The Journey, Preparing for the Future

Jeffrey J. Tamburo
Dianne O’Connor
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Transition

- **Process of change:** A process or period in which something undergoes a change and passes from one state, stage, form, or activity to another.
Transition.....

IT’S NOT AN EVENT
The period of transition to adulthood—associated with one’s social role marked by the expectation of being employed, completing education, living independently, developing new life-long relationships, and contributing to society—is daunting for many young people, especially for youth with disabilities.

*Johnson, Stodden, Emanuel, Luecking, & Mack, 2002; Osgood, Foster, Flanagan, & Ruth, 2005; Swail & Brand, 2004; Wagner, 2005*
Their transition is confounded by the challenges posed by the disability condition, disadvantaged demographic characteristics (e.g., low socio-economic status, ethnic minority, single-coordination resulting from systematic barriers.)

Davis & Butler, 2002; Osgood et al., 2005 Stodden, Dowrick, Stodden, & Gilmore, 2000; Wagner et al., 2003
There has also been a change in where services are delivered to persons with disabilities.
Independence  

Interdependence
Prevalence

- Intellectual disabilities: 30/1000
- ID Requiring pervasive support: 3/1000
- Fetal Alcohol Spectrum Disorders: 10/1000
- Autism: 5.2–7.6/1000
- Cerebral palsy: 1.2–2.8/1000
- Spina Bifida: 0.6/1000

- Prevalence among US adults age 18–29 years
  - Developmental Disabilities: 30.8/1000
  - Diabetes: 28/1000
I have learned, and grown, more since Dylan's birth than any other time in my life. You learn patience, and you get to witness miracles that you otherwise would have been too busy to have noticed... You learn acceptance, you realize you have been wrong to judge, and you learn that there is a thing called unconditional love.
The Journey, When and where to start?

- How is a child identified?
- Access Information and Services
- Brothers and Sisters and other family members
- Supporting and Empowering the family
- Teach child about diagnosis
- Working with professionals
- What is a CSE meeting?
- What is an IEP?
- What are OPWDD, OMH, VESID, OCFS, etc
- Transitional services to adulthood
How is a child identified?

- By you, the parent
- By a caregiver or family member
- By your pediatrician
- By specialist in various fields...psychiatry, neurology, dysmorphologist, geneticist, developmental pediatrician
- Early Intervention specialists, PT, OT, Speech

No parent wants his or her child to be sick, disabled, or harmed in any way. It is not an experience anyone expects to have; rather, it is a journey that is unplanned. The terrain families must travel is often rough in places.
Learn what you can about diagnosis

- Your child
- Your child’s learning style
- Doctor
- Specialist
- Friends
- Family
- Internet
- Support group

Collecting and using the information available on disability issues is a critical part of being a parent of a child with special needs.

Much of the information that will be helpful to you is in the hands, heads, and hearts of other parents like yourself.
Teach child about diagnosis

- Knowledge supports self-esteem
- Assessment testing—facts about tests foster self-esteem
- Assessments help teachers understand his thinking processes and learning preferences
- Build self-esteem by listening to and valuing your child's opinions
- Encourage teachers to "Set Up" your child for self-esteem success
- Help your child identify his/her own interests and skills
- Schedule fun time to make social skills and making friends a priority
Many, many siblings swing back and forth between positive and negative emotions. "Just as parents need information, so do siblings, on their level."

Grandparents are often greatly affected by their grandchild with a disability.

It is important to remember that everyone will need support and information.
Supporting and Empowering the Family

- You are the HEART of the family
- Take some time to care for yourselves
- Protect your relationship. It is the important to make time for each other: meeting for lunch, getting away for a few hours together, sharing an activity.
“We need respect, we need to have our contribution valued. We need to participate, not merely be involved. It is, after all, the parent who knew the child first and who knows the child best. Our relationship with our sons and daughters is personal and spans a lifetime.”

parent Cory Moore
The best relationships are characterized by mutual respect, trust, and openness.

You have intimate knowledge of your child with special needs.

The professional has specialized knowledge to contribute—that of his or her discipline.
The act of teaching involves knowing when to provide support and when to let go. Be careful not to incorporate more support than necessary.
What’s the purpose of Transition Planning?

Life is a process of beginnings and endings. In both life and nature, there are times when things move slowly and don't seem to change very much. Then, suddenly, things change quickly. Moving from August to September, the weather changes gradually at first, and then it seems that suddenly summer is over. It is the same in our lives; transitions are as natural as the changing seasons.
When do you start Transition Planning?

From the first day you set eyes on your child

- We all have thoughts, dreams and goals of what our child will be one day. Those thoughts, dreams, and goals change over time when new information about our child is presented to us.

- Our children also have thoughts, dreams, and goals of what they want to do. We can help them achieve those thoughts, goals, and dreams.
School transitions

To prepare students with disabilities to live, learn, and work within the community.

To provide students with career and life skills, knowledge and experiences.

