

Planning for Success:

ICF-Based Toolkit to Facilitate Transition to Adulthood

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**LIVING IN OUR ENVIRONMENT:
The Promise of ICF**

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The Problem:

- Youth in transition experience two disconnected processes
 - Educational/Vocational transition
 - Health transition
- These two processes are rarely coordinated
- Only 6% of US families rate transition as positive

Solution: ICF-CY for transition planning

- ICF emphasizes function at different levels
- Systematic approach
- Comprehensive review of domains
- Integrates social and medical perspectives
- Appropriate for the interdisciplinary team
- Strength-based

Initial Community Input

- We presented idea to families at annual state-wide transition conference July 2005.
- Concept of an ICF-planner received enthusiastically
- Parents emphasized need for help with medical transition
- Parents requested a user-friendly version tool

Creation of a User-Friendly Tool

- Interdisciplinary team worked on project
 - Anthropology, Dentistry, Dietetics, Education, Nursing
 - OT, Pediatrics, PT, Psychology, Public Health
 - Speech and Language Pathology, Social Work
- Translated items from Body Structure/Function and Activity/Participation into yes-no questions
- Integrated Environmental items
- Set language at 5th grade reading level

The Planned Process

- Youth and/or family download the planner from our website
- Youth and/or family answer all of the questions either on- or off-line
- Responses uploaded
- Responses converted into summaries to guide transition planning
 - Medical summaries emphasize Body Structures/Functions
 - Education and social service summaries emphasize Activities/Participation

Summaries

- Body Structures/Functions
 - “No Reported Problems”
 - “Reported Problems”
- Activities/Participation
 - “My Strengths”
 - “My Challenges”
 - Free Text: “What I Want to Work On”

Resources

- Website will include lists of resources organized by ICF domain
 - Health care providers
 - Health insurance companies
 - Vocational training
 - Housing
 - Recreation
- Families use summary to find resources they need

Longitudinal Planning

- Youth and families may start using the tool as early as age 10
- Youth and families revisit questionnaire on annual basis for reassessments
- Resources may change with age

Pilot Data

- Focus groups of young adults with cognitive impairments and their parents
 - Tool facilitated comprehensive dialogue between youths and parents
 - Tool identified gaps between youths and parents in estimates of functioning
 - Completion of tool led to identification of previously unrecognized problems in participants—e.g. obstructive sleep apnea
- Team modified tool on the basis of recommendations

Large-Scale Testing to Begin

- Question: Does this tool improve transition planning? Does the tool facilitate medical transition?
- Participants: Youth and families
 - Youth with developmental, motor, and sensory disabilities, chronic health conditions
 - Members of diverse and under-represented ethnic groups
- Outcomes
 - Ease of use
 - Utility of summaries
 - Success in accessing resources

Future Applications

- Spanish language version
- Other adult transitions (e.g., move to independent living, death of caregiver)
- Other child transitions (e.g., preschool to school)

Research Questions

- How do various methods for preparing youth for transition affect the adult's level of functioning?
- How do environmental factors impact functioning of youth in transition?
 - Public policies
 - Availability of resources
 - Family and employer attitudes
- How does functioning change after completion of public education?

Summary

- ICF-based assessment tool for transition
- Pilot was well received by youth and families
- Yes/no questions generate summaries
- Large scale testing to begin this summer
- Future clinical and research applications

Thank You

- Please contact me with questions, comments, at: Randall.Phelps@chp.edu
- Our Website: www.uclid.org