine how use of the ICF can be beneficial in multiple ways.

- **As a dialogue tool.** The categories listed in the ICF could form the basis for either planned or spontaneous dialogue with an individual or family meant to stimulate creative problem solving, work through life-stage transitions, or otherwise encourage a fuller discussion of an individual’s needs and priorities not elicited in routine clinical practice. As well, by focusing dialogue around common themes (such as ‘environmental supports’), healthcare team and family members may find they are better able to articulate and align with shared goals, thereby reducing or avoiding conflict.
- **As a decision aid.** When considering the merits of a therapy, intervention, or major change in care routines, it may be helpful to use the ICF in discrete moments, to map out the expected as well as possible outcomes of a major decision and assess the potential impacts in terms that may be more relevant to the individual and family than would otherwise be explored in a conventional biomedical approach. For example, a family considering a range of augmentative communication devices for their young child may find it beneficial to consider not only the impact on language development, and also how the device will impact (for example) participation in a preferred sport.
- **As a planning and communications support tool for families.** The biomedical approach in clinical practice may feel safe and familiar for both families and healthcare team members. However, the ICF approach presents opportunities for individuals and families to *organise* their thinking towards needs, goals, and priorities, which may lead to improved communication between family members, enriched understanding of their own situation, and opportunity for reflection. Individuals and families may or may not choose to share resulting thoughts with healthcare team members. When used in this way, the tool is available to support families in whichever ways work for them.
- **As a compassionate intervention.** Individuals and families accept their diagnoses and associated characteristics to varying degrees; some integrate their conditions as an important part of their identity, while others, on the opposite end of the spectrum, deny their condition or hold out unreasonable hope for a cure. For most people, their reality exists somewhere in the middle. While pursuit of biomedical solutions may be productive and in fact entirely reasonable, it may also help individuals and families to experience progress in ways that do not rely on massive scientific breakthrough or innovation. By introducing non-biomedical considerations into the discussion, the ICF approach may bring a sense of possibility to a family at a time when biomedicine alone may provide little or none.

On a broader level, development and application of the ICF should continue in partnership with individuals and families. This should happen at policy levels as well as at community and interpersonal levels. Indeed, use of the ICF as a conceptual and communications tool in clinical practice should be negotiated with each individual and family – creative adaptations and variations may be required in order for everyone involved to feel its use is effective and practical.

References

- ADA National Network (2015) *Guidelines for Writing About People With Disabilities*. <https://adata.org/factsheet/ADANN-writing>.
- Dunn DS, Andrews EE (2015) Person-first and identity-first language: Developing psychologists' cultural competence using disability language. *Am Psychol* 70: 255–264.
- Getfield J (2013) Let's find the missing family-centred pieces. *BLOOM*, 16 December. <http://bloom-parentingkidswithdisabilities.blogspot.com/2013/12/lets-find-missing-family-centred-pieces.html>.
- Grant K (2017) Patients resort to paying consultants to help navigate Canada's Byzantine health-care system. *The Globe and Mail*, 14 April. <https://www.theglobeandmail.com/news/national/consultants-are-helping-the-sick-navigate-canadas-health-care-system/article34714551/>.
- Ogden J, Bavalia K, Bull M, et al. (2004) I want more time with my doctor: a quantitative study of time and the consultation. *Fam Pract* 21: 479–483.