

The WHO's ICF and the 'F-Words for Child Development': Impact Around the World

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My Goals with this Talk...

- 1. ... to present ideas about how we can *think*, and *talk*, and *act* when considering 'health' and 'disability'... and
- 2. ... to provide evidence that this expansion in our thinking really matters!

YOU will decide if this happens...







An Overview of My Ideas

- As a 'developmental' pediatrician I have worked for many decades with children with *disabilities* and their families.
- •I believe that the WHO's ICF framework for health has transformed our thinking. In this talk I would like to consider four themes...





My Themes for Today...

- First, let's look back ôô at how we have traditionally talked about and acted concerning health conditions;
- Second, we will consider these ideas as they concern parents and families who have worries about their child's health or development;
- Third, we will explore the WHO's ICF framework and our 'F-words for Child Development' to bring the ICF to life; and



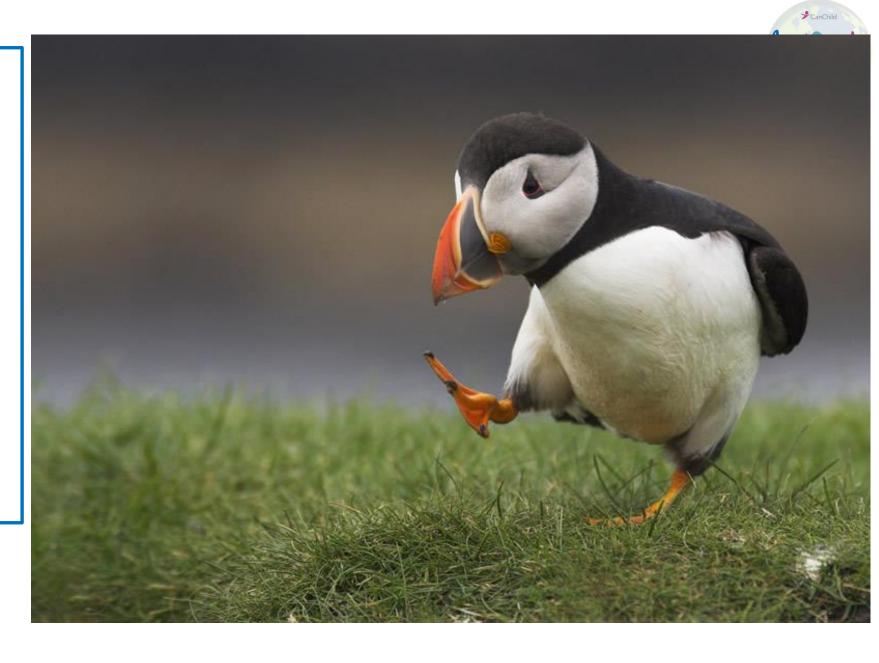
My Themes for Today...

- Finally, we will look at:
 - the *application* of these ideas by parents and service providers...
 - the *impact the F-words are having* on families, on service providers, on programs for children with impairments and their families, on the wider community, and even on policy makers, and...
 - some *tools* people have created to apply them...



So let us go on a journey together...

We'll look back 66 in order to see where we have come from, where we are now, and where we might be going.







Theme 1: Where Did We Start? ôô Let's look back at the past!

- WHAT has been the 'culture of disability'?
- Think about our training in childhood disability
- How were we trained to think and act?
- We adopted ideas from <u>acute care medicine</u>!
- We adopted ideas from <u>adult rehabilitation</u>!



In our clinical training...

- We were taught to believe...
 - We need a medical understanding ('diagnosis') of problems
 - Treatment based on diagnosis should aim to 'fix' problems
 - 'Normal' function is the treatment goal (certainly for children with developmental challenges getting 'rehabilitation')
 - Service providers are the experts
- We believed: experts should diagnose, treat, and fix!



Alas...



- We cannot 'fix' or 'cure' most conditions in medicine...
- For children with developmental issues and functional challenges, people have been pessimistic, and asked "...but what can you do for them?"
- ANSWER? New ideas, like the ICF framework and the Fwords, have expanded the discussion considerably!
- Let's see whether you agree with this statement!



