

**Evolving in Rehabilitation:
Where Do We Go from Here...
New Directions to Pursue in
Pediatric Rehabilitation.**



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***or... How to answer the question
people always ask us:***

“...but what can you do for them?”







My Objective...

- In this talk I will bring together several threads of new thinking and activity that I believe can be woven together to form a rich, exciting tapestry of opportunities and ideas for the field of what I like to call 'Applied Child Development'.





Looking back briefly...

This is our clinical heritage ...

- The biomedical model of disease
- Acute-care models diagnosis \leftrightarrow Rx
- A sense of futility about 'chronic' disorders (especially N-D ones)
- Judging the book by the cover
- 'Received wisdom' about 'these kids'...
- Community attitudes re. disability





The Problem Is...

- These concepts and approaches do not serve us well in childhood disability or paediatric 'rehabilitation'
- We need to look forward, and to embrace other ways of thinking and acting...





Where Are We Now, and Where Are We Going?

Let's consider three groups of new ideas that should inform our thinking and our actions...

A: Key Conceptual Developments

B: New Research Methods and Models

C: Collaborations and Partnerships







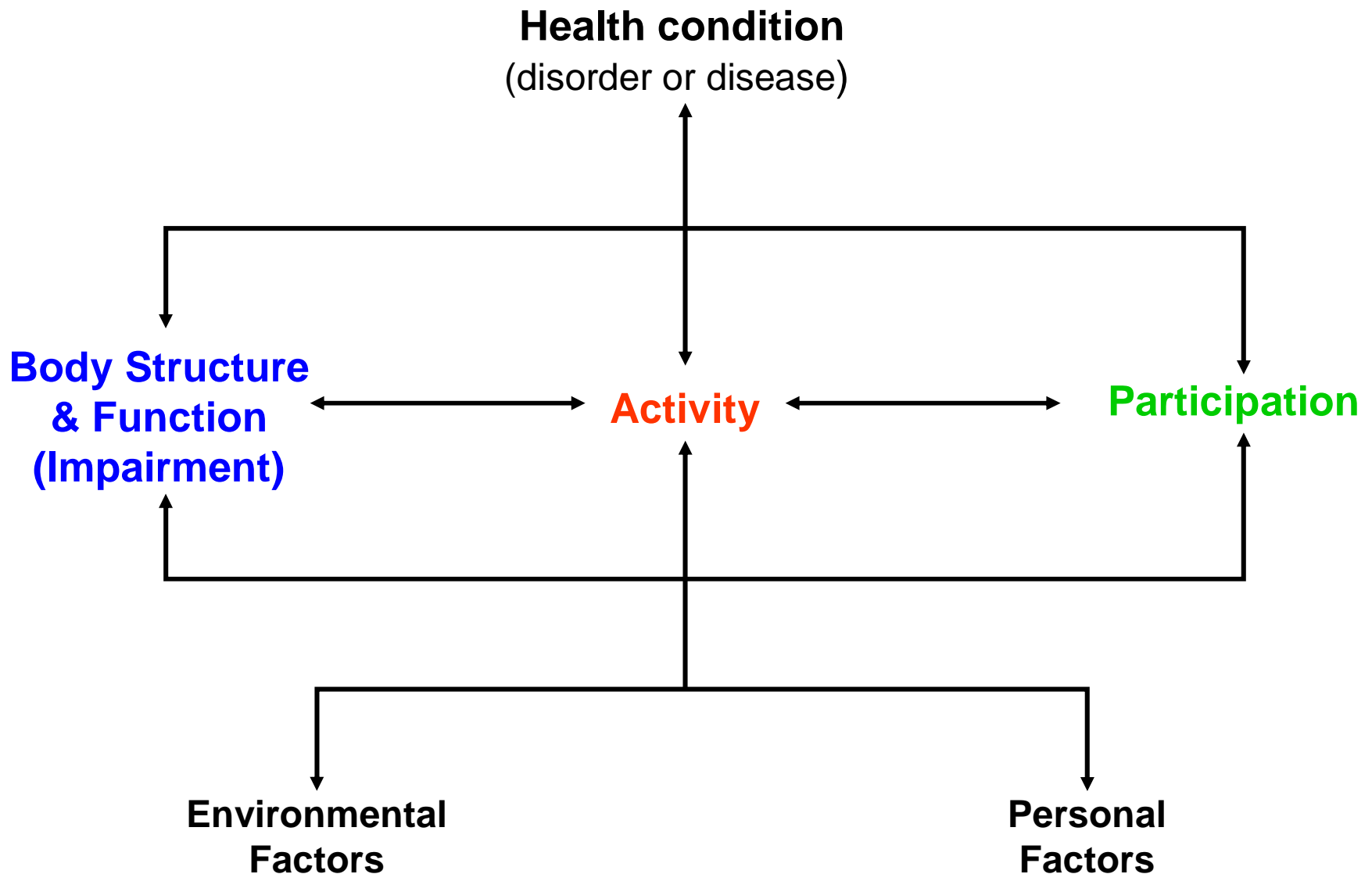
Where Are We Now, and Where Are We Going?

