



Why, and How, Should “Participation” Be A **Family** Affair? Ideas for Your Consideration

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Thank you, CAPA 2022 Organizers!

- This long-delayed event is finally happening!
- My only regret is being unable to be there in person with many great friends and colleagues.
- My talk will sound familiar – but I hope it will remind people of what we still need to do.



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It's late in the meeting.
I hope this is interesting...!



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A: The Title: **Participation** for ALL!

- I assume this refers to people with impairments as well as us 'general population' (*whom some people with impairments call the 'temporarily able-bodied'!*)
- Given that most child-onset impairments start in early childhood, and threaten the trajectories of both *children's* and *families'* lives, I want to focus on **FAMILY** as part of the 'all'.



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The Title: **Participation** for ALL!

- People at the conference have already heard from world experts on many themes from many countries...
- I have had the privilege of working with many of you, but don't have the detailed insights you all bring to the special themes you have presented.
- So you are wondering what I have to add?
- Me too!



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The Title: **Participation** for ALL!

- I'd like to propose a focus on *Knowledge Translation*
 - WE know these themes, but I believe we need to inform 'everyone' outside of conferences like this!
- In advocating for opportunities for equitable community engagement for the young people with whom we are concerned, these ideas need to be explicit in all we do, with everyone who 'needs to know'.



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Guess what I heard recently...

L. Smitheringale





B: Background context...

- What's changing in the world of 'childhood disability'?
- People at this conference – **we!** – know these ideas
- I believe we should always start our discussions with people with them – they are our 'context'!
- **WE** need to help **OTHERS** be aware of these seismic shifts in our field, so that they can understand what might otherwise seem to be odd ideas!



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What do people SEE –
and NOT see?



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B: Mainstream Ideas in 2022 (i)

- In contrast to the biomedical traditions of ‘childhood disability’, focusing on the **child’s** diagnosis and treatment, we now recognize the **primacy of the FAMILY** in all our work in ‘developmental disability’
 - It is the **parents/family** who seek our help, with their child as the ‘presenting concern’...
 - It is to **parents/family** that we offer perspectives, counselling, advice...
 - It is **parents/family** whom we expect to implement the best of our advice...



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B: Mainstream Ideas in 2022... (ii)

- We are thinking ‘**developmentally**’ – and considering **children’s** (and **families**) progress in functioning and development rather than in *normative* terms.
- In contrast to the targeted standard being ‘normal’ function, we now promote and celebrate **variations in ‘functioning’** – individual achievement – to whatever degree and by whatever means.



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B: Mainstream Ideas in 2022...(iii)

- We embrace Pless and Pinkerton's 1975 '**non-categorical**' **approach** to all childhood disability: common themes that affect children with neurodisabilities, and their families.
- We have moved from *impairment* as a 'within-the-person' problem to be fixed, to an ecological/environmental challenge that requires **family** engagement, community resources, imagination and a shift to 'participation' and self-actualization.



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B: Mainstream Ideas in 2022...(iv)

- All of these ideas are well integrated in **WHO's ICF framework for health**, and in our **F-words animation** of these concepts, the value of which to **families** and colleagues is widely recognized around the world.



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The ICF Framework¹ and the 'F-Words'²



Fitness

Everyone needs to stay fit and healthy, including me! Help me find ways to keep fit.



Function

I might do things differently but I CAN do them. How I do it is not important. Please let me try!



Friends

Having childhood friends is important. Please give me opportunities to make friends with my peers.



Body Structure and Function

Activity

Participation



Environmental Factors

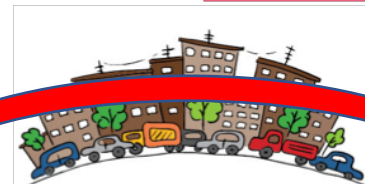
Personal Factors

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.

Fun

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.



Future



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.

For more information visit the F-words Knowledge Hub:

www.canchild.ca/f-words





OMG!



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C: Who needs to know these ideas?

- **FAMILIES**... to whom we can and should introduce these concepts early in their journey with their child into the world of 'childhood disability'
- HOW? Our Canada-Australia **ENVISAGE** program (*ENabling VISions And Growing Expectations*) brings these and related ideas to parents of preschoolers, to very positive effect, as assessed both quantitatively and qualitatively...



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C: Who needs to know these ideas?

- **SERVICE PROVIDERS...**

- In our current study (**ENVISAGE-SP**), we are exploring whether, how, and how well we can bring these concepts to frontline service providers
 - For them to understand as part of the paradigm shift...
 - For them to apply with **families...**



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Obviously we don't always see eye to eye!



C: Who needs to know these ideas?

- **COMMUNITY LEADERS...** the people who develop, fund, run, and administer recreation programs, and who need to be aware of the importance of these programs being universally accessible to all, including children with impairments and their **families!**
- **POLICY MAKERS...** for whom the ICF and F-words concepts make a lot of sense (MCCSS experience).



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Of course there can and should be discussion and often agreement!



D: How do we do this?

- Engage the **family** from the outset of our work with them, and learn:
 - What are their values?
 - E.g., What do they like to do **as a family**?
 - What did **the family** like/want/plan to do **before** their child with an impairment came along?
- Is anything stopping them from ‘participating’?
- How can we help?





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D: How else do we do this?

- What does the **child/youth** like/want to do?
 - If they are not doing those things, why not?
 - Resources/access/attitudes?
 - Family issues/fears/uncertainties?
 - Other explanations?
- How can ‘we’ help to address and knock down these barriers?





We need to look into these things!



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Let's take
a brief break!



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To Conclude...

- I have stated the obvious by situating **family** at the centre of all our work in ‘childhood disability’.
- I know that people in this conference know this ‘truth’ – I am simply suggesting that we all do this at every opportunity – to help **families**, and everyone else, have the same focus on **family** and on **participation** as we all do!



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