# Research of Interventions in Cerebral Palsy

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# Just a few issues....

- Recruitment and Heterogeneity
- Defining the intervention
- What is the outcome of interest, and how do you measure it?
- Intervention across the lifespan

#### Recruitment

- Cerebral palsy is the most common childhood onset physical disability
  - 3 to 4/1000 births



Should be no problem, right?

# Heterogeneity

- Based on Etiology
  - Mix premies with IVH with Holoprosencephaly?
  - What about later onset (e.g. stroke at 15 months)
- Presentation
  - Hypertonicity and Dyskinesia
  - Topography (Hemiplegic, Diplegic, etc.)
  - GMFCS/MACS/CFCS
    - The 125 types of CP

# Single Center Study?

- Difficult to find the group
- Registry efforts



# Multicenter?



- Different foci
- Favorite measures
- Differing capabilities

#### Intervention

- ▶ COMPLEX
  - "Rehabilitation Program"
  - "Standard Therapy"
  - "Physical Therapy"

Defining the intervention



# Interventions-Focused





What is the control group?

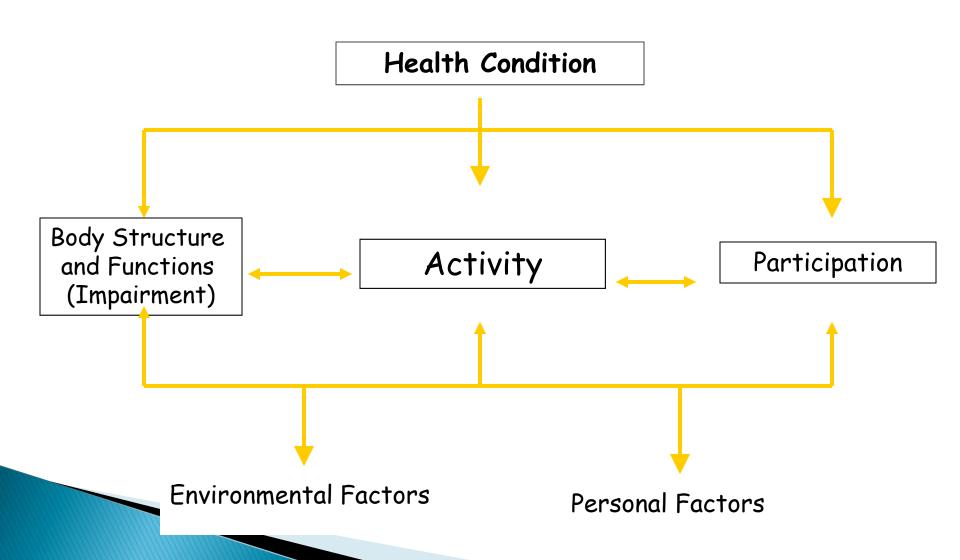
### Interventions--Medical



- Technique
- Dosage
- Complications of recruitment



#### International Classification of Functioning, Disability and Health (ICF) Framework (2001)



# **Negative Outcome**

- No effect of intervention
- Or—Insufficient measurement technique
  - Ceiling and Floor effect
  - Is the measure sensitive enough?
  - Is it measuring the right thing?
  - The challenges of measuring quality
    - Of movement
    - Of experience
    - Of life

# Quality of Life

- QOL often found to be high
  - SPARCLE Study
    - Similar QOL between CP and TD
    - Pain differentiated
- Do interventions affect QOL
  - What is QOL based on?
  - How do interventions affect that?

#### LIFESPAN ISSUES:

#### What have we done to these kids?





- What are the long term effects?
- What are the desired outcomes?
- Lots of things happen in life
  - The Cheerios Project

# Understanding Adults with CP



- Clinic Bias
- Busy adults
  - Complex data collections
  - Complex intervention programs
- Different treatment histories



#### Summary



