

PREPARING FOR INDEPENDENCE:

EASING THE TRANSITION BETWEEN ADOLESCENCE AND ADULTHOOD FOR INDIVIDUALS WITH DISABILITIES

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Objectives

- Identify strategies to facilitate transition between adolescence and adulthood,
- Recognize transition as a process that starts in childhood,
- Discuss areas to consider as adolescents enter adulthood,
- Determine at least 2 ways transition services can be improved or initiated within your own organization or setting.



Transition to Adulthood

- The process of learning and growing to become an independent adult
- Areas of Transition to Adulthood
 - Independent living
 - Community engagement
 - School/work



Are Adults with Disabilities Transitioning Well?

- Young adults with disabilities **2** years post high school:
 - 30% are in school
 - 40% are employed
 - 12% are living independently
 - 25% are involved in organized social activities

(Wagner, Newman, & Cameto, 2005)

Are Adults with Disabilities Transitioning Well?



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- Young adults with disabilities **8** years post high school:
 - 60% are in school, 19% college or university
 - 60% are employed, avg. wage \$10.40
 - 45% are living independently
 - 52% are involved in organized social activities

(Newman, Wagner, Knokey, et. al 2011).

WHEN DOES TRANSITION START?



Transition Occurs Throughout the Lifespan

TODAY
is the
DAY



Teamwork

- ◎ Team Captain: Child/Adolescent
- ◎ Co-Captain: Family/Caregivers
- ◎ Members:
 - Doctors/Medical team
 - Therapy Team
 - School
 - Community Resources

*The team is always changing with the needs of the client, but transition support from all is needed for success!

Transition

◎ Barriers

- Pediatric Healthcare Providers
- Youth themselves
- Parents
- Adult Healthcare providers

◎ Suggestions

- Start Early!
- Coordinated Team Approach
- Transition Clinics: tours, open houses
- Interested Adult Healthcare providers



Transition Skill Building

- ⦿ Allow Choice: grade for skill level and safety
- ⦿ Encourage Independence: provide safe and structured opportunities
- ⦿ Discuss Life Goals: ask questions, begin to problem solve, dream
- ⦿ Educate about and support opportunities for community and social engagement



Person-Centered Care

- ⦿ Collaborative care NOT directed care
- ⦿ Let go of what you feel is best and allow the client to assist in their own future planning
- ⦿ Provide supports and accommodations needed for success
- ⦿ Provide opportunities to learn new skills and increase participation

(Orentlicher & Micheals, 2003; Wehmeyer, 2002)



Self-Determination

- Definition: Skills and attitudes that enable a person to gain more control over his or her life
- Skills included: self-advocacy, problem solving, self-regulation, goal-oriented, independence in choice making, pride, creativity, initiation

(Wehmeyer & Palmer, 2003, and Wehmeyer 1998).

Self-Determination Research

- ⦿ High SD positively correlates with increased QOL
- ⦿ Not related to cognition level: IQ and high SD level not highly correlated
- ⦿ Increased SD positively correlates with independent living, employment, access to benefits, and financial independence

(Wehmeyer & Palmer, 2003, and Wehmeyer 1998)

SUPPORTING TRANSITION THROUGHOUT THE LIFESPAN



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AGES 4 TO 6 YEARS



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Child Role

- Making choices
- Playing and exploring the environment
- Completing self-cares: dressing, teeth brushing, self-feeding
- Getting into trouble
- Chores:
 - Setting the table, picking up toys, picking out clothing for the next day



Provider/Caregiver Role

- Focus on strengths and foster safety and success
- Begin to educate child on condition: name, special needs associated with their condition
- Encourage choice making
- Teach consequences of choices/behaviors

AGES 7 TO 11 YEARS



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Child Role

- ◎ Complete self-cares
- ◎ Chores (2-3)
 - Take out the trash, unpack dishwasher, put laundry away
- ◎ Speak for themselves
 - Ask 1-2 questions at the doctors
- ◎ Know medications
- ◎ Plan for emergencies/safety

Provider / Caregiver Role



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- ⦿ Educate on gaps and misunderstandings of child's special needs
- ⦿ Encourage child to speak to medical/service providers with support as needed.
 - Providers look at the child when talking, direct appropriate questions to the child
- ⦿ Give opportunities / experiences for independence:
 - shopping, public transit, spending allowance, cooking, cleaning
- ⦿ Sexuality / safe relationship discussions

AGES 12 TO 16 YEARS



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Child Role

- ⦿ Independence in self-cares/directs self-cares
- ⦿ Complete school work
- ⦿ Chores (4-6)
 - completes on a consistent basis
- ⦿ Increase independence with independent living skills:
 - cooking, cleaning, laundry, shopping, money management, medication management, schedule/appointment management, way finding, transportation
- ⦿ Find a volunteer or part-time job that meets interests and skill level

Provider / Caregiver Role



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- Support self-advocacy
- Discuss: dating, making friends, peer pressure, and positive choice making
- Awareness of social media
- Future exploration
- Allow child to attend part of their medical appointments alone and/or allow child to speak throughout the appointment