Theme 2: New ideas about 'HEALTH'

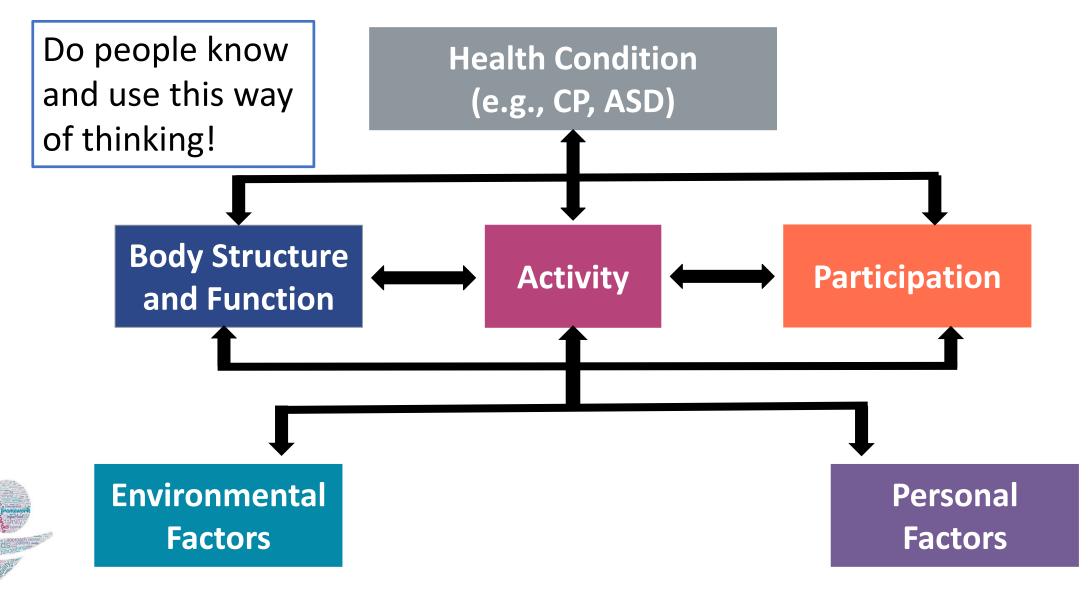


- Health is 'the <u>ability</u> to <u>adapt</u> and <u>self-manage</u> in the face of social, physical and emotional challenges' (Huber et al. 2011).
- In other words, functioning (however it is done, regardless of ability/disability) can be understood as the evidence of health.
- Now we have the ICF to help and guide us!



Theme 3: WHO's ICF Framework

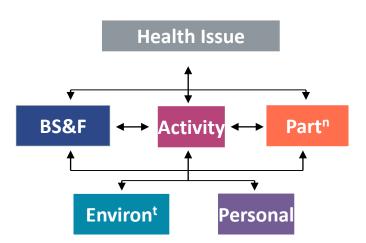






Why do we like the ICF?

- It is a framework for health for everyone
- The words are 'neutral'
- Everything is interconnected
- This is a 'dynamic system', so <u>where</u> we start our interventions may be less important than we used to think
- It focuses on strengths what people CAN do!



The F-words for Child Development



Child: care, health and development

Review Article

doi:10.1111/j.1365-2214.2011.01338.x



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Presented > 200 times locally & internationally