Article Source: http://EzineArticles.com/9419
Planned and Purposeful
Transition Skill: Speak Up
Transition Skill: Scheduling an Appt
Section 504 covers students with disabilities who attend school receiving Federal financial assistance. It requires that school districts provide a free appropriate public education to qualified students who have physical or mental impairment that substantially limits one or more major life activities.
Improving educational results for children with disabilities is an essential element of our nation’s policy of ensuring equality of opportunity, full participation, independent living and economic self-sufficiency for individuals with disabilities.

- Congress, 1997, IDEA Reauthorization
Social Development

- Relationships with peers and adults
- Feelings about self
- Social Adjustment to school and community environment
Projected Post-School Outcomes

- Ages 15 and over
- Employment
- Post-secondary Education/Training
- Community Living
I went to my CSE so that I could graduate with an IEP and then went to ACCES–VR (formerly VESID) to write my IPE (formerly IWRP) and they referred me to the ARC and LDA who referred me to the DDSO to determine me eligibility for OPWDD (formerly OMRDD) so that I could then be assigned an MSC who could then help me make an IEP.
Alphabet Soup

- EI
- CPSE
- CSE
- VESID
- CBVH
- BOCES
- OMRDD
- OPWDD
- DDSO

- OCFS
- DDS
- JJ
- OMH
- LDA
- ISP
- IEP
- MSC
So, you have choices to make. Dreams, Job, Housing, Recreation, Continued Education, Vocational Training, Relationships.
Fear of the Unknown....

- Where will they live?
- What resources will they have?
- Who will be their circle of support?
- Who will ne their friends?
- Will they work/volunteer?
Empowering youth with the skills and knowledge they need to advocate for themselves is a natural step on the journey to adulthood.

When you get to a fork in the road...take it.

Yogi Berra
Fostering Independence

- Work to assume they only receive as much support as they need
- Assure they have a voice
- Assume they are seen as a person and not as their disability
- Remember the joy that any level of independence brings

- And remember… you will not always be there.
## Different agencies—Different ages of transition to adulthood

<table>
<thead>
<tr>
<th>Agency</th>
<th>Age Interval</th>
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<tbody>
<tr>
<td>EI</td>
<td>Birth to 3 years of age</td>
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<tr>
<td>CPSE</td>
<td>3 to 5 years of age</td>
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<tr>
<td>Public Education</td>
<td>21 years of age</td>
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<tr>
<td>OPWDD</td>
<td>21 years of age</td>
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<tr>
<td>OMH</td>
<td>18 years of age</td>
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<tr>
<td>VESID</td>
<td>Ongoing</td>
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Typical supports provided at the workplace

- Orientation
- Job Training
- Ongoing Job Performance
- Emotional Support
- Learning Social Expectations
- Negotiating Problematic Coworker Relationships
- Reciprocal Relationships
- Time Management
- Developing Support Network
ACCES–VR (VESID)

- Documentation of Disability
- Eligibility for Services
- Barrier to Employment
- Direct Job Placement
- Supported Employment
- Job Training and Education
OPWDD (OMRDD)

NYS Office for People with Developmental Disabilities
13 DDSO Offices Statewide
Eligibility Determination
  - Documentation of cognitive functioning (IQ)
  - Documentation of adaptive functioning (if IQ > 60)
Medicaid Service Coordination (MSC)
Other services
  - Day Habilitation
  - Residential Habilitation
  - Supportive Employment
Post Secondary Education

- Have all evaluations updated before leaving HS
- Section 504 and Title II protect elementary, secondary and postsecondary students from discrimination.
- If you meet the essential requirements for admission, a postsecondary school may not deny your admission simply because you have a disability.
- If you want the school to provide an academic adjustment, you must identify yourself as having a disability.
The appropriate academic adjustment must be determined based on your disability and individual needs. Academic adjustments may include auxiliary aids and modifications to academic requirements as are necessary to ensure equal educational opportunity.

Section 504 of the Rehabilitation Act of 1973 (Section 504) and Title II of the Americans with Disabilities Act of 1990 (Title II)
Don’t Forget Other Transitions

Health Care Transition
1. Health Care Financing
2. Adult Providers
3. Health Care Skills

Adult Living
1. Independent Living Skills
2. Housing
3. Managing Money
4. Guardianship and alternatives
Time to start transition planning!
You've got to start somewhere!
Way to go!
Great progress!
You are getting there!
High five!
Keep up the good work!
You are on a roll!
Awesome!
You're on the homestretch!
Congratulations on your Healthy Transitions!
Planning is Crucial: Wills, Trusts, and Guardianships

When a family has a member with a disability, planning for the future, including developing a comprehensive and realistic estate plan, is critical. Involving the whole family in the planning process can help avoid problems in the future.
Resources


- www.orphan.org: Information on scholarships, mentoring, internships and advocacy.

- www.statevoucher.org: The NYS Education & Training Voucher Program (ETV)
Thank you!

Jeffery J. Tamburo
Jtamburo@enablecny.org
(315) 410-3385

Dianne O’Connor
Dianneo’connor@oasas.state.ny.us
(518) 346-1715