Transition Planning: Helping Families
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What are Good Transition Outcomes?
• Employment
• Education or Training Necessary to Achieve One’s Life Goals
• Community Living
• Satisfying Social Life and Friendships
• Happiness
• Appropriate Health Care

GOOD NEWS
• We know more about what it takes to help youth with disabilities succeed in adult life than we have ever known in the past.
• We know more about effective transition supports than we have in the past.
• New technologies provide youth with disabilities greater opportunities for communication, and for participation in work, postsecondary education, and in their communities.
Bad News

- The adult service system remains woefully underfunded.
- Schools do not do a good job helping youth plan transitions to school or work.
- Efforts among key organizations and agencies are often uncoordinated.
- Efforts to improve transition from child to adult health care have had limited success.

IDEA and Transition

- Include transition goals in IEP by age 16 (Maine = age 14)
- Provide transition services that are:
  - Coordinated.
  - Results-oriented.
  - Focused on academic and functional achievement.
  - Focused on movement to post-school activities.

Transition goals must be:

- Based on age-appropriate assessment of strengths, needs, interests & preferences.
- Measurable.
- Focused on post-secondary outcomes:
  - Training and Education.
  - Employment.
  - Where appropriate, independent living skills.
And…

- Students must be invited to participate!
- Families must be involved!
- “The ultimate responsibility for providing transition services rests with the school district (or state education agency if district fails) and there is no provision for a waiver of this requirement,” (Bateman, 1995).

Transition Services Needed to Meet Goals

- Related Services
- Instruction
- Employment
- Community Experience
- Daily Living Skills
- Post-School Adult Living Objectives
- Functional Vocational Evaluation (if appropriate)

Measurable Goals

- The fact that the written goal has numbers in it does not mean that it is “measurable.”
- For example: “Jaime will use sentences when speaking with 85% accuracy.”
- Or: “Rob will demonstrate appropriate workplace behavior on 3 out of 4 occasions.”
Questions Families Should Ask about Transition Goals

- Is this goal contributing in some way to my child achieving her/his goals for adult life?
- Is the goal helping my child develop specific skills that will be useful to her in adult life?
- Do the goals make sense?

What Families Should Know about Age-Appropriate Assessment

- Designed to assist a student in developing and refining adult goals.
- Meant to describe types of skills & knowledge student needs to develop in order to achieve targeted adult goals.
- A dynamic, ongoing process
  - Ohio Center for Autism and Low Incidence
    http://www.ocali.org
- It is not just the re-administration of the same old tests!

Age Appropriate Assessment (2)

Formal Assessments
- Adaptive Behavior/Daily Living Skills
- General and Specific Aptitude Tests
- Interest Inventories
- Intelligence Tests
- Achievement Tests
- Temperament Inventories/Instruments
- Career Maturity and Employability Tests
- Self-Determination Assessments
- Transition Planning Inventories.
Age Appropriate Assessment (3)

Informal
- Interviews and Questionnaires
- Direct Observation
- Curriculum Based Assessments
- Environmental Analysis (Ecological Assessment and/or Job Analysis)
- Career Exploration Activities
- Person- and Family-Centered Planning

Families should be on the lookout for:

• The Cut and Paste IEP
• The Creationist IEP
• Its Not My Job IEP

Cut and Paste IEP

All the goals could be cut and pasted from another transition IEP. Examples:
- Student and family will connect with VR after graduation.
- Student and family will talk with Agency ABC about getting adult supports.
- Student will learn vocational skills by participating in life skills program.
- Student will get a job after graduation in her area of interest _____.
- Student will learn social skills by participating in social skills group.
- Student will prepare for postsecondary education by participating in academic classes.
Creationist IEP

• Goals do not evolve.
• What is good for student at 14 is good when she is 21.

“Its Not Our Job” IEP

Under “Transition Services” school personnel are seldom listed as “persons responsible.”
Examples:
– Student will explore colleges that he might be interested in – Person(s) responsible: Student
– Student will get a job when she graduates from college – Person(s) responsible: VR, Student, Family
– Student will continue to participate in community activities with family Person(s) responsible: Student, Family

Factors associated with good transition outcomes

• Collaboration
• Instruction and Experience with Self-Determination and Self-Advocacy
• Work Experience
• Student-Focused Planning
• Family Involvement
Collaboration

Interagency collaboration among schools, community service agencies, and employers is associated with better transition outcomes.

Collaboration: The Reality

• VR counselors attend transition planning meetings for 32% of youth with ID and 24% of youth with other disabilities.
• Staff from other agencies attend transition planning meetings for 16% of youth with ID and 8% of youth with other disabilities.
• Potential employers are contacted as part of transition planning for 42% of youth with ID and 36% of youth with other disabilities.

