
Lifespan Issues

Participation and Transition

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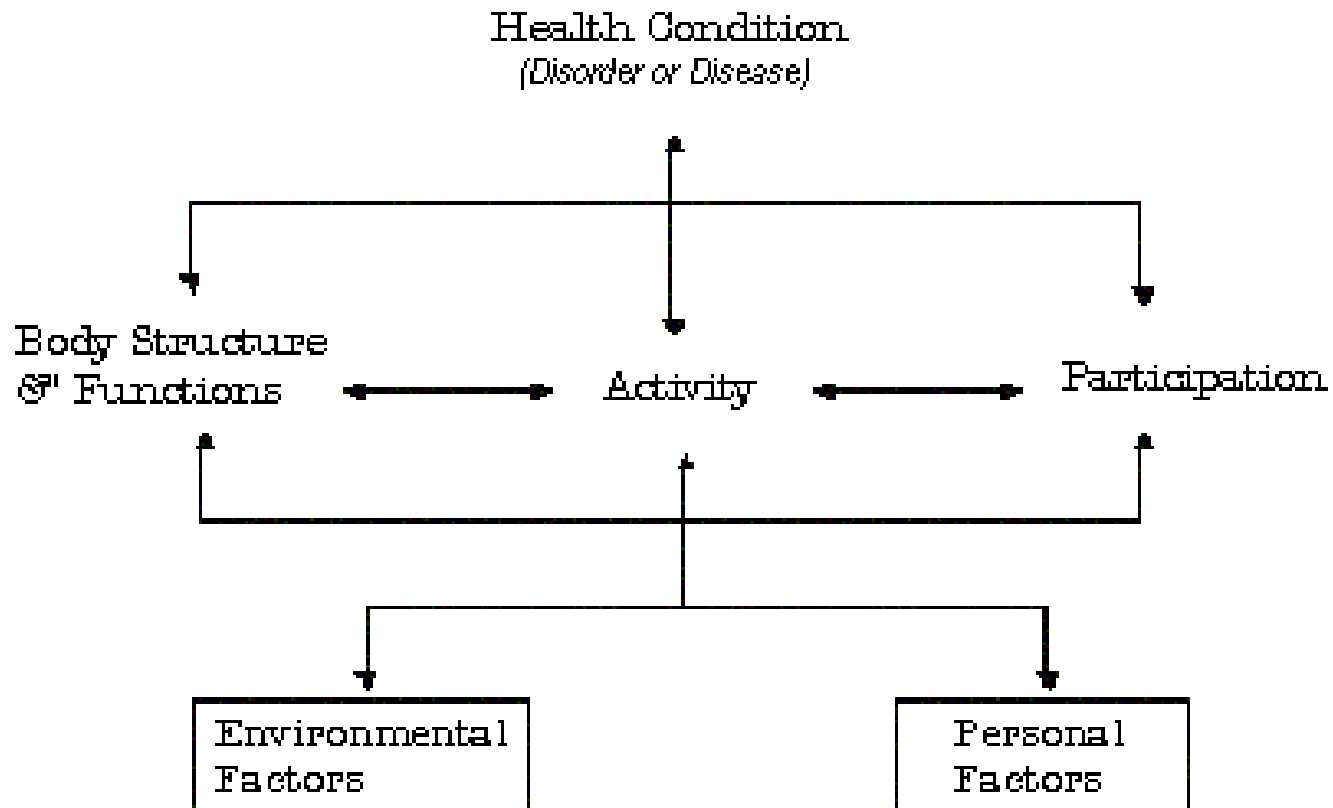
CP Research in the 80's



“Life is doing stuff”



WHO International Classification of Functioning, Disability and Health



Participation

Assistive Devices for
Children with
Functional
Impairments: Impact on
Child and Caregiver
Function

Henderson et al DMCN
2008

An evidence based
review



Assistive Devices for Children with Functional Impairments

- 54 studies included, all but 5 had child-focused outcomes
 - Outcomes primarily focused on domains of Activity and Participation, most in the school setting
 - Outcomes positive, few statistically so
 - Limited information on caregivers, what exists is mixed
-

Assistive Devices for Children with Functional Impairments



PECS

- Structure/function: Joint attention
- Activity: Communication
- Participation: Play
- Personal Factor: Behavior
- Environment: (School)

Charlop-Christy J App Behav Anal 2002

Assistive Devices for Children with Functional Impairments



Gastrostomy

- Body Structure/Function: weight gain
- Activity: taking medications
- Participation: school attendance
- Personal Factors: normalcy
- Environmental Factors: Social Stigma