A: Key Conceptual Developments

1. WHO's International Classification of Functioning (ICF) (shown on the next slide)



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





How Does ICF Help Us?

- It is a dynamic system – everything is connected to everything else
- There are many 'points of entry' for interventions – beyond the traditional focus on treating the 'impairment' to 'fix' things (or not!)





How Does ICF Help Us?

- Note the importance of **'participation'**
- The formal acknowledgment of the role of **'environmental'** & **'personal'** factors
- Huge value as a **stimulus** to us to think more broadly about what we do



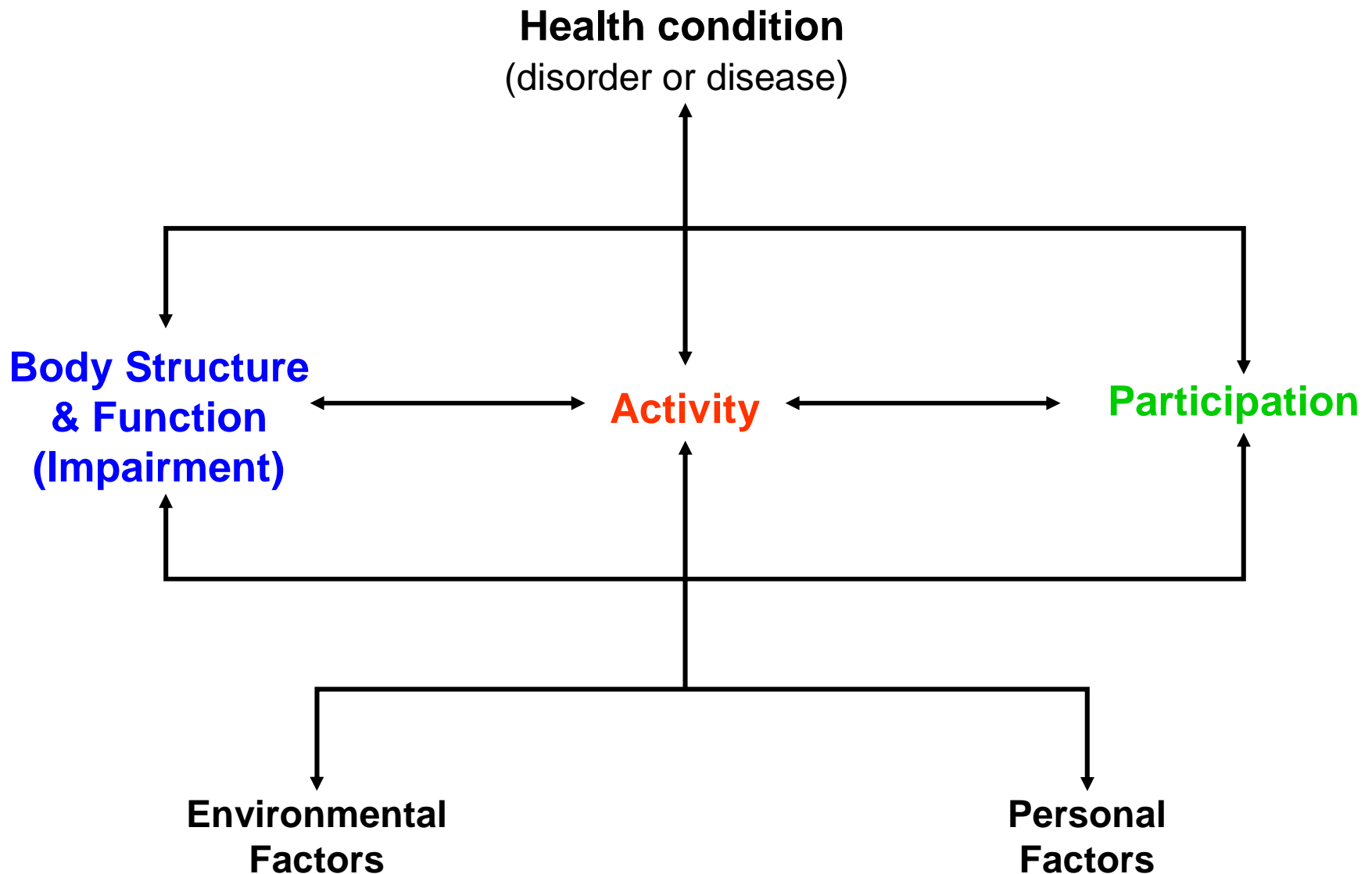


From our research (VW)...

- We can now explore whether a change in one component of the framework is associated with changes elsewhere
- One example – changes in spasticity (BS&F) after Botox do NOT necessarily cause changes in Activity or in children's Participation



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





Where Are We Now, and Where Are We Going?

A: Key Conceptual Developments

1. International Classification of Functioning (ICF)
2. **Focus on Family – Family-Centred Service**
 - FCS is a widely accepted value system and is often considered a ‘best practice’
 - There are formal guidelines re. what FCS means, and how to teach and practice it
 - The value of FCS has been credibly shown





What Do We Know?

- There is a sound conceptual framework of FCS
- There are valid and reliable measures of FCS (MPOC-20 and MPOC-SP)
- Evidence links 'better' FCS to parents' satisfaction, stress and mental health





Where Are We Now, and Where Are We Going?

A: Key Conceptual Developments

1. International Classification of Functioning (ICF)
2. Focus on the Family
3. **Focus on Child Development as a guide**
 - We speak of 'developmental' disabilities
 - Interventions can target **development** and **function** as well as the biomedical issues
 - **Augmentative and alternative RxS** can be used to **promote function** without guilt (though not without arguments)!



