Transition Planning for Youth with Developmental Disabilities

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This presentation will not include discussion of pharmaceuticals or devices that have not been approved by the FDA, not 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

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:
- 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-speciality clinics have transition coordinators, but they tend to focus on specific medical issues
- Children’s Hospital of Pittsburgh—abrupt discontinuation
- Boston, Doernbecker, others: youth wards

“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?

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**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

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**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**

- **Health Condition** (disorder/disease)

- **Body Function & Structure** (Impairment)
  - **Activities** (Limitation)
  - **Participation** (Restriction)

- **Environmental Factors**
- **Personal Factors**

**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

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  - Political life and citizenship

- **Health Condition** (disorder/disease)
  - *Sickle Cell Anemia*
  - *Multiple Strokes*

- **Activities** (Limitation)
  - Difficulty with:
  - Learning
  - Attending to task
  - Completing work
  - Not leaving home

- **Participation** (Restriction)
  - School failure
  - Decreased participation in sports
  - Not going out with friends

- **Environmental Factors**
  - Single parent
  - Lack of IEP
  - Frequent Hospitalizations
  - Has friends

- **Personal Factors**
  - Low motivation
  - Dependent
  - Likes sports
  - Friendly
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

“Oliver”, 16 y.o.: Pre-Assessment

- Cerebral Palsy
- Intellectual Disability
- Autism
- Sleep Disorder
- Allergic Rhinitis
- Enuresis
- Vision Impairment
- Hearing Impairment
- Receiving Life-Skills, OT, PT, and has multiple sub-specialists
- Struggling in Life Skills class
- Limited activities Outside of school
- Asocial
- Moody
- Low motivation
- Transition Plan
  - Focused on Independence
  - Likes sports
  - Friendly
- Single parent
- Learning Support
- Frequent Hospitalizations
- Has friends
- Re-open Individualized Educational Plan
- Improved School Performance
- Participating in sports
- Going Out with Friends More
- Improved:
  - Learning
  - Improved Attention
  - Completing Tasks
  - Able to Leave House
- Limited activities:
  - Communication
  - Motor control
  - Endurance
  - Self-care difficulties
- Independent
- Likes sports
- Friendly
- Decreased
- Has friends
- Low motivation
- Transition Plan
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  - Endurance
  - Self-care difficulties
- Independent
- Likes sports
- Friendly
- Decreased
- Has friends
“Oliver”, 16 y.o.: Post-Assessment

Health Condition (disorder/disease) Cerebral Palsy
Intellectual Disability
Autism

Body Function & Structure (Impairment)

Activities (Limitation)

Participation (Restriction)

Limitations in:

*Struggling in Communication
*Limited activities Outside of school

Environmental Factors

Receives Life-Skills, OT, PT, and has multiple sub-specialists
Recognition of learned helplessness

Personal Factors

*Asocial
*Moody

*Sleep Disorder + co alertness
*Allergic Rhinitis attention
*Enuresis
*Vision Impairment
*Hearing Impairment

Health Condition (disorder/disease) Sleep Disorder

Activities (Limitation)

Participation (Restriction)

Self-care difficulties

Environmental Factors

Receives Life-Skills, OT, PT, and has multiple sub-specialists
Recognition of learned helplessness

Personal Factors

*Asocial
*Moody

“Oliver”: Plan

Health Condition (disorder/disease) Cerebral Palsy
Intellectual Disability
Autism

Body Function & Structure (Impairment)

Activities (Limitation)

Participation (Restriction)

*Sleep Disorder + co alertness, attention
*Rule-out sz d/o
Stimulant Rx

Self-care

Environmental Factors

Receives Life-Skills, OT, PT, and has multiple sub-specialists
Recognition of learned helplessness

Personal Factors

*Asocial
*Moody

“Charles”, 24 y.o.: Pre-Assessment

Health Condition (disorder/disease) Down Syndrome
Intellectual Disability
Obsessive Compulsive Disorder

Body Function & Structure (Impairment)

Activities (Limitation)

Participation (Restriction)

*Hearing loss
*Healthy

*Socially withdrawn
*Multiple rituals, routines
*Social isolation

Environmental Factors

*Loving parents
*Very stressed and isolated parents

Personal Factors

*Friendly—becoming less so
*Social isolation

“Charles”: Post-Assessment

Health Condition (disorder/disease) Down Syndrome
Intellectual Disability
Obsessive Compulsive Disorder

Body Function & Structure (Impairment)

Activities (Limitation)

Participation (Restriction)

*Hearing loss
*Obstructive sleep apnea
*Encopresis
*Severe vitamin D deficiency

Environmental Factors

*Loving parents
*Very stressed and isolated parents
*Lacks ASL partners

Personal Factors

*Friendly—becoming less so
*Sexual/Romantic frustration

“Charles”: Plan

Health Condition (disorder/disease) Down Syndrome
Intellectual Disability
Obsessive Compulsive Disorder

Body Function & Structure (Impairment)

Activities (Limitation)

Participation (Restriction)

