

# Participation and Pediatric Rehabilitation How Do We Get There?

Leaders in Rehabilitation Conference  
March 2009



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## The Map

Change in OT and PT intervention focus

Different approaches to achieve  
function/participation

What therapists and families told us

How could we do it better?



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## Changes in Pediatric Occupational and Physical Therapy

Professional driven

Typical  
development as  
gold standard

Emphasis on Early  
Treatment



Family-centred

Functional abilities

Lifespan approach  
Effective  
transitions



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## Intervention Focus

- Moved from child to child and family
- Changed from an emphasis of typical movement patterns and developmental skills to a concern to optimize functional abilities and social success of child



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## Catalysts for Change

- Family-centered philosophy
- Disability movement
- International Classification of Functioning Disability and Health
- Dynamic systems theory to explain development



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## Family centered Philosophy



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- Family/professional collaboration
- Family is constant
- Exchanging complete and unbiased information
- Honouring diversity and different coping methods
- Family to family support
- Flexible, accessible and comprehensive support systems



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## Voices of Person with Disabilities



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## International Classification of Functioning Disability and Health



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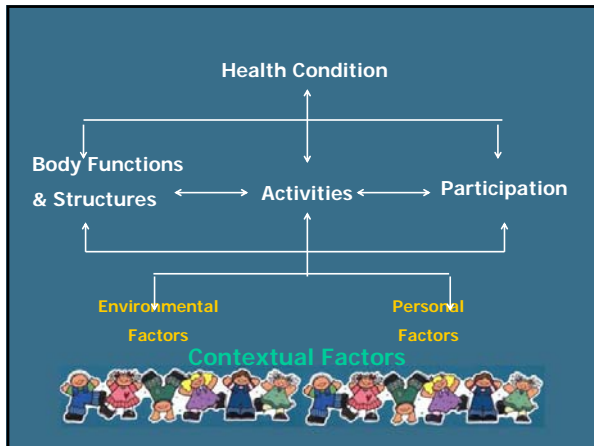
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## Dynamic Systems Theory to Explain Development

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- ### Dynamic Systems Model
- spontaneous self-organization of motor behavior from the interaction of many contributing subsystems in the child, environment, task
- Tenets:
- movement influenced by functional goal
  - non-linearity
  - product of all contributing subsystems (child, environment, task)
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## Dynamic Systems Model

- non-hierarchical
- CNS is important, but other systems considered



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## Dynamic Systems Theory

- Movement is driven by function
- Movement solutions depend on context
- No one right way to move



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## Changing philosophical approach to rehabilitation



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## Common Goal

FUNCTION!



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PARTICIPATION



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## Remediation

- Change child's abilities
- Emphasis on components of movement
- Emphasis on quality of movement, using typical movement as gold standard
- Assumption that changing body function/structure components will change activity/participation components



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## Goal in Context

- Look at child in context
- Expect different movement solutions in different contexts
- Evaluate the interaction of child, task and environment
- Work on goal not on parts of goal
- Work at component of activity to activity



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## Top Down or Bottom-Up

| <u>Top-Down</u>  | <u>Bottom-up</u>   |
|--|--|
| <ul style="list-style-type: none"><li>• Start with functional goal in context</li><li>• Identify possible constraints within person, task and environment</li><li>• Change important constraints</li></ul> | <ul style="list-style-type: none"><li>• Assess impairments</li><li>• Remediate impairments</li><li>• Assume that improvement in body function/structure will result in improved activity/participation</li></ul> |



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## Intervention Tension



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## Adaptive movement strategies



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## What does practice look like?



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## Rehabilitation Services for Children with Cerebral Palsy



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## Research Questions

- 1) How have the principles of family-centred care, functional goals, and transition planning been translated into practice?
- 2) What are parents' experiences in regards to the 3 principles?



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## Participant Recruitment

- Program managers and therapists
  - Programs within 1 rural and 1 urban site in each health region
- Programs were categorized into age group served
  - 0-3, 3-6, and 6-18
- Included health and education-based programs



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## What Therapists Told Us



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## Functional Goals

- Therapists are focused on functional abilities of children (61% identified functional goals)
- Therapists working with younger children (under 3) identified more goals focused on components of movement (e.g. ↓spasticity, ↑ strength)




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## Therapists' goals

| Goal                    | Age category of clients |     |      |
|-------------------------|-------------------------|-----|------|
|                         | 0-2                     | 3-5 | 6-18 |
| Body Function Structure | 9                       | 4   | 0    |
| Activity                | 6                       | 15  | 12   |
| Participation           | 0                       | 3   | 5    |




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## Acceptance of adaptive movement strategies

| Acceptance of adaptive movement strategies   | Age Group   |             |              |
|--|-------------|-------------|--------------|
|  | 0-3<br>n=15 | 3-6<br>n=21 | 6-18<br>n=17 |
| Accepts no use of adaptive movement strategies   | 1           | 7           | 3            |
| Accepts limited use of adaptive movement strategies but prefers typical movement patterns    | 12          | 9           | 7            |
| Accepts use of adaptive movement strategies as an alternative to typical movement strategies | 2           | 6           | 7            |




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## What parents told us



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## Parents' Goals

- Happiness and social acceptance
- Movement is about functional success
- Physical health and avoidance of medical procedures



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## What parents told us - FCS

- inconsistent access to information about services and general supports in their communities
- Isolated from each other and view other parents as one of their most important information sources



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## What parents told us - FCS

Having to continually advocate for services, particularly after the preschool years

- More consultation (focused on education)
- less direct intervention during the school-aged years
- Limited access to health-based services for 'hands on' therapy



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*'He had an IPP goal that he will make eye contact while speaking, 5 out of 7 times. My kid cannot wear pants with a button in them because he can't get the button undone to go into the bathroom. THAT is important to us. '*



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## Putting It All Together

How can we get it right?



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Participation is important to persons with disabilities and their families



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### Some ideas

- Strength based approach to assessment and intervention
- Community based wellness centres
- Prime service provider model
- Lifespan approach
- Community integration
- More activity/participation measures



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Think Outside the Box



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## Dialogue

- Families
- Policy makers
- Service providers



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