Transition Readiness and Resources
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Agenda

• Role of physicians
• Difficult topics
• Barriers to discussing these topics
• Strategies for having these conversations
• Resources
Transition

• Equally challenging for parents and young adults.
• Describe leaving high school as “falling off a cliff.”
Pediatrician Advantage

- Trusted relationship
- Traveling through time –
  - understanding family culture
  - Understanding family perspective
Pediatricians & Families

- Well baby checks
- Helping children grow & thrive
- Having tough conversations
Complexities of Care

• Attending to
  – physical needs
  – Emotional & social issues
• Understanding the stress of parent caregivers from early childhood on
• Understanding how the disability has affected the developmental process
• Guiding the parents of a young child through the important tasks of childhood and adolescence, can set the stage for both the parents and their disabled child to have independent, yet supportive lives

Setting the Stage for Parents and Their Child

- Encouraging skills of independence, including their health care
- Providing resources for personal counseling services [http://greatergood.berkeley.edu/article/item/can_mindfulness_help_mothers_of_severely_disabled_children](http://greatergood.berkeley.edu/article/item/can_mindfulness_help_mothers_of_severely_disabled_children)
- Giving teens age-appropriate information about disabilities
- Providing sex education & sexual health care, preparation for parenthood, and genetic counseling
- Promoting early vocational awareness, alternatives to work, and leisure time
Encouraging Skills of Independence

- **Decorating Cake for Papaw**
- [https://www.facebook.com/tammy.vice/posts/10153094620961343](https://www.facebook.com/tammy.vice/posts/10153094620961343)
- “We have a lot of fun. It took so long to see her take an interest in things. I'm very thankful to see her joy. It was worth the wait. 😊” Morgan’s Mom
Age Appropriate Information About Disabilities

• To better understand needed supports
• To be able to advocate for themselves
• “I used to be ashamed about my disability and the fact that I couldn’t read very well or very fast, but as I have gotten older, I know that I need to explain how I work and learn best to my boss. Now, I feel like I am a good employee.”
• Important to get parent’s view & discuss.
• Self Disclosure: Advantages Disadvantages Self-image, Impact Self-advocacy
Sex, Drugs & Rock ‘n’ Roll

- Myths and Misperceptions of Disability and Sexuality
  http://ahs.uic.edu/media/uicedu/ahs/documents/dhd/sdc/MythsAndMisperceptions.pdf
- Myth #1 People with disabilities are asexual.
- Fact: All humans are sexual, regardless of how we express our sexuality.
  – People with disabilities are sexual and express their sexuality in ways as diverse as everyone else.
  – A study by the center for research on women with disabilities showed that women with and without disabilities reported the same level of sexual desire.
  – All people—including people with developmental disabilities—are sexual.
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Bodies, Behavior, Relationships

• Body changes & sexuality
  http://kc.vanderbilt.edu/healthybodies/  Also available in Spanish
• Education that is broad in scope, and continues over extended period of time
  – Learning appropriate time & place for behaviors
  – Opportunities for developmentally appropriate socializing
  – Good & bad touch
• Ongoing conversations, feedback
Promoting early vocational awareness, from early ages

• Identifying strengths, interests
• Opportunities to learn what works & what doesn’t work – volunteering & in transition programs
• To find passion, inspiration, creativity, the intrinsic value of working – independence, feeling valued, accomplishment, pride, establishing a place in the world
• Earning desired items to learn the idea of exchange, the value of money, instrumental value of work
• Sharing family responsibilities
• Learning to problem solve, know when to ask for support
• Using social capital
• The dignity of risk
Other Important Topics During Transition

- Encouraging independence while ensuring safety
- Adult consent & confidentiality
- Possible benefit eligibility

- Self-determination & needed support
  - MPOA
  - POA, Rep. Payee
  - Conservatorship
- Planning for the future
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Typical Barriers to These Conversations

• Sense of being overwhelmed
• Procrastination/denial
• Hard to know the best plan, who to ask
• Not sure who to trust, how to insure safety
• Not sure to whom to turn this over
• Difficult to face mortality
The Need for Information Exchange

• Questions for parents to ask themselves
  – What information would others need to help insure the happiness and safety of your son or daughter?
  – What do you know about the role your non-disabled children want or are able to provide in the care of your child with a disability?
  – Where can they find important health information and documents needed for your son or daughter’s care?
Keeping Records

• Family Information Notebook (FIN)
  https://www.childrenshospital.vanderbilt.org/guide.php?mid=564
• Letter of Intent
Letter of Intent

- Family Story – Family Uniqueness
- Medical care needed
- Maintaining, building & strengthening relationships
- Housing
- Benefit enrollment information

- Work
- Community Involvement
- Religious or Spiritual Needs
- Leisure
- Transportation
- Estate/Legal Plans
The Need for Information Exchange

- Questions for siblings to ask themselves
  - Self assessment
    - What is your own level of readiness and willingness to have these conversations?
    - What is your current role in the life of your sib & should that change?
    - What future role do you see yourself playing?
  - What information do you need from your parents to help insure the happiness and safety of your sibling?
Questions for Siblings, cont.

– What do you want your parents to understand about the role you want or are able to provide in the care of your brother or sister?
  • What parts could you provide or oversee in the future?
    – Advocacy
    – Financial planning/management and/or support
    – Caregiving (direct and indirect)
  • Who & what resources would you have for support?
Family Discussions

• What goals are shared by family members?
  – Helping insure the young adult with a disability will have a happy & fulfilled life?
  – Recording important information?
  – Taking steps for benefits or legal arrangements?

• What steps can be determined to reach these goals?

• How could siblings begin to become more involved?
  – Finding information/resources?
  – Arranging meetings?
  – Accompanying to appointments?
  – Recording conversations/family history?
Independence & Support – Educating Families

• **Durable Power of Attorney** – Gives “co-pilot” the legal power to manage financial affairs. The person giving the power to a PoA does not lose power themselves.

• **Representative Payee** – manages Social Security disability financial benefits on someone’s behalf.

• **Durable Power of Attorney for Health Care** – can be effective immediately, along with the patient, or can become effective when the person becomes incapacitated.

• **Conservatorship**
CONSERVATORSHIP and ALTERNATIVES TO CONSERVATORSHIP, The Arc Tennessee

- Overview of Guardianship and Conservatorship
- Alternatives to Conservatorship
- Conservatorship
  - Reasons for Conservatorship
  - Rights of the Individual
  - Types of Conservatorships
- The Process
- Checklist
- Resources

Resources for Future Planning

• The Arc's Center for Future Planning provides reliable information and assistance in these areas to individuals with I/DD, their family members and friends, support professionals and the community: person-centered planning, decision-making, housing options, and financial planning.
  – To download the flyer click [HERE](#).
  – To read about Finding and Choosing a Lawyer click [HERE](#).
  – Tips for Siblings can be found [HERE](#).
Possible Adult Benefits

• Secondary Education Transition Services
• Vocational Rehabilitation Services
• Social Security Disability benefits – SSI or SSDI
  – Financial assistance
  – Health Insurance
• Medicaid Waiver
• Family Support
Navigating Disability Resources

• Services for People with Disabilities, Families and the Community
  http://vkc.mc.vanderbilt.edu/vkc/services/family/
  – Tennessee Disability Pathfinder
    http://kc.vanderbilt.edu/pathfinder/
  – Contact the Vanderbilt Autism Resource Line
    http://vkc.mc.vanderbilt.edu/vkc/triad/services/resource/
  – Vanderbilt Kennedy Center Social Worker
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