*Reduced isolation
*Improved self-care and work

Environmental Factors

*Peer mentor
*Less stressed and isolated parents
*Parents as ASL partners

Personal Factors

*Improved self-esteem
*Friendlier again

“Krystal”, 18 y.o.: Pre-Assessment

Health Condition (disorder/disease) Depression
Social Anxiety
ADD

Body Function & Structure (Impairment)

Activities (Limitation)

Participation (Restriction)

*Average cognition
*Learning Disability
*Impaired executive function

Environmental Factors

*No IEP
*No work experience
*Controlling ex-boyfriend

Personal Factors

*Planning to Drop-out

“Krystal”, 18 y.o.: Plan

Health Condition (disorder/disease) Depression
Social Anxiety
ADD

Body Function & Structure (Impairment)

Activities (Limitation)

Participation (Restriction)

*Social isolation
*Lack of structured Activities
*Sexually Active

Environmental Factors

*Peer mentor
*Less stressed and isolated parents
*Parents as ASL partners

Personal Factors

*Improved self-esteem
*Friendlier again

“Krystal” Plan

Health Condition (disorder/disease) Depression
Social Anxiety
ADD

Body Function & Structure (Impairment)

Activities (Limitation)

Participation (Restriction)

*Reduced isolation
*Reduced sexual/romantic frustration

Environmental Factors

*Peer mentor
*Less stressed and isolated parents
*Parents as ASL partners

Personal Factors

*Improved self-esteem
*Friendlier again
“Krystal”: Post-Assessment

Health Condition (disorder/disease)
- Social Anxiety
- Depression
- ADHD

Body Function & Structure (Impairment)
- Average cognition
- Difficulties with:
  - Concentration
  - Impulse control
  - Poor sleep
  - Low energy

Activities (Limitation)
- Socially withdrawn
- Failing academically
- Difficulties communicating
- Need for social activities
- No idea how to make Dr appts or talk to Dr

Participation (Restriction)
- Social isolation
- Lack of structured activities
- Sexually active

Environmental Factors
- No IEP
- No work experience
- No car, limited bus (rural area)

Personal Factors
- Planning to drop out
- Low motivation

“Krystal”: Plan

Health Condition (disorder/disease)
- Social Anxiety
- Depression
- ADHD

Body Function & Structure (Impairment)
- Average cognition
- Difficulties with:
  - Concentration
  - Impulse control
  - Poor sleep
  - Low energy
  - Ref’d for sleep study

Activities (Limitation)
- Socially withdrawn
- Failing academically
- Learning to communicate
- Need for social activities
- Learning to make Dr appts or talk to Dr

Participation (Restriction)
- Social isolation
- Lack of structured activities
- Sexually active

Environmental Factors
- IEP re-introduced
- Socially active
- Not sexually active

Personal Factors
- Making friends
- Busy with school and work
- No car, limited bus (rural area)

“Mel”, 15 y.o.: Pre-Assessment

Health Condition (disorder/disease)
- Autism

Body Function & Structure (Impairment)
- Above average cognition
- Impaired social skills

Activities (Limitation)
- Independent in school work, self care, Lessons, etc
- Spends 1 hour daily throwing ball against wall in room

Participation (Restriction)
- Sociable success
- Academically successful
- Doing sports
- Piano

Environmental Factors
- History of IEP, speech therapy, and social skills therapy
- No current IEP
- Very supportive mom

Personal Factors
- Very motivated
- Hard working

“Mel”: Plan

Health Condition (disorder/disease)
- Autism

Body Function & Structure (Impairment)
- Above average cognition
- Impaired social skills
- Unwanted erections
- Difficulty with stress management

Activities (Limitation)
- Independent in school work, self care, Lessons, etc
- Spends 1 hour daily throwing ball against wall in room

Participation (Restriction)
- Sociable successful
- Academically successful
- Doing sports
- Piano

Environmental Factors
- History of IEP, speech therapy, and social skills therapy
- No current IEP
- Very supportive mom

Personal Factors
- Very motivated
- Hard working

Summary

- Hypothesis: Successful transition depends on successful transition planning
- Elements of successful transition planning:
  - Comprehensive
  - Integrate 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: Deschutes County: 541-322-7557
• Refer to “Dream it/Do it” camp, Chuck Davis: 503.494.3281, davichar@ohsu.edu
• CDRC—Monthly clinics starting now!
• Sexuality: Teaching Children with Down Syndrome about their Bodies, Boundaries, and Sexuality, Terri Couwenhoven, Woodbine House.
• Asperger’s Syndrome and Sexuality, Isabelle Henault

Selected Websites:

• http://www.orpti.org/ OR Parent Training and Information
• http://www.hrtw.org/ Healthy and Ready to Work
• http://www.youthhood.org/ Nice, youth-friendly website
• http://www.aap.org/publiced/autismtoolkit.cfm
• http://www.aahd.org
• http://www.autism-society.org
• http://www.apse.org (supported employment)
• http://www.aheadd.org (higher ed in ASD)

Questions?

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