



Transition Readiness and Resources

April 24, 2015

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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.”

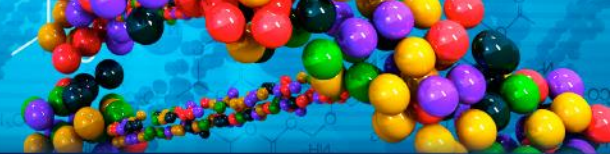




Pediatrician Advantage

- 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

Source: <http://www.ncbi.nlm.nih.gov/pubmed/7720408>



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
- 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
- Source: <http://www.ncbi.nlm.nih.gov/pubmed/7720408>



Encouraging Skills of Independence



- [Decorating Cake for Papaw](#)
- <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
- Resource: http://www.ncwd-youth.info/assets/guides/411/411_Disability_Disclosure_unit3.pdf



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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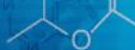
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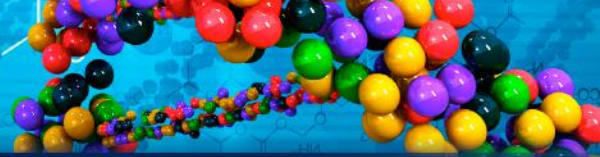
Bodies, Behavior, Relationships

- 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
- <http://www.advocatesforyouth.org/publications/publications-a-z/479-sex-education-for-physically-emotionally-and-mentally-challenged-youth>



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 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



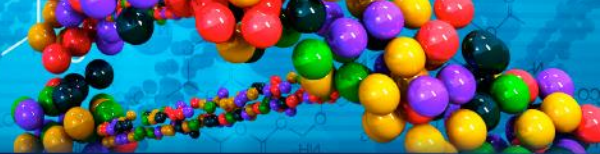
Letter of Intent

- 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?



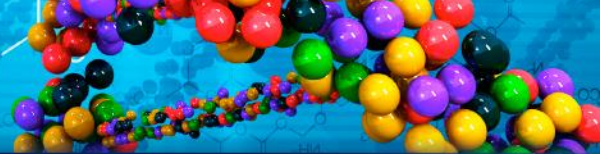
Family Discussions

- 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

http://www.thearctn.org/Assets/Docs/Conservatorship_Handbook.pdf



Resources for Future Planning

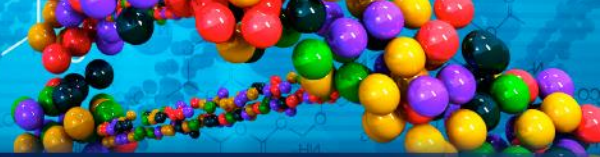
- The Arc's [Center for Future Planning](#) provides reliable information and assistance in these areas to individuals with I/DD, their family members and friends, support professionals and the community: person-centered planning, decision-making, housing options, and financial planning.
 - To download the flyer click [HERE](#). T
 - o 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
 - Carol Rabideau, LCSW
 - carol.rabideau@vanderbilt.edu
 - 615 936-5122