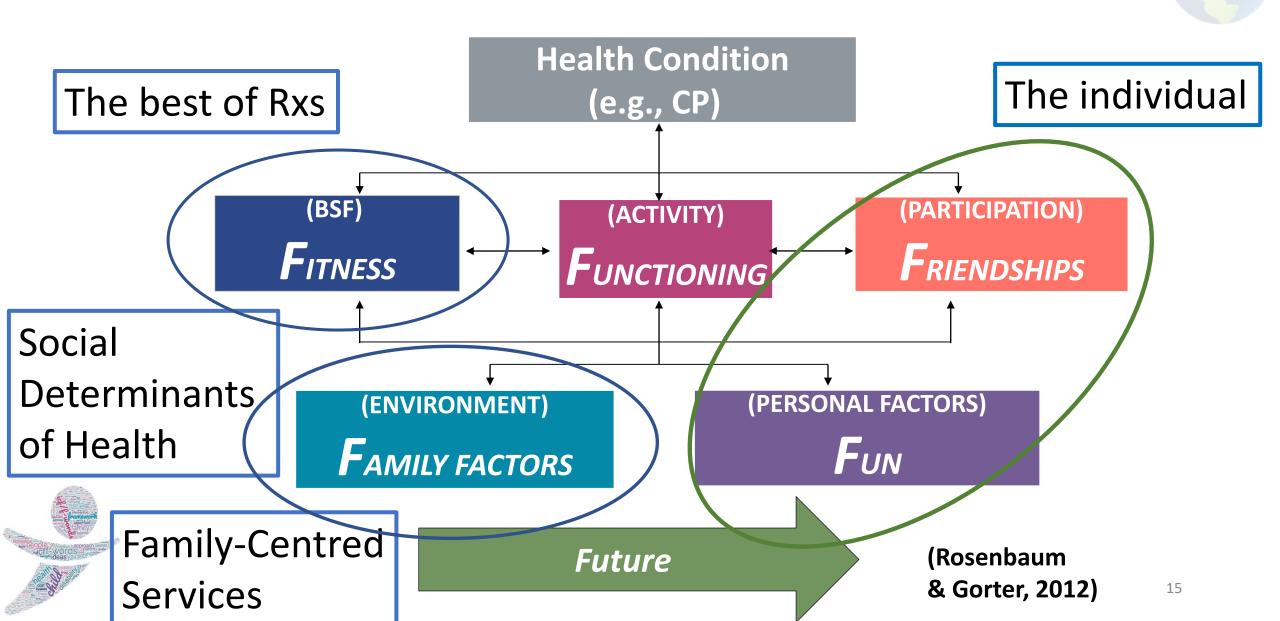


Shared around the world and translated into >35 languages

Free: https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2214.2011.01338.x



"I See F-words" (ICF) in Child Development



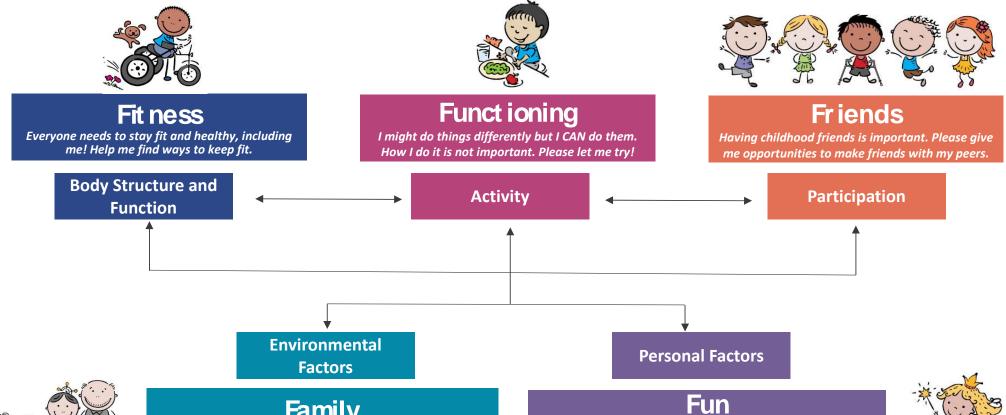


OMG... we never saw things that way before!





The ICF Framework¹ and the 'F-Words'²





Family

They know me best and I trust them to do what's best for me. Listen to them. Talk to them. Hear them. Respect them.

Childhood is about having fun and play. This is how I learn and grow. Please help me do the activities that I find the most fun.



CanChild



Fut ure

For more remarkable F-words Knowledge Hu

sanchild.ca/f-words

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.

ICF modellen¹ og de 6 f-ord²

Kroppens funktioner og anatomi



Alle har brug for at holde sig sunde og raske - både fysisk og mentalt. Hjælp mig med at holde mig sund.

Fysisk og mental sundhed

Aktiviteter



Jeg udfører måske ting anderledes, men jeg KAN udføre dem. Hvordan jeg gør det, er op til mig. Lad mig prøve!

Færdigheder

Deltagelse



At have venner er vigtigt. Giv mig muligheden for at være en del af et fællesskab.

Fællesskaber

Omgivelsesfaktorer



Min familie og jeg kender mig bedst. Involvér os. Lyt til os. Respektér os.

Familie

Personlige faktorer



Livet handler om at have det sjovt. Giv mig mulighed for at lave de aktiviteter, jeg bedst kan lide.