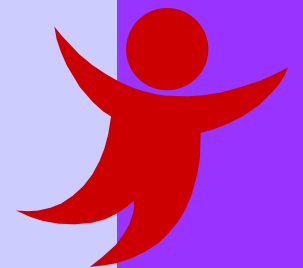
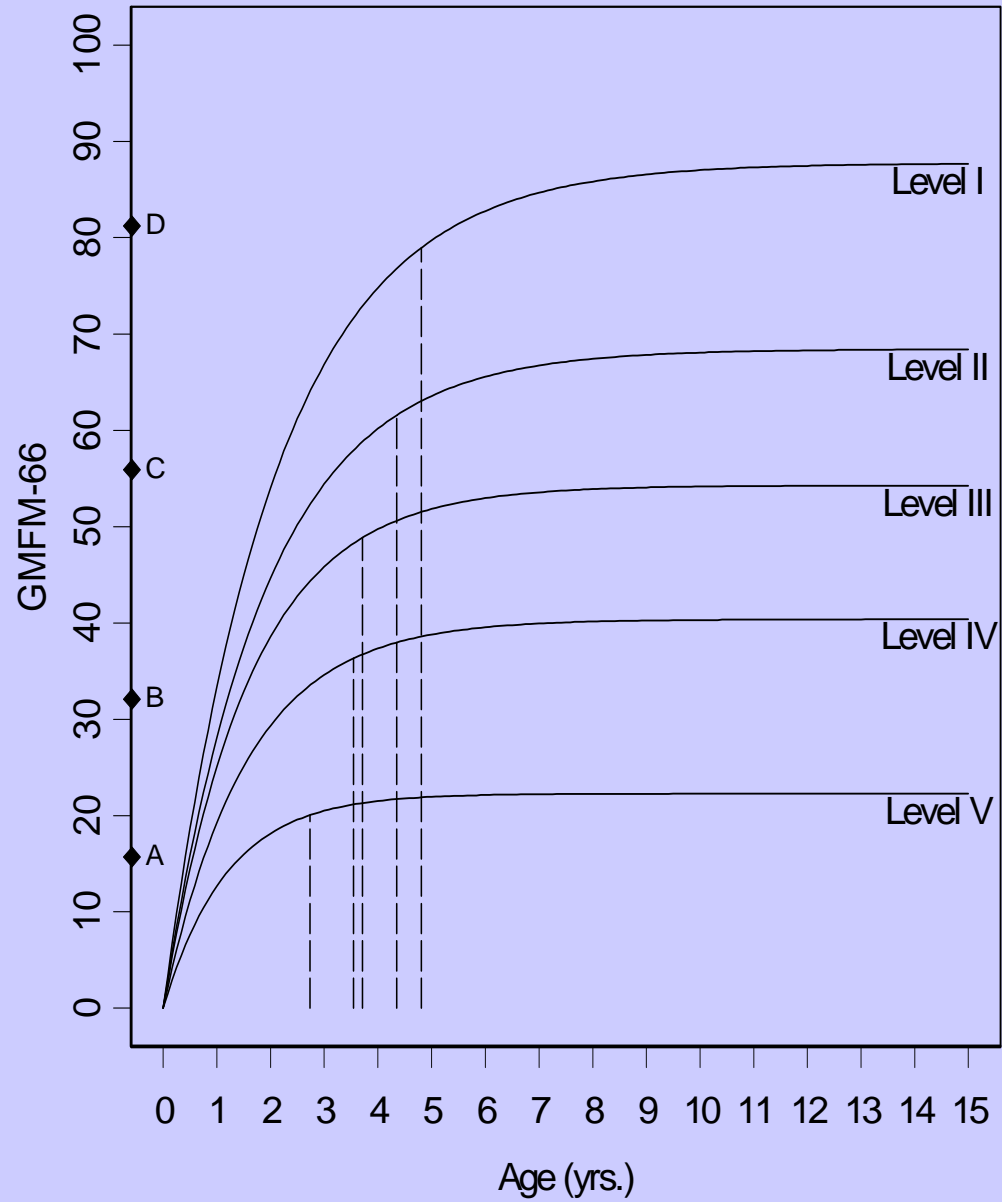


Where Are We, and Where Are We Going?

B: New Research Methods/Models

- **Prospective longitudinal studies**
 - We are beginning to learn about the 'natural history' by studying people over time as well as cross-sectionally
 - By classifying and stratifying we are learning about **variations** in development and function.







Functional Classification Systems

- These replace the (useless) words 'mild', 'moderate' and 'severe'!
- **GMFCS**: reliable and valid way to describe gross motor function in CP
- **MACS**: reliable and valid way to describe 'manual abilities' in CP
- **CFCS** (in progress): for communicative function in people with CP





Where Are We, and Where Are We Going?

