

# The C6 Seminar Series

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Tales of CanChild's journey of discovery



# CONTEXT: Where have we been?

- Our 20<sup>th</sup> century faith in biomedical science helped us understand – get beneath the surface of – diseases and find the best (biomedical) approaches to them.
- There is no question that the field of health moved light years ahead in the past 100 years... no one will dispute that!
- Unfortunately, we often ignored Osler's dictum:  
***“The good physician treats the disease; the great physician treats the patient who has the disease.”***
- And where are we today?...



# The ICF Framework<sup>1</sup> and the 'F-Words'<sup>2</sup>



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

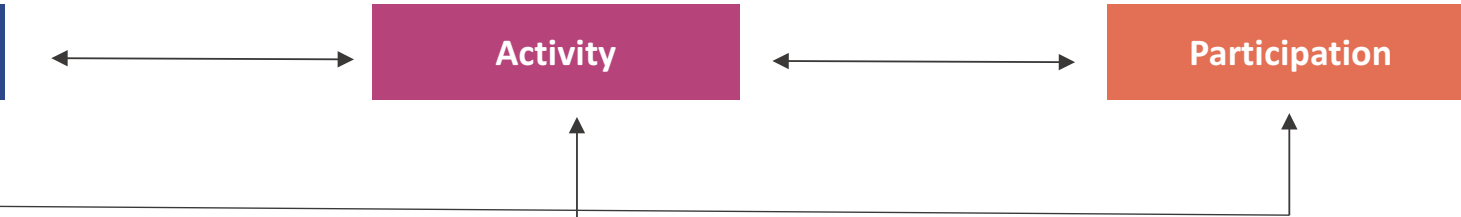
**Functioning**  
*I might do things differently but I CAN do them. How I do it is not important. Please let me try!*

**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.

OMG... we  
never saw  
things  
that way!



# “You have textbooks; we have story books”

- The words of a wise parent, and now a research colleague.
- Rosenbaum (2020). ‘You have textbooks; we have story books.’ Disability as perceived by professionals and parents. *Editorial*. *Developmental Medicine and Child Neurology* June Jun;62(6):660. doi: 10.1111/dmcn.14491.
- Video Podcast:  
<https://www.youtube.com/watch?v=E9NyZAUIqfA>



# What has taken us so long?

- Hopefully in 2022, in the field of child health, we don't even question the responsibility and appropriateness of:
  - actively **seeking** the advice of...
  - actively **listening to** the ideas of...
  - actively **considering** how to implement ideas of...
  - actively **engaging with**...
- ... 'them' – the people who 'know' from lived experience
- The voices are those of PARENTS, CHILDREN and YOUTH



# What are (some of) the issues?

Let's start with the obvious:

- What are **families'** issues?  
*(We kinda' know... **NOT!**)*
- What are **we** wanting to study?  
*(Why are these issues in scope for us?)*
- Can we REALLY understand WHAT and HOW to study these issues without the 'insiders' views?  
*(Welcome to the 21<sup>st</sup> century!)*





# CanChild's Positive Experiences

- Started in the early 1990s with our work to measure family-centred service (FCS) – relatively ‘passive’
  - Engaged leaders of parent groups, who helped us get a 71% response rate from 280 parent informants...
  - Used the findings to seek parent input on content of our measure (MPOC) from three parent focus groups
  - Result: a decent measure that parents liked (“You are asking us great questions!”) [“Of course we were: people like you told us what to ask!”]



# We Gradually Got Smarter: Now

- Current work includes CIHR-funded research programs:
  - ENVISAGE...
  - MPOC 2.0...
- ... in which parents are central to every step, as equals:
  - Named **co-investigators** and **co-authors**
  - **Co-developers** and **co-presenters**
- Replicated in Croatia – different language and culture



# Current Issues and Challenges

- Who and how to recruit parents (and young people)?
  - ?representativeness – cultural, linguistic, SES factors
- What is the currency for recognition for their input?
  - Money?
  - What else matters to them?
  - Can we be flexible and individualize ‘recognition’?
- Granting agencies expect PPI (Patient and Public Involvement)
  - are they willing to put their money on the line?





