

Child Health in the 21st Century: How Health Professionals Might Change our Thinking



Concerning Children, Youth & Families with Multiple Complex Needs

Peter Rosenbaum, MD, FRCP(C)

Professor of Paediatrics

McMaster University

Co-Founder, *CanChild*



To Understand Where We are Going, Let's Look at Where We Have Been

- 'New' ideas always have a context...
- 'New' ideas are often a reaction to 'old' ideas...
- One might ask whether what we call 'new' is really new...
- This will be a focus for discussion with all of you!



Looking back: *Where have we (HCPs) come from?*

- Our models of ***training & clinical exposure*** were traditionally based on...
 - Hospital-based training – where we saw the sickest and most complex kids
 - Acute care models that linked ‘diagnosis’ and ‘treatment’ – (and the frequent absence of both in children with complex disorders!)
 - The ‘expert’ model – ‘me doctor/PT/OT/RN..., you patient (parent)’ – where the power rested with the professionals



Looking back: *Where have we (HCPs) come from?*

- Our models of ***training & clinical exposure*** were traditionally based on...
 - Reinforcing cleverness – the premium put on making the right diagnosis ... but less obviously on skills associated with caring and counselling
 - Relative absence of training in 'Truth Disclosure' or in counselling with compassion and skill



Looking back: *Where have we (HCPs) come from?*

- Our models of *thinking* about what we can/cannot (and should/should not be expected) to do with 'These Children...'
 - The premium on the latest drug or operation that may have a dramatic effect – what does society (and therefore doctors) value!
 - The notion that many of the conditions that lead to children being considered to have 'disabilities' are 'hopeless', insofar as they cannot be cured (as if we cure diabetes, epilepsy or CF!)



Looking back: *Where have we (HCPs) come from?*

- Our models of *thinking* about what we can/cannot (and should/should not be expected to) do with 'These Children ...'
 - The belief that much of what this work is about is 'pastoral care' – and that this is not what we went to medical school to learn to practice!
 - A relative absence of thinking about 'secondary' and 'tertiary' prevention (which would allow us to reframe some of our thinking more positively)



Looking back: *Where have we (HCPs) come from?*

- Our models of **remuneration**.
“This work doesn’t pay the way other aspects of clinical work do!”
 - Why would people even think about going into chronic care paediatrics when it is poorly paid, and often seems to be unrewarding in so many other ways as well?



Looking back: *Where have we (HCPs) come from?*

- Our ***attitudes about disability*** as citizens of the community... when **we** value learning and achievement so much...
 - How much do kids with complex disorders frighten and even threaten us, at a time in our (young) lives when we are starting our own families...



Looking back: *Where have we (HCPs) come from?*

- The **'received wisdom'** about 'These Children' and 'These Families' – much of it based not on good evidence but on selective experience and 'prejudice' (in the sense of pre-judging)
 - e.g., the way in which people say that 'these children' destroy families, leading to marital break-up, etc.



Looking back: *Where have we (HCPs) come from?*

- Our ***primary focus on children*** (and maybe youth) (as opposed to families)
- Our uncertainty about our roles and abilities in helping families when kids become adults
- Our belief that we are experts and parents are there to give the history and carry out our 'orders'!



