

Transition Planning for Youth with Developmental Disabilities

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Disclosures

I have no disclosures of financial or other interests.

This presentation will not include discussion of pharmaceuticals or devices that have not been approved by the FDA, nor will any brand names be mentioned.

Overview

- Overview of existing transition processes
- Case-study to illustrate the use of the International Classification of Functioning for comprehensive functional assessment in transition planning
- Overview of "Planning for Success", a novel computerized transition planning tool based on the ICF
- 4 case studies of the application of "Planning for Success"
- Some practical tips

Adolescence:



The Transition Problem

- Youth in transition experience disconnected processes
 - Educational/Vocational transition
 - Health transition
 - Social services transition
- These processes are rarely coordinated
- Transition involves loss of entitlement services
- Only 6% of US families rate transition as positive

A Solution?: Transition Checklists

- Limitations of Existing Checklists:
 - They are not comprehensive—usually medically-centered, education-centered, or social service centered
 - They don't facilitate interdisciplinary communication
 - They are generic
 - They do not involve the youth and family in the process

Educational/Vocational Transition Process:

- Mandated process for all students with IEPs
- Mandated to start at age 14-16 (practically speaking, this usually means by 16+), thru 21
- Still, this is years of intensive transition work
- One of the main liabilities of this process is the lack of medical input
- Also, a student must have an IEP to receive transition services

Social Services Transition Process:

- Available to youth with Developmental Disabilities services
- Youth without such eligibility are left out (even less inclusive than educational transition)
- Often too superficial and generic
 - “Carl’s” story....

Medical Transition Process:

Medical Transition Process:

- Professional consensus that we need to be writing “transfer notes”
- Some medical homes do this well, but there is no mandated process or standard of care
- Some sub-specialty clinics have transition coordinators, but they tend to focus on specific medical issues
- Children’s Hospital of Pittsburgh....

“Temisha”, 15 y.o. girl with sickle-cell anemia:

- G’ma’s primary concern is that Temisha is excessively dependent on her and her 5 sisters.
- Temisha refuses to leave the house unaccompanied.
- Requires daily reminders to take her medication.
- Temisha doesn’t apply herself in school.
- She misses a large amount of school due to pain crises and scheduled visits with sub-specialists.
- G’ma is concerned that Temisha will have great difficulty functioning independently as an adult.

Past Medical History:

- Sickle cell anemia
- Multiple silent mini-strokes; receives monthly scheduled transfusions.
- History of multiple admissions for pain crises.

Medications:

- Folate, daily
- Penicillin, daily
- Tylenol with codeine, prn, pain.

Social History:

- Temisha has lived with grandmother and five teenaged sisters for 10 years.
- Failing all of her classes in high-school. Was receiving Learning Support through middle school, but when family moved to a new school district last year, Individualized Educational Plan was discontinued. She is now in all mainstream classes.
- Used to participate in volleyball and track, but has not participated in sports since middle school.
- She has made friends at her new school but she never sees her friends outside of school

Interdisciplinary Assessment:

- Cognitive and academic assessments indicate that Temisha has a Non-Verbal Learning Disability
- Significant inattentive symptoms and impairment of performance in organization and completion of assignments and other tasks.
- Significant levels of anxiety, particularly in the area of harm avoidance.
- Symptoms of depression, particularly negative mood, ineffectiveness, and anhedonia.
- Significant amount of pain on a daily basis, particularly in hands and legs. Severe headaches approximately once a week.

Questions:

- How might you organize these data?
- How might you prioritize among the findings to develop treatment plans?

Multi-Axial Assessment? ICD-9:

- Axis I: Clinical disorders
- Axis II: Personality Disorders/MR
- Axis III: General Medical Conditions
- Axis IV: Psychosocial and Environmental Problems
- **Axis V: Global Assessment of Functioning**

Limitations of ICD-9:

- Focus on diagnoses and disorders
- Focus on the individual
- “Functioning” reduced to a single numerical value
- GAF, like IQ, can be a gateway to services
- GAF tells little about a person’s life

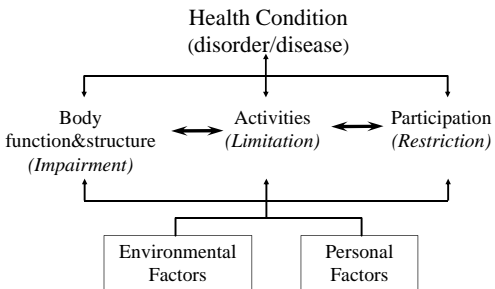
**Multi-Axial Assessment-Revised,
ICD-10:**