Individualized Transition Plan

- ⦿ Initiate no later than age 16
 - IEP team may determine it is appropriate to initiate earlier.
- ⦿ The IEP must be updated annually and include:
 - Appropriate and measurable post-secondary goals based upon age appropriate transition assessments related to:
 - Training / Education
 - Employment, and, where appropriate
 - Independent living skills
 - The transition services (including courses of study) needed to assist the child to reach post-secondary goals

AGES 17 TO 30 YEARS



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Young Adult Role

- ◎ Independent living skills:
 - cooking, cleaning, home management, self-management, medical management, transportation, budgeting, etc.
- ◎ Understand needs for:
 - Work and environmental modifications / access
 - Identify home accessibility needs and best fit environment
- ◎ Begin to manage PCA supports
- ◎ Transition to adult healthcare providers



Provider / Caregiver Role

- ⦿ Work with young adult to plan their future
- ⦿ Let go where possible and support where needed
- ⦿ Guardianship / trusts
- ⦿ Income support applications
- ⦿ Supported housing needs
- ⦿ Encourage the young adult to lead the conversation, ask questions, and take ownership of their own medical and personal needs

CONSIDERATIONS FOR THE FUTURE



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Equipment Needs

- ◎ Does your client have equipment at school that they will not have access to once they graduate?
 - Stander, walker, gait trainer
 - AAC devices, switches
 - Tablets, computer access supplies
 - Mobility or positioning devices



Living Considerations

- ◎ What does my client want / need for successful living supports?
 - Stay at home
 - Personal Care Attendants (PCAs)
 - Assisted living (group home)
 - Respite

- ◎ Funding
 - Income support applications
 - Guardianship / trusts

Education, Work, Leisure

⦿ Education

- Transition programs: Age 21
- Continuing education courses, community education

⦿ Work programs

- Day program
- Vocational Rehabilitation

⦿ Leisure

- Special Olympics
- Community programming / classes
- Independent living skills classes
- Social groups



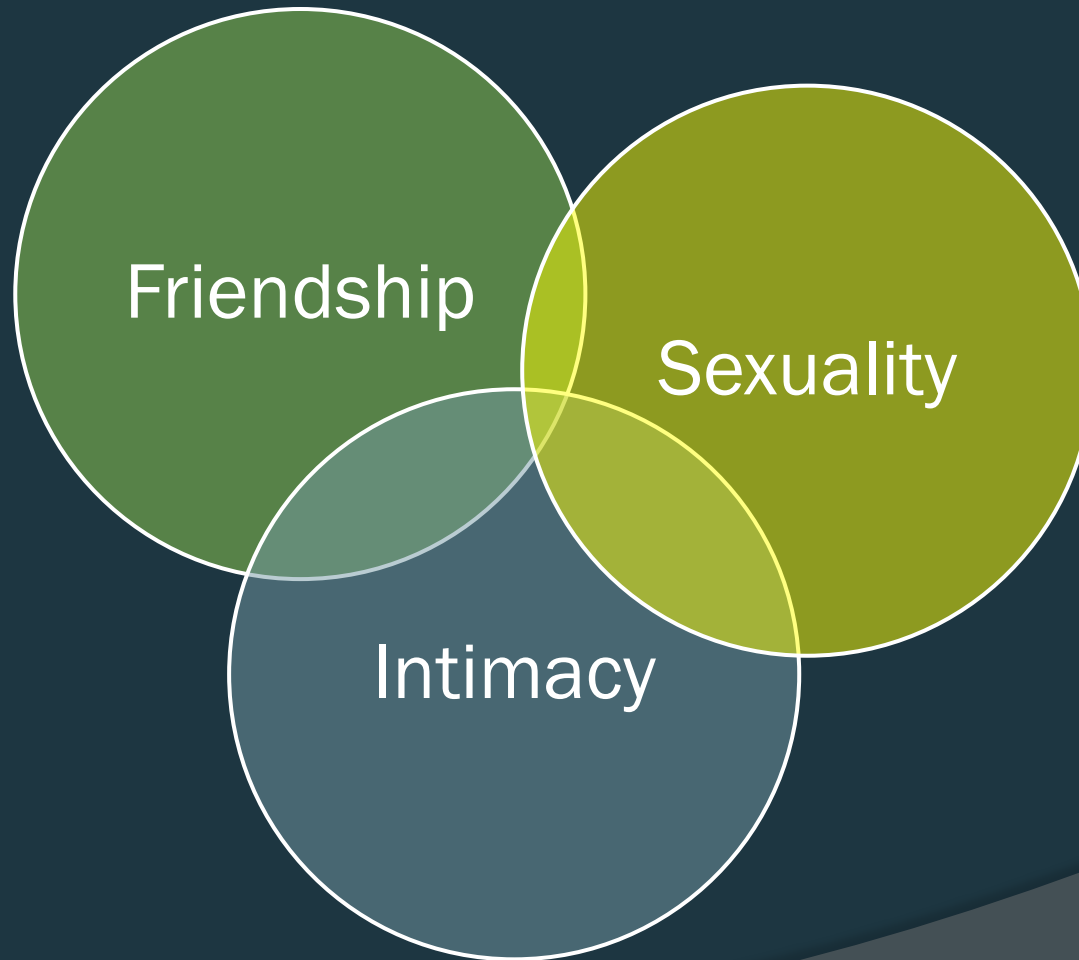
Safety and Vulnerability

- Guardianship
- Financial Support
- Medical Decision Making
- Sexuality and Relationships