Brotherson J Assoc Pers Sev Handicaps 1995

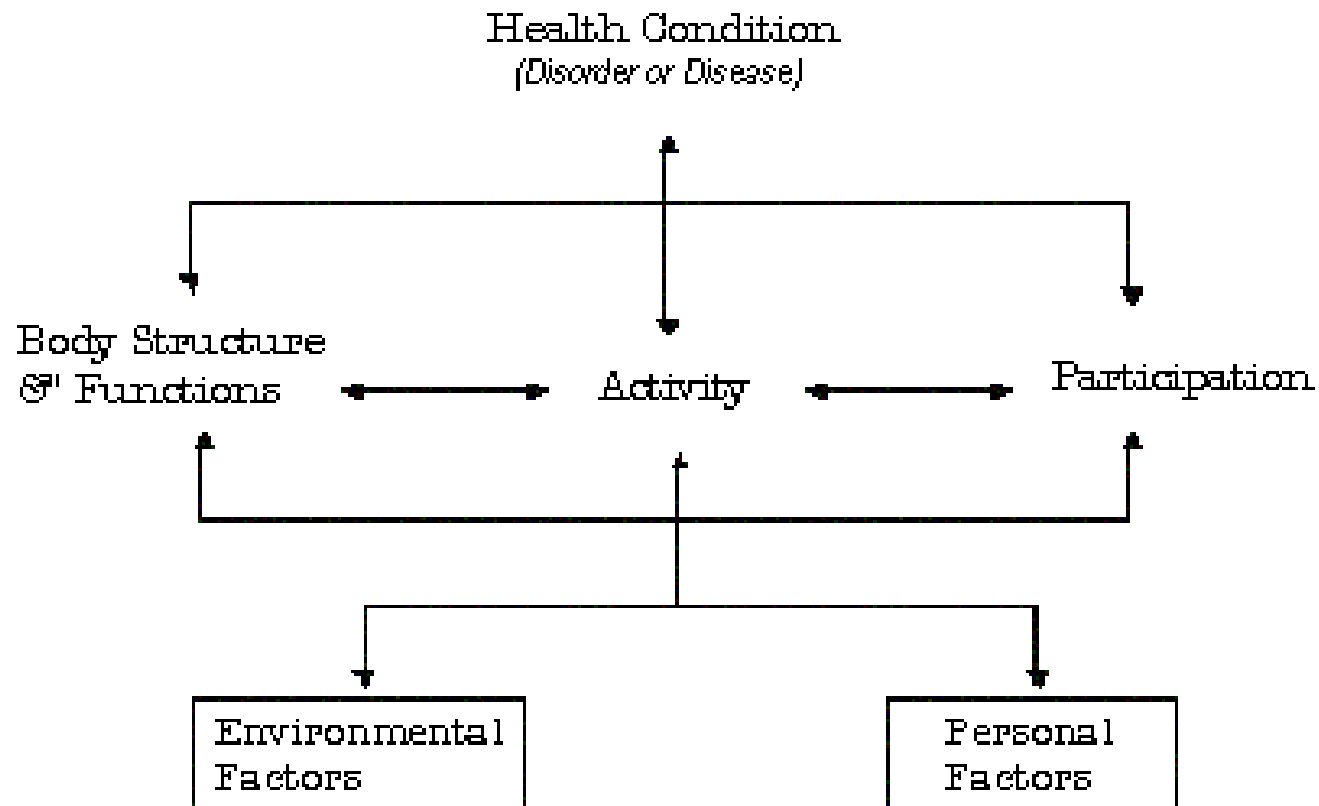
Transition

- Transition of adolescents with special needs to adult – centered health care
- AAP/AAFP/ACP Consensus statement
 - Care
 - Training
 - Funding

Pediatr 2002



Transition



Transition



Team Approach versus ad hoc health services for young people with physical disabilities: a retrospective cohort study

Bent N et al Lancet 2002

Reviewed in the NHS
Economic Evaluation
Database

Team Approach versus ad hoc Health Services

- Retrospective, case-control study
 - Mixed population of physical disabilities
 - Blinded interviewers
 - 3 groups:
 - Young Adult Team: multidisciplinary transition service for persons w/ physical disabilities
 - Routine care/physical disabilities
 - College student controls
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Team Approach versus ad hoc health services

Primary Outcome Measure: Participation 😊

(London Handicap Scale)

Secondary Outcomes:

- **Body Functions** (Nottingham Health Profile)
 - **Activity Limitation** (Barthel Index Score)
 - **Psychosocial Measures** (self-esteem, stress and self efficacy)
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Team Approach versus ad hoc health services

- Logistic regression showed inclusion on YAT service was a strong determinant of participation in society (odds ratio 3.0, confidence interval 1.45-7.21)
 - YAT group had higher London and Barthel scores than the ad hoc group
 - College students had higher self-esteem & less stress but lower self-efficacy and were lonelier
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Team Approach versus ad hoc health services: Cost analysis

Cost of outpatient care per person over the 6 month period:

- YAT #650
- Ad Hoc #798

No hospitalization costs

No economic analysis of the “value-added” or costs of participation

Team Approach versus ad hoc health services

Limitations

- Retrospective – are the groups truly matched?
- How generalizable?



Team Approach versus ad hoc health services



How do we use this data in the “real world”?

Team Approach versus ad hoc health services

Persons with CP & their families

+

Clinicians

+

Researchers

+

Insurers
