Lifespan Issues
Participation and Transition

Nancy N Dodge MD, FAAP
Neurodevelopmental Pediatrics
Helen DeVos Children’s Hospital
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

Health Condition
(Disorder or Disease)

Body Structure & Functions
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Activity
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Participation

Environmental Factors
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Personal Factors
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
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)
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
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