- Axis I: Chronic medical illnesses or disorders
- Axis II: Acute, intermittent, episodic conditions
- Axis III: Developmental, behavioral, and mental health conditions
- Axis IV: Psychosocial and Environmental Features
- **Axis V: ICF**

International Classification of Functioning (ICF)-WHO

- Focus on function over diagnosis
 - Includes strengths as well as challenges
 - Shifts focus from clinic to community
- ICF adds 3 levels of functioning --body, individual, and societal perspectives
 - Emphasizes context
 - Distinguishes impairment and disability
- Elaborates on function
 - Comprehensive
 - Domains are therapeutically significant

Conceptual Model of the ICF



Body Functions and Structures

- **Mental Functions**
- Sensory Functions and Pain
- **Voice and Speech Functions**
- Cardiovascular, Hematological, Immunological, and Respiratory
- Digestive, Metabolic, and Endocrine
- Genitourinary and Reproductive
- Neuromusculoskeletal and Movement Related
- Skin and Related Structures

Body Functions and Structures

- Mental functions
 - Intellectual
 - Sleep
 - Attention
 - Memory
 - Emotional
 - Language
 - Perceptual

Activities and Participation

- Learning and applying knowledge
- General tasks and demands
- Communication
- Mobility
- Self care
- Domestic Life
- Interpersonal interactions and relationships
- Community, social, and civic life

Activities and Participation

- Community, Social, and Civic Life
 - Informal education
 - School education
 - Remunerative employment
 - Basic economic transactions
 - Activities and community life
 - Recreation and leisure
 - Religion and spirituality
 - Political life and citizenship

We Converted ICF into User-Friendly Tool:

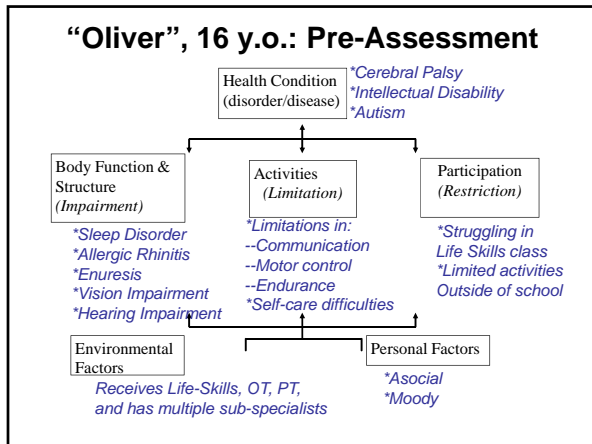
- Interdisciplinary team worked on project:
Anthropology, Dentistry, Dietetics, Education, Nursing, OT, Pediatrics, PT, Psychology, Public Health, Speech and Language Pathology, Social Work
- Translated items from Body Structure/Function and Activity/Participation into yes-no questions
- Augmented oral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

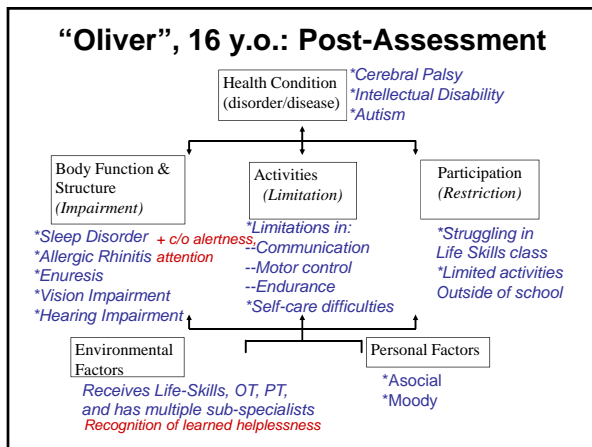
“Planning for Success”:

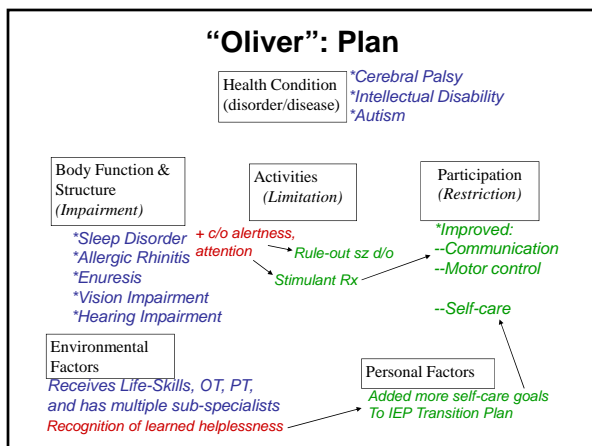
- Go to <http://transition.uclid.org>
- Create free password-protected account
- Log on
- Youth and/or family go through questionnaire (over several sittings)
- Responses are converted into customized transition planners:
 - Health summary
 - Activities summary
- Youth and/or family use customized planners to guide their discussions with educators, social workers, and health care providers