B: New Research Methods & Models

- Prospective longitudinal studies
- **Qualitative research methods**
 - These have finally become part of mainstream clinical research!
 - Complementary to quantitative methods
 - They provide a level of personal insight not possible with quantitative approaches
 - People now speak of 'mixed methods' research...





Where Are We, and Where Are We Going?

B: New Research Methods & Models

- Prospective longitudinal studies
- Qualitative research methods
- **Using variation to explore relationships**
 - **The opposite of the RCT** – taking advantage of variation in cross-sectional research studies
 - Cannot prove causal connections, but can explore a host of relationships as a guide to further, more detailed research
 - May help us to abolish some myths!





Where Are We, and Where Are We Going?

B: New Research Methods & Models

- Prospective longitudinal studies
- Qualitative research methods
- Using variation to explore relationships
- **Multi-variable models and thinking**
 - We are moving beyond studies of one factor at a time to look at a host of factors together, in order to control for 'everything' and tease out the key elements of the story
 - The next two slides provide one example



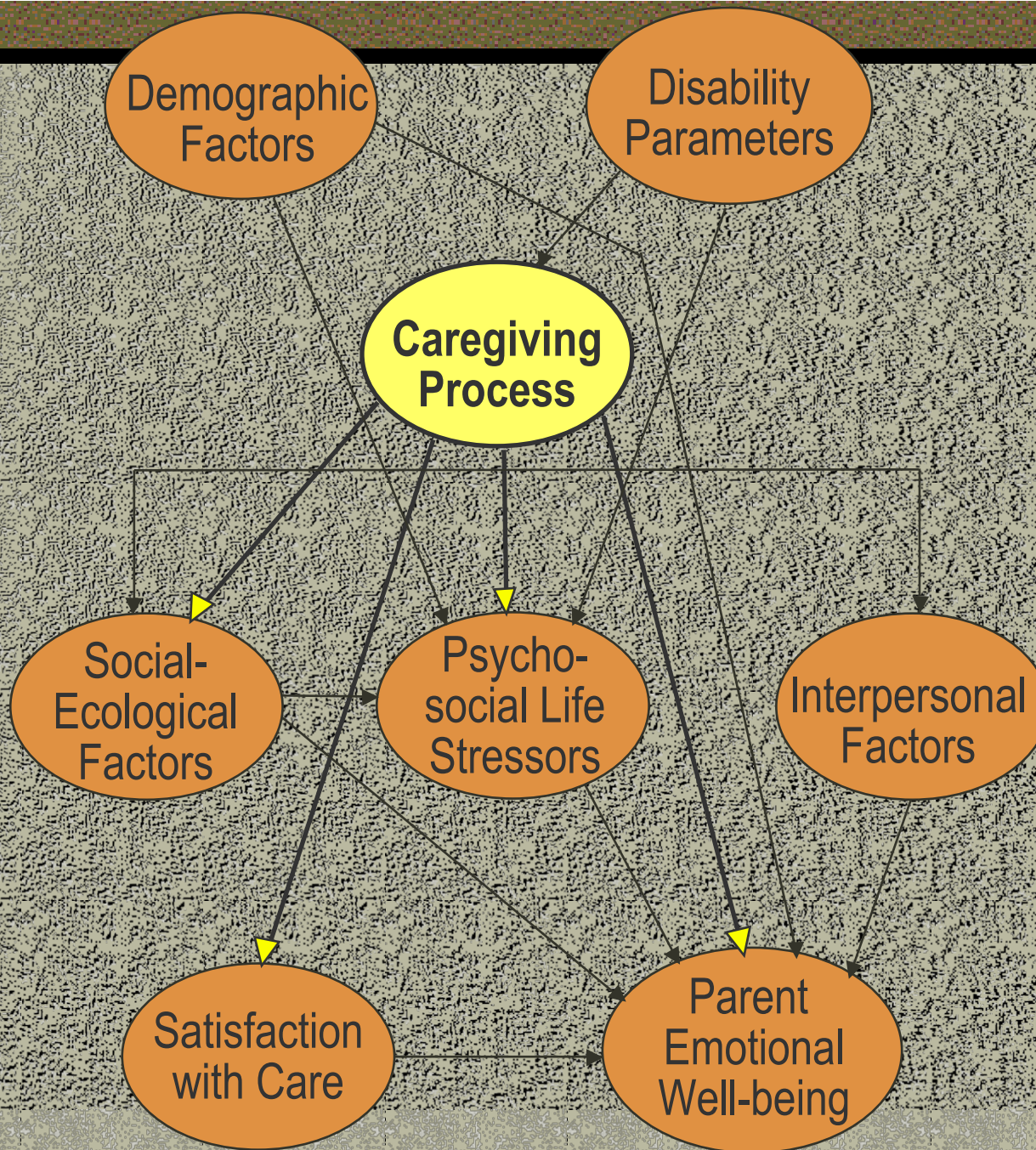


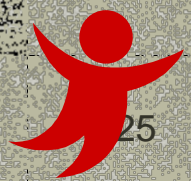
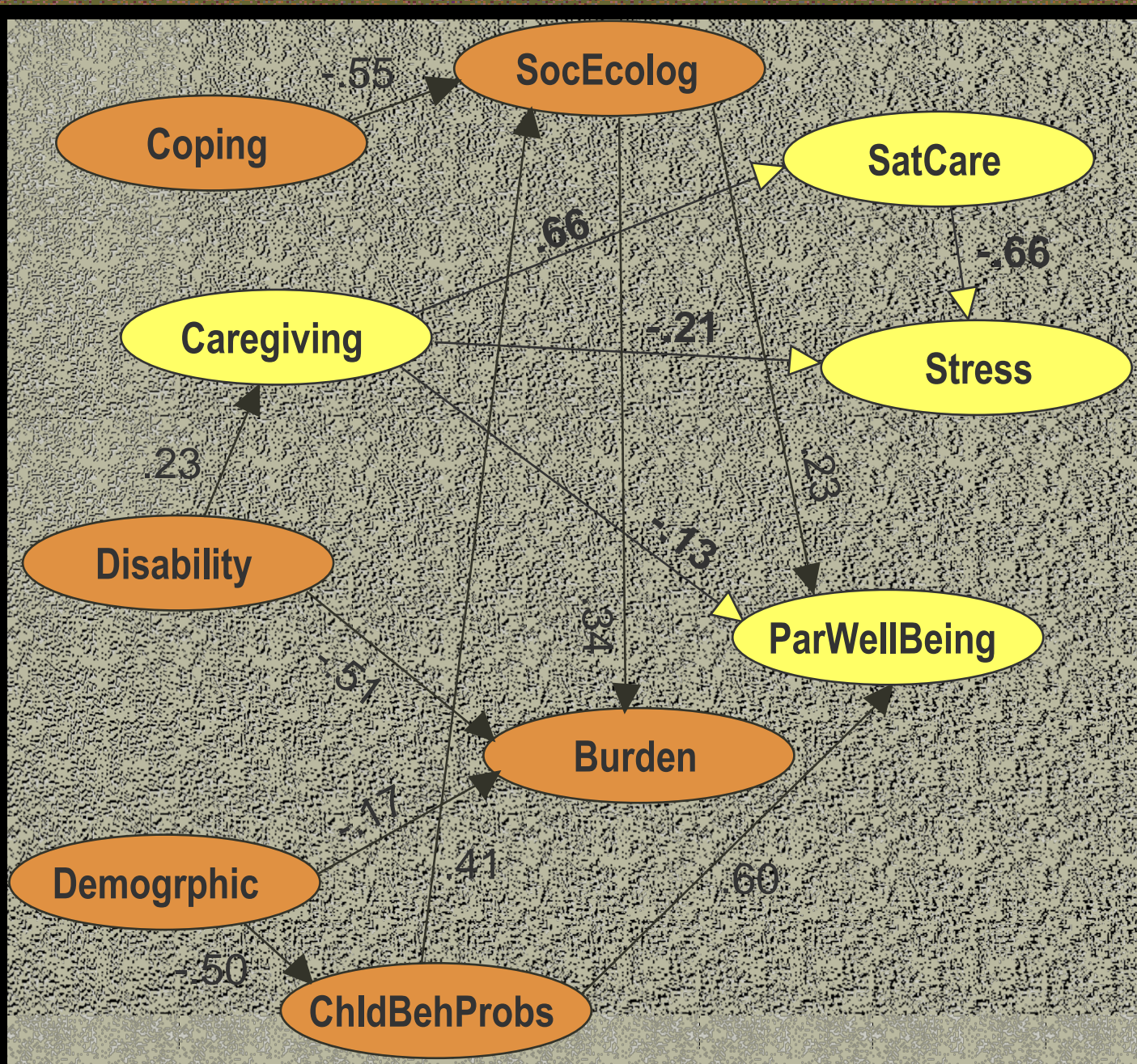
Prognostic
Indicators