Fornøjelse

Fremtid

Hjælp mig med at finde måder at deltage og være en del af fremtidige fællesskaber.

For more information visit the F-words Knowledge Hub: www.canchild.ca/f-words





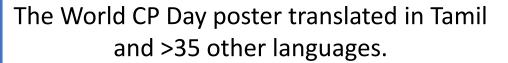
- 1) World Health Organization. (2001) International Classification of Functioning, Disability and Health (ICF)
- Rosenbaum P & Gorter JW. (2012). The 'F-words' in childhood disability: I swear this is how we should think! Child Care Health Dev; 38.



The F-words/ICF translated in Urdu and many other languages.

https://www.canchild.ca/en/research-inpractice/f-words-in-childhood-disability/fwords-translations







≯CanChild

Child Development

Child Develop

Theme 4: IMPACT of these ideas!

- Parents love them... the ideas are liberating!
- Service providers use them...
- Whole programs have rebuilt all of what they do around them...
- Government ministries are promoting them (MCCSS)
- We are involved in research with colleagues in many countries – at THEIR request.
- Here are some examples of people's experiences...



From a mother

You will gather information from reports, testing and IEP goals and this will give you invaluable insight into my son's needs. For a fuller picture of my awesome child, however, I would like to present you with the following document from my child, about my child.





From another *parent*

The F-words are brilliant and take the focus off disabilities and put it on abilities...that is part of the current paradigm shift for me. It's a new way of thinking. How do we move forward with this framework, and how can we improve our daughter's life in the context of her school, and our family and friend network?



Parent and Youth

- •It's been huge for us, although they are just six simple words, they've just changed the whole way we look at living. (Parent)
- •They're my F-words, my dreams, my goals, my ambitions. (Youth)





From a *Program Manager*

I think it's a really... universal language that we can use across teams, across agencies, across systems, that really works from a family-centred place.





From a colleague

I am writing a quick email to share a happy story:

"Today in clinic I saw a child (who has CP and is functioning at a GMFCS V)— whose mother attended CP-NET Science and Family Day last Wednesday. She reported to me that her entire approach to raising her son has shifted from one of 'fixing' to embracing the Fwords and a wellness approach. She came to clinic with her goals related to the F words all worked out and felt very empowered! I couldn't be more pleased"



From another colleague

Today I saw a 6-year-old girl with CP GMFCS V, refugee from ... via ... parents tried Stem Cell Therapy in ... and came here with hopes to help her. We had a long consult with a whole team... trying to answer all the questions they had. I tried to explain what we understand by a functional approach and what the purpose of therapy is.... At the end, I showed them the Fwords poster in Arabic, they read carefully, asked if these words are meant to be the child speaking and I confirmed. The mom commented under tears "This is beautiful, that's what I wish for my daughter."



BUT... There are challenges

"I would say that we still continue to experience some barriers for some of our working community partners in making that shift ... I am referring to all community members, so social services, child welfare, our mental health, our school system."





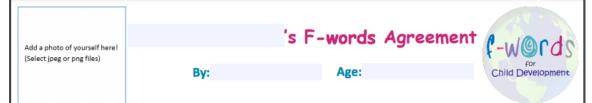
Examples of a few tools

- The F-words tools have been created by parents and colleagues and are shared by them, with their permission, on the CanChild website.
- These are free for your use!
- Go to www.canchild.ca/f-words



F-words Agreement - Kay 2013





© Please consider these things when we work together ©

FUNCTION - I want to do stuff! It may not matter if I don't do it like everyone else!

FAMILY - They know me best and I trust them to do what's best for me.

Listen to them. Talk to them. Hear them. Respect them...

FITNESS - Everyone needs to stay fit and healthy and I am no different.

I might need to use different ways of getting fit and staying fit and need help to do this....

FUN - Whatever floats my boat!.....

FRIENDS - to meet, get to know, have fun with, to learn with, to grow old with....

FUTURE - The future is Now - Tomorrow is what I make of today.

I don't want opportunities to pass me by. Help me achieve what I can today.