Looking forward: *What is Exciting and Possible Today and Tomorrow?*

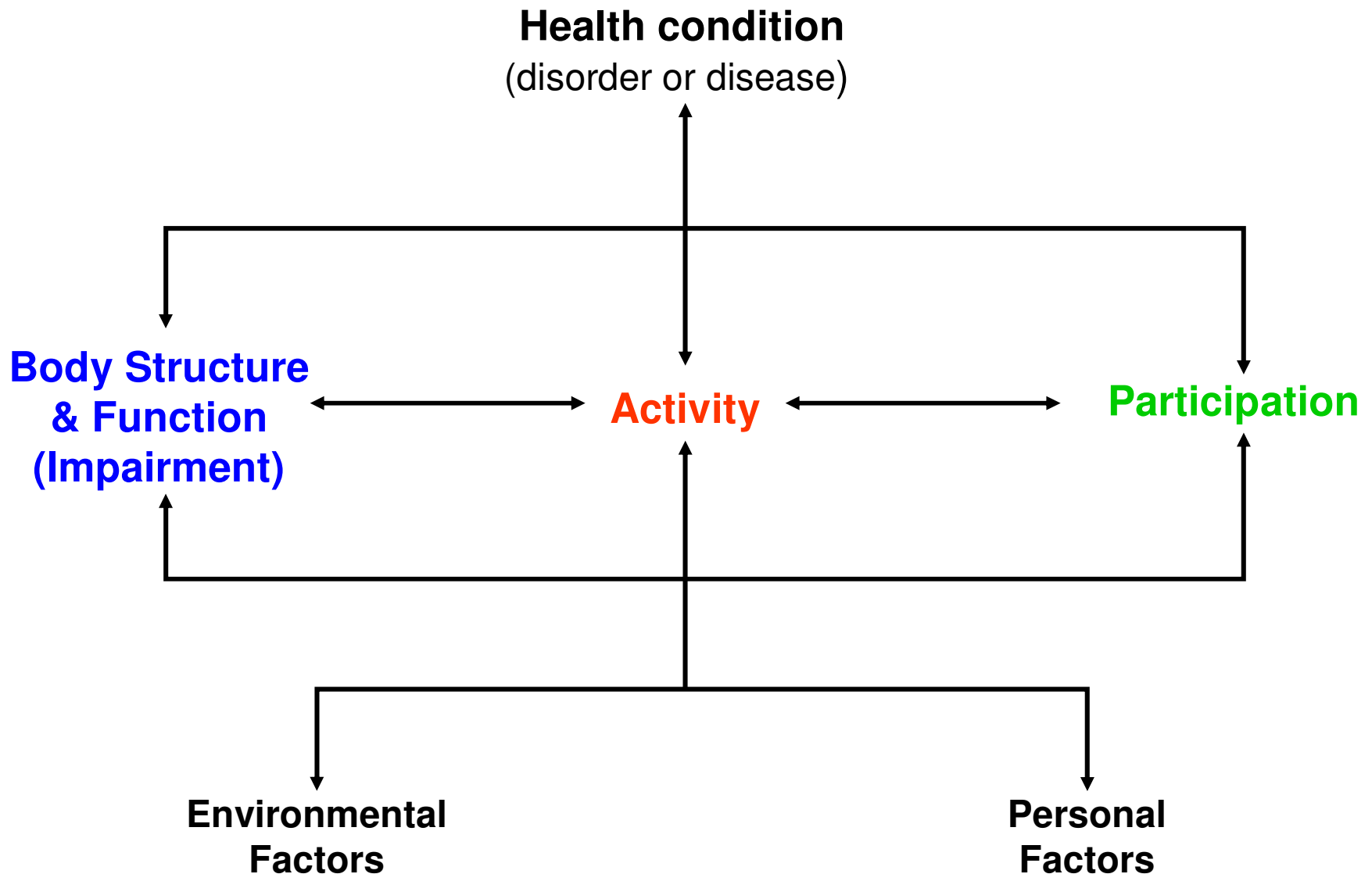
- ***New and important ways of thinking*** about health, and about child health
 - **WHO's ICF framework**
 - **Family-Centred Service (FCS)**
 - **New funding paradigms**
 - **New research paradigms**



Looking forward: *What is Exciting & Possible Today and Tomorrow (i)?*

- **The WHO *International Classification of Functioning, Health and Disability* (ICF) – an interactionist framework that is having a huge impact in the disability field**
- **The next slide shows the framework...**

International Classification of Functioning, Disability and Health (ICF) Framework (WHO, 2002)





How Is This Exciting?

- Provides many more 'points of entry' for what we can offer to kids and families
- Provides opportunities to make a difference even without curing the condition.
- Brings in the role of family and community as elements of the 'environment' that have become 'legitimate' aspects to consider in the lives of children and families



Looking forward: *What is Exciting & Possible Today and Tomorrow (ii)?*

- ***The concepts and practices associated with Family-Centred Service (FCS)***
 - What can we do additional to our traditional 'doctor' role that turns out to be important to and valued by families?
 - The reality that parents and families are playing – and are expecting to play – a very different role than has traditionally been expected/allowed



Looking forward: *What is Exciting & Possible Today and Tomorrow (iii)?*

- ***New ways of remunerating people*** who are committed to working with children and youth with complex conditions and their families
 - E.g., Embedding practitioners within multi-professional settings where our skills are complemented by those of a host of others who (truth be told) do most of the work and will do it better with us – as we will do our better with them!



- E.g., competitive salaries – which of course depend on the community valuing this population and this work!
- Relaxing the boundaries between children and adults – to enable people with these interests to move with kids with complex disorders and their families at least a little way into the world of 'adults' – to make transitions more effective for all concerned



Looking forward: *What is Exciting & Possible Today and Tomorrow (iv)?*

■ ***New models of research***

- New research techniques – both quantitative and qualitative – that inform our understanding of issues
- Relative availability of \$\$ to support such endeavours – CIHR is very 'open' to varied research



- New research partnerships among people with shared interests
 - Parents and families
 - Researchers from related fields
 - Colleagues from related fields
 - Policy makers who are responsible to move the political agenda forward – and want to do so with the best available evidence
 - National and international collaborations...



Possible Rx...Political Will

- Political will to modify the way we train physicians, and especially (in this context) paediatricians in the 21st C.
- Requires changes in other sectors as well, such as nursing, developmental therapies, psychology, etc... to share both the work and the responsibilities



Possible Rx...Political Will

- Political will to adopt new funding models for (child) health care – models that put a premium on quality of care over volume, and do not penalize people for doing this type of work
- Includes the need to co-locate (and fund) people in teams...



Possible Rx...Political Will

- Political will to create collaborative models of team-based services in which the physicians who do this type of work are part of effective interdisciplinary teams; where teamwork among service providers is prized; and teamwork with families is a core value



Thanks for Listening...

There will hopefully be
plenty of time for
discussion
debate!