(Grigal, Hart & Migliore, 2011)

Self-Determination

• Youth with greater self-determination skills have better employment, independent living, and postsecondary outcomes.
• All youth can benefit from:
  – Instruction in Self-determination
  – Opportunities to Practice Self-determination
Self-Determination (2)

“[A] combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior. An understanding of one’s strengths and limitations, together with a belief of oneself as capable and effective are essential to self-determination…

Self-Determination (3)

... When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults in our society.”

(Field, Martin, Miller, Ward, & Wehmeyer, 1998)

Self-Determination: The Reality

- Families and teachers think self-determination is important.
- Youth – especially those with more significant disabilities - often receive little instruction in or opportunities to practice self-determination.
Self-Advocacy

• Being able to advocate for oneself is an important skill that youth with disabilities will need in postsecondary education, employment, community, and residential settings.

• In reality, students have little opportunity to learn or practice self-advocacy skills.

Work Experience

Paid work experience in high school is the strongest predictor of post-school employment.

Work Experience (2)

Other work-related predictors:
– Work Study
– Vocational Instruction
– Career Maturity
– Expectation that Youth will Work
– School-to-Work Programs
– Individualized Supports
– Job Development Based on Individual Interests
Work Experience – The Reality

- Post-school unemployment rate is high for youth with disabilities.
- Youth with disabilities have fewer jobs in HS than those without disabilities.
- Employment preparation activities in HS are limited.
- Employment programs for youth with more significant disabilities often fail to consider individual preferences or passions.

Student-Focused Planning

- Active student participation in planning and decision-making;
- Opportunities to exercise self-determination and self-advocacy; and
- Planning that is based on student’s own goals and vision for the future.

Student-Focused Planning – The Reality

- Students seldom participate actively in the transition planning process.
- Students and families often feel alienated from a process that is often dominated by professionals.
- Planning may consist of matching youth to available programs rather than on individual and family conceptions of a successful future – especially for those with more significant disabilities.
Family Involvement – The Reality

• Families do not have access to information about the supports and services that may be available to their children as adults.
• Families often feel frustrated by a process they see as being professionally dominated.
• Family involvement in transition planning is not at a level consistent with federal mandates.

Summary of Performance (SOP)

• Purpose = to help establish eligibility for accommodations & supports in postsecondary settings.
• Must be completed in student’s last year of high school.
• May be necessary for student’s application to college.
• Must include recommendations to help student’s reach postsecondary goals.

Families and SOP

• Families need to make sure that the SOP provides useful information to the youth, potential employers, post-secondary educational institution.
• Families and, when possible the student should begin talking with school personnel about what is needed in the SOP before the student’s final year in school.
What families and youth need to know about post-secondary education.

- IDEA no longer applies, even in educational settings.
- Eligibility requirements vary.
- Qualifying for services vs. Receiving services.

Assistive Technology

- Ideally, assistive technology should be addressed in the transition plan.
- Students should be exploring and trying out assistive technology that will be useful to them when they leave high school.

Advocacy Tips for Families and Youth

- Insist that transition planning is focused on the vision that you and your child have for a desirable future.
- Come to transition meeting with suggestions, services, supports, and planning that may be necessary for your child to reach his or her desired goals.
- When asking for assessment in a particular domain, provide school personnel with assessment resources.
- Work with your son or daughter in advance of the meeting so she or he can self-advocate. Talk with your child and school about the possibility of a self-directed IEP meeting.
Advocacy Tips (2)

- Clarify who will be responsible for each transition goal.
- If the connection between the goal and the services needed to achieve that goal are vague, ask that it be spelled out more clearly.
- If a meeting participant indicates that something cannot be done, ask to see a copy of the policy or regulation.
- Discuss what should be included in SOP.

Advocacy Tips (3)

- If necessary, ask school personnel to indicate in the transition plan how progress towards goals will be measured. Do not accept vague answers.
- Ask that adult agencies including Vocational Rehabilitation be invited to the meeting.
- If VR counselor seems unwilling to provide appropriate services,
- Ask how school staff are making sure that any skills taught can be generalized to potential post-school environments.

Collective Action

Even great transition plans will work only if the services and supports needed are available when the student leaves school.

Families may need to connect with other families and engage in advocacy, lobbying, or litigation efforts.
The Medical Home

- “A model of delivering primary medical care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective” (p. 184).
- Provision of primary care including acute and chronic care, preventative services, developmental assessments, health care supervision, patient and parent counseling, nutrition, safety, and psychosocial issues.
- Interaction with other programs and schools.
- Maintenance of an accessible, comprehensive, central record.