Professional
Caregiving

Mediating
Variables

Outcomes







Where Are We, and Where Are We Going?

B: New Research Methods & Models

- Prospective longitudinal studies
- Qualitative research methods
- Using variation to explore relationships
- Multi-variable models and thinking
- **Advanced analytic techniques**
 - Structural Equation and 'Causal' Modelling
 - Longitudinal modelling (e.g., HLM)





Where Are We, and Where Are We Going?

C: Collaborations and Partnerships

■ Varied backgrounds

- We are increasingly transdisciplinary
- We are taking advantage of the skills and perspectives of colleagues from widely varied backgrounds
- The 'whole' is clearly much larger than the sum of even the excellent 'parts' → new insights into old problems (e.g., ASOME)





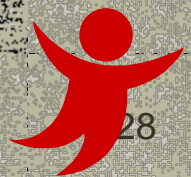
Where Are We, and Where Are We Going?

C: Collaborations and Partnerships

- Varied backgrounds

- **Across geographical boundaries**

- People are connecting nationally and internationally
- Happening across Canada (CN-CYR)
- MACS: developed in Sweden, Australia & Canada; CFCS is going on in the US; our current GMFCS work involves people from all over the world





Where Are We, and Where Are We Going?

C: Collaborations and Partnerships

- Varied backgrounds
- Across geographical boundaries
- **Across sectors**
 - Researchers are formally embedded with policy makers – examples can be found in Finland, Belgium, Canada (BC and Ontario) (*CanChild* and MCYS)
 - This dialogue can inform everyone's work





Where Are We, and Where Are We Going?

C: Collaborations and Partnerships

- Varied backgrounds
- Across geographical boundaries
- Across sectors
- **Among agencies**
 - Joint planning (e.g., CAPHC and CIHR, BKR and CIHR)
 - Joint funding of studies – e.g., ACCFCR and NIH





So: Where Have We Come From?

- The biomedical model of disease
- Acute-care models diagnosis \leftrightarrow Rx
- A sense of futility about 'chronic' disorders (especially N-D ones)
- Judging the book by the cover
- 'Received wisdom' about 'these kids'...
- Community attitudes re. disability





...and Where are We Going?

A: Key Conceptual Developments

B: New Research Methods & Model

C: Collaborations & Partnerships...

...and that's why I believe:

**There Has Never Been
a More Exciting Time
to Pursue New Directions
in Pediatric Rehabilitation.**





Thanks for Listening

For more on childhood
disability go to:

www.canchild.ca

I'd be happy to take
comments and questions
and open a dialogue