Thank you



© Diane Kay, Parent (2013)

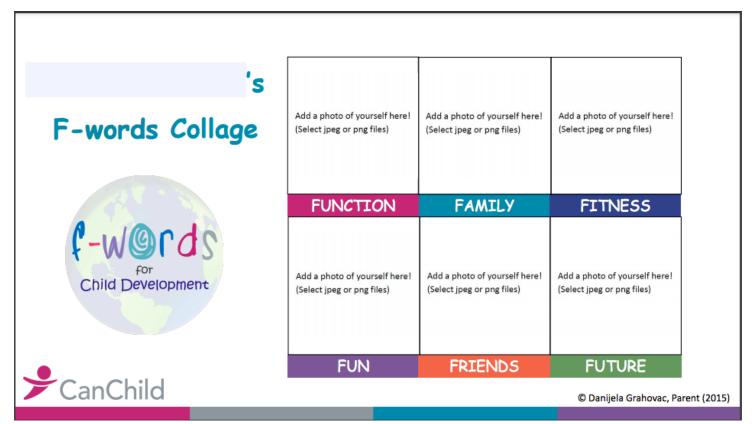
"To me the Agreement represents an informal but serious pact between the child and whoever they rely on for support."

- Parent



F-words Collage - Grahovac 2015





"The collage to me is good for my students who are maybe nonverbal. And where I'm trying to like do more pictures and simplify language."

- Occupational Therapist





Vasilijes's F-words Collage









FAMILY

FITNESS









FUN

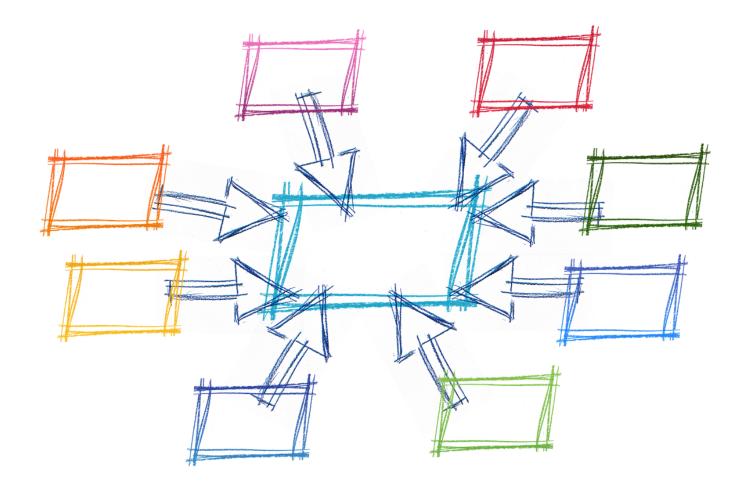
FRIENDS

FUTURE



Goal setting with the F-words...







F-words Goal Sheet



> CanChild	My F-words Goal Sheet	r-words
Name:	Today's Date:	Child Development
Instructions: Please use this form to write down one goal for each of the F-words – Function, Family, Fitness, Fun, Friends & Future and explain why this goal is important to you. These can be goals you would like to work on at home, in therapy, in school, and/or in the community. Together let's work on the goals that are meaningful to you!		
FUNCTION:		
Goal:		
Why?!		
FAMILY:		
Goal:		
Why?!		
FITNESS:		
Goal:		
Why?!		
FUN:		
Goal:		
Why?!		
FRIENDS:		
Goal:		
Why?!		
FUTURE:		
Goal:		
Why?!		
	(Adapted from Fuller & Susini Goal Sh	neet, 2015)

"I think the F-words Goal Sheet is going to be very useful. I like that there is a place for each goal and why they are important! Having this shows why something is important to the child and family, when it may not be clear otherwise." - Clinician





F-Words Drawings by a 7-year old

Impact of these changes...





We are focusing on the CAN vs CAN'T

- Ideas we need to **promote**: development, child/family strengths, achievement, being family-centred, lifecourse thinking....
- Ideas to <u>de-emphasize</u>: fixing, normality, <u>disability</u>



In Summary

- New ideas and frameworks expand the 'spotlight'.
- We are not throwing out whatever 'works'.
- Instead, we are thinking more broadly!
- The evidence suggests that these ideas and tools make a difference to people's lives.
- They are free for the taking!
- Please share YOUR experiences with us.







Thanks... Now it is time to **DISCUSS! DO NOT** BE SHY!