The Medical Home (2)

“Provision of developmentally appropriate and culturally competent health assessments and counseling to ensure successful transition to adult-oriented health care, work, and independence in a deliberate, coordinated way.” (p.183)

American Academy of Pediatrics (2011, p. 183)

“After nearly a decade of effort, widespread implementation of health transition supports as a basic standard of high-quality care has not been realized. To date, only limited progress can be documented.”
Health Care Transition Plans

- Nationally, just over 40% of YSHCN have health care transition plans (Cheak-Zamora et al., 2013).
- Youth with ASD have healthcare transition plans at about half the rate.
- Having multiple medical conditions actually reduces the odds that youth with ASD will have a health care transition plan!!

Obstacles to Effective Transition From Pediatric to Adult Health Care

- Shortages of key personnel – Especially in poor and rural areas.
- Few models of high-quality transition supports.
- Inability of families to identify primary care provider who can coordinate care.
- Lack of expertise by primary care providers.
- Lack of time and sufficient compensation.
- Focus on disability-related issues can result in neglect of standard preventative care and screenings.

Obstacles to Effective Transition From Pediatric to Adult Health Care (2)

- Children with special health care needs (CShCN) often have unmet health care and family support needs that can be ameliorated by the presence of insurance, higher family incomes, and the receipt of care within a medical home (McGrath et al 2010; Strickland et al 2009).
- Nationally, 33.5% of CShCN lacked sufficient health insurance.
Recommendations from AAP (2011)

• Make the health care transition as seamless as possible.
• Medical home teams should adopt explicit office policy describing approach to health care transition.
• Medical home teams should receive training and technical assistance related to transition.
• Collaborate with family including in the support of broader transition efforts (vocational, career, educational, independent living)

Recommendations from AAP (2011) (2)

• Subspecialists may need to build capacity to serve young adult patients with special health care needs.
• Inform parents and youth about role of medical provider in transition.
• Families and medical providers should begin to prepare YSHCN to take a greater role in managing their own health care – starting as early as age 12.
• Written care plan should include a section on “transition” by age 14.

Recommendations from AAP (2011) (3)

• “Document progress to allow for ongoing reassessment and movement of medical information to the receiving (adult care) provider” (p. 193). Medical documentation should include:
  – Transition Plan
  – Longitudinal Readiness Checklists
  – Portable Medical Summary
• For those in need of chronic care management (CCM) it is important to determine if patient can make decision, and if not, who should.

**Family-Centered Transition Planning for Students with Autism Spectrum Disorders**

University of New Hampshire
Institute on Disability

University of Maine
Center on Community Inclusion and Disability Studies

**FCTP Components**

- **Parent Training (SPED):** 5 Saturdays
- **Person-Centered Planning:** 5 - 9 in-home mtgs.
- **Career Exploration:** 4 - 6 months
Parent Training

- Orientation to adult service system –
- Learning how to re-order thinking – asking, “What do you want?” before “How will you do it?”
- Planning tools that focus on the individual (strengths, support needs, skills, challenges and preferences).

Person-Centered Planning

- Who is the person?
- Individuals to include in planning process.
- Individual preferences (general, employment, home, learning, choice-making)

Person-Centered Planning (2)

- Scheduling – routines – what would a perfect day look like and include?
- What is the vision or what are the dreams of the individual (incorporate information from above tools/planning)
- Action plan – what do you do with the information generated in planning meetings?
Career Exploration

- What have we learned about general and employment preferences for the person?
- Networks, connections uncovered in planning process? (relationships)
- Interests and motivators discovered?

Career Exploration (2)

- Consider variety of approaches (workplace visits, job shadowing, volunteering, internships).
- How to use learning that happens through career exploration – (what did student like/successful – dislike/unsuccessful?)
- Learning from both failures and successes.

Survey Results

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Increasing Access and Success in the STEM Disciplines

• University of Maine
• Experimental Program to Stimulate Competitive Research (EPSCoR)
• Participants:
  – Students with a disability in 9th, 10th, or 11th Grade in 2011-12 School Year
  – Who are interested in pursuing postsecondary education and a STEM career

Project Components

• Three six-hour workshops held simultaneously in Orono and Portland
• Visits to STEM-related University of Maine programs
• Three Person-Centered Planning Meetings
• Support to find Internships and Mentors

Training Session Topics

• Critical junctures
• Differences between college and high school for students with disabilities
• How to obtain supports at postsecondary level
• Disclosure
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<th>Training Session Topics (2)</th>
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<tr>
<td>• Possible jobs in STEM fields</td>
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<td>• Establishing and pursuing goals</td>
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<td>• Financial aid</td>
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<td>• Technological supports for students with disabilities</td>
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<tr>
<td>• Students, Family Members and Others</td>
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<tr>
<td>• Develop a Personalized Plan for Transitioning to Postsecondary Education</td>
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<tr>
<td>• Identify Internship and Mentorship Opportunities</td>
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<td>• Build Self-Determination Skills</td>
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