Relationship Education



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5 Premises of the Philosophy of Adolescent & Adult Sexuality



1. There is no positive correlation between knowledge of, & interest in sexuality.
2. Adolescence is marked by curiosity / exploration; this phase of development is completely healthy.
3. Ignorance breeds fear - Information allows an individual to develop their own judgment & responses
4. A behavior is less likely to be excessive if recognized, accepted, & appropriate in a given context, rather than forbidden.
5. Urges & sexual desires cannot be repressed; they must be directed towards appropriate expression.

What do Youth with Disabilities Know About Sex?



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- ◎ People with congenital physical disabilities have lower levels of sexual knowledge (43% accuracy on a questionnaire) than those without disabilities
 - Participants with Cerebral Palsy had the least accurate knowledge
- ◎ Youth want to know more! 54% of adults do too! (Cho *et al* 2004)

Rights

- The right to grow up, i.e. to be treated with respect and dignity accorded to other adults.
- The right to know, i.e. to have access to as much information about themselves and their bodies and those of other people, their emotions, appropriate social behavior as they can assimilate.
- The right to express oneself sexually and to make and break relationships.
- The right not to be at the mercy of the individual sexual attitudes of different caregivers.
- The right not to be sexually abused.
- The right to humane and dignified environments (acceptance, peace, dignity).

A CLOSER LOOK AT INDEPENDENT LIVING SKILLS



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General Information

- Current living situation and supports
- Desired living situation
- Patient goals for their future



Standardized Assessments



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- The REAL: Roll Evaluation of Activities of Life (0 - 18.11 years)
- SIB-R: Scales of Independent Behavior (3 months - 80 years)
- CHORES: Children Helping Out: Responsibilities and Supports (6 - 14 years)
- Arc's Self-Determination Scale (14 - 21 years)
- COPM: Canadian Occupational Performance Measure

Independent Living Skills



Medical Knowledge

- Knowledge of own medical condition
- Who to access for primary care
- Understanding of medical instructions / medical literacy
- Knows how / where to obtain needed DME





Self-Care Skills

- Dressing (independence level and appropriateness)
- Bathing
- Toileting
- Hygiene: tooth brushing, shaving, deodorant
- Hair and make-up

Cooking

- ⦿ Safety
- ⦿ Use of stove
- ⦿ Use of microwave
- ⦿ Appropriate clean up
- ⦿ Reads nutrition label
- ⦿ Appropriate meal planning



Household Tasks

- ⦿ Cleaning
- ⦿ Shopping
- ⦿ Child care
- ⦿ Pet care



<http://attitudelive.com/information-and-resources/parenting-disability>



Money Management

- ⦿ Identifies coins
- ⦿ Counts money
- ⦿ Makes change
- ⦿ Writes checks
- ⦿ Balances checkbook
- ⦿ Budgeting decision making
- ⦿ Chooses best cell phone plan
- ⦿ Banking

Laundry

- Sorting
- Stain removal
- Dry cleaning





Safety & Judgement

- Kitchen safety
- Verbal problem solving questions
- Picture safety cards





Medication Management

- Knows how to refill prescriptions
- Knows who to contact re: medication questions
- Knows what to do about missed doses
- Can put meds in med box appropriately

Telephone / Computer

- Able to access phone number of business
- Use of phone to business for information
- Use of computer
- Computer / phone safety





Transportation

- ⦿ Mobility: community / household
- ⦿ Driving
- ⦿ Medical transport
- ⦿ Public transportation
- ⦿ Community/ County transportation options.

Social / Emotional Support



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- Has access to emotional supports
- Has access to social supports





Survey & Certificates

Please let us know your thoughts.

A link for a survey will be sent to all registrants. Please share with all attendees.

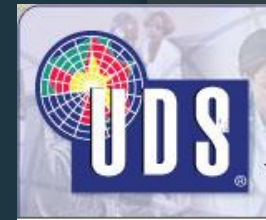
A certificate of attendance may be requested via the survey.

[surveymonkey.com/r/
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To obtain CEUs for today's event, each participant must have attended the full presentation and complete an online evaluation in order to download a certificate.

An evaluation link and instructions will be sent to all registrants. Please share with all attendees.

Questions?



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Discussion Questions



1. In what ways do I / does my organization prepare clients and their families for transition from adolescence into adulthood? What are we already doing? Is it effective?
2. How can I / my organization improve the way we serve clients and their families regarding transition issues?
3. How can I help clients / families create personal goals regarding transition?
4. What points or ideas resonated with me during this presentation?
5. How can I encourage my clients and their families to be more proactive about transition?
6. When do we discuss transition topics in my organization / practice? Who is involved? Is there anyone else who should be included?
7. When / who discusses sexuality in my organization? Do we need more training or resources?
8. How do we document transition related discussions or activities?

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