Longitudinal Planning

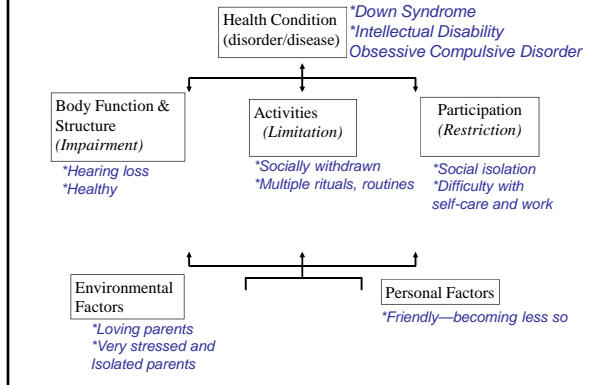
- Youth and families may start using the tool in early adolescence
- Youth and families may revisit questionnaire as desired for reassessments



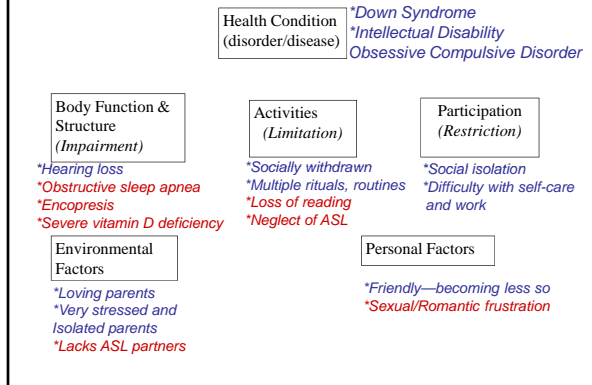




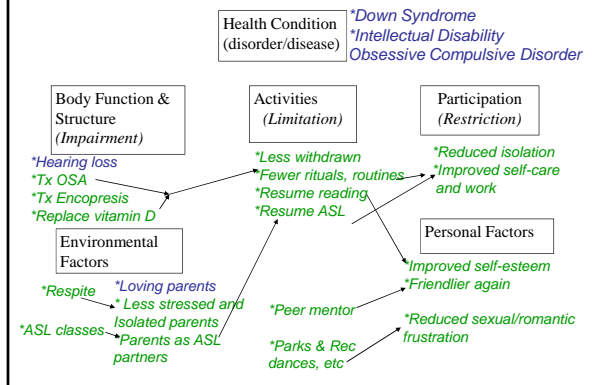
“Charles”, 24 y.o.: Pre-Assessment



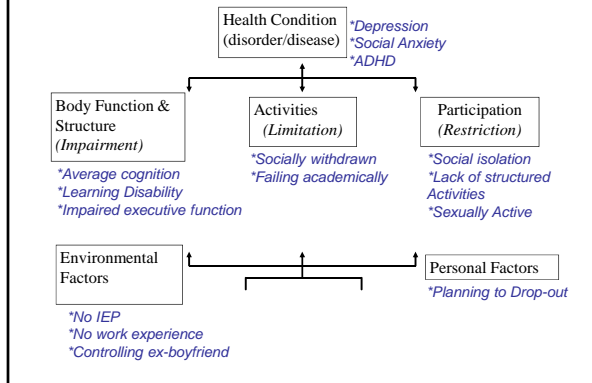
“Charles”: Post-Assessment



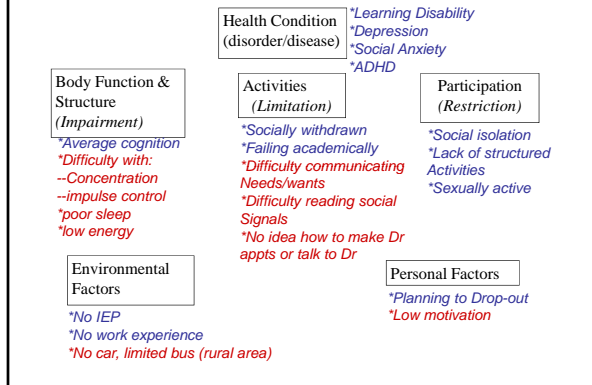
“Charles”: Plan



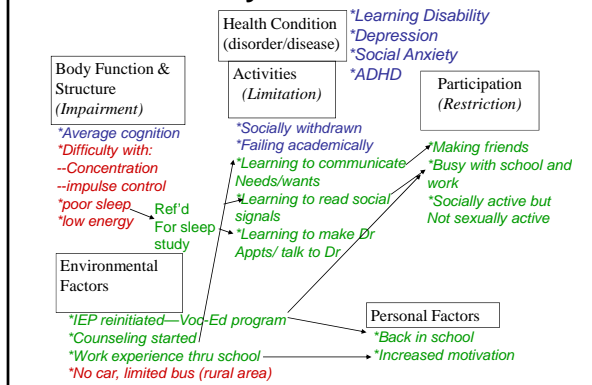
“Krystal”, 18 y.o.: Pre-Assessment

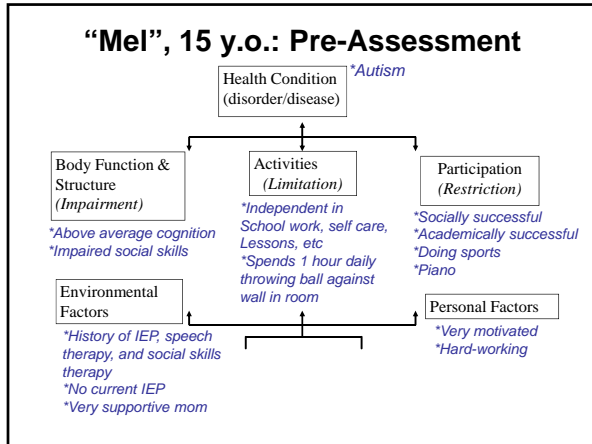


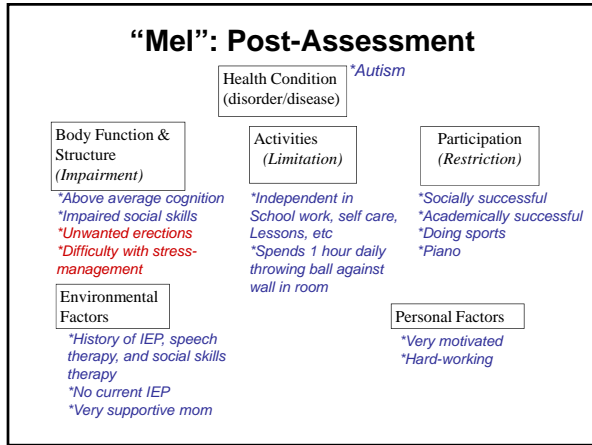
“Krystal”: Post-Assessment

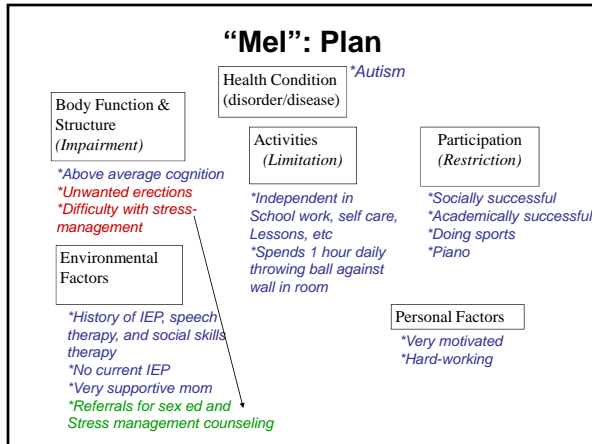


“Krystal”: Plan









Summary

- Hypothesis: Successful transition depends on successful transition planning
- Elements of successful transition planning:
 - Comprehensive
 - Integrates medical, educational, and social information
 - Client/ family centered
 - Includes strengths
 - Community oriented

“...what you get out of it depends on what you put into it.”—Tom Lehrer

Practical tips

- Regular “transition appointments”, starting in tweenhood
- Refer families to IEP transition process
- Refer families to Office of Developmental Disabilities: 360-750-4250 /Toll Free: 1-888-877-3490
- Refer to “Dream it/Do it” camp, Chuck Davis: 503.494.3281, davichar@ohsu.edu
- CDRC
- <http://www.orpti.org/>
- <http://www.hrtw.org/>
- <http://www.youthhood.org/>
- Sexuality: Teaching Children with Down Syndrome about their Bodies, Boundaries, and Sexuality, Terri Couwenhoven, Woodbine House.
- Coming soon, I hope: “Planning for Success”—will be free, public.

Questions?

- Please write/call with questions/comments:

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