Transition to adult care and life for women with physical disabilities

Ellen Fremion, MD
Internal Medicine-Pediatrics
Assistant professor
Baylor College of Medicine
Goals and Objectives

- Individual and Family Role Changes During Transition
- Navigate Transition Planning
  - Funding
  - Providers
  - Adaptive adult life
- Address Health Concerns
  - Changes in body function
  - Bowel, Bladder, Sexual Health
  - Adult health issues
  - Mental Health
- Keeping a Positive Perspective During Transition
Meet Maria

- Maria is 17 years old and a junior in High School.
- She has mid-lumbar spina bifida and neurogenic bowel and bladder.
- She lives with her mom and younger sister. She enjoys helping her family, and hanging out with her boyfriend on the weekend.
- She would like to go to college and be a social worker.
- She is here for follow up at her annual Spina Bifida Clinic visit with her mom.
Role Changes During Transition

Care Management
- Teens become more independent in management. They progressively attain skills, manage routines, monitor for problems, and then navigating care.
- Parents change from manager to monitor to coach to advisor.

Medical Decisions
- Teen changes assenting to consenting at age 18.
- Parent changes from decision maker to decision supporter.

Supporting the change
- Set expectations and maintain confidentiality
- Practice!
- Evaluate level of independence and create action plans towards goals
Maria is changing!

- Maria is able to cath her bladder independently, but sometimes needs help with doing regimens on time. What goal and action plan can help Maria grow in independence?
  - Maria can make a daily routine chart and set alarms in her phone as reminders.
  - Mom can follow up daily and then weekly with Maria to see how plans are going.
  - The doctor explains to Maria and mom that it is important for Maria to practice meeting with the doctor by herself for part of each exam.
Navigate Transition Planning: Funding

- **Turning 18/Medicaid**
  - The individual gives consent for medical treatment if able.
  - Apply for adult disability determination and Supplemental Social Income/Medicaid (www.ssa.gov).

- **Private Insurance**
  - Adults who are dependent can stay on parent’s private insurance past age 26. Parents must ask for an adult dependent form from their employer’s HR before the adult turns 26.

- **Medicare**
  - Adults who are dependent on their parents are eligible for Medicare benefit from their parents, but may lose Medicaid. Adults with disabilities can re-enroll in Medicaid under the Pickle Amendment.
  - Adults who have worked at least 10 years and paid Medicare taxes can be eligible for Medicare (www.medicare.gov).
Navigate Transition Planning: Providers

- Transition to adult care
  - often occurs between ages 18-21
- Insurance, facility access, specialization are factors in determining adult providers

- How to prepare:
  - Talk about transition with your pediatric doctors around age 14.
  - Get organized with care team, needed items, and care plan
  - Prepare for meeting your new adult doctor: make a question list, teach them about your needs, bring your care plan with you
  - [www.gottransition.org](http://www.gottransition.org)
Navigate Transition Planning: Adaptive Adult Life

- **Preparing for living independently**
  - What home environment adaptations are needed?
  - What provider or nursing services are needed?
  - What about transportation?
  - How independent is individual’s self-management and care navigation?
  - Practice self-advocacy discussions.
  - Make goals and action steps to improve independence.

- **Working/Higher Education**
  - Vocational rehabilitation
  - ADA rights ([www.ADA.gov](http://www.ADA.gov))
  - Insurance may change based on the amount you work
Transition Planning for Maria

- **Funding**
  - Maria has pediatric Medicaid and pediatric disability determination due to her mobility impairment. What does Maria need to do at age 18?
    - *Go to the social security office for adult disability determination*

- **Providers**
  - Maria works with her doctor team to make a medical summary. What should be included?
    - *Diagnoses, surgeries, medications, supplies, care team, and current care plans*
  - Maria and her pediatric doctors decide that they will continue to see her through age 18. She is given a list of recommendations for adult providers to review.

- **Adaptive adult life**
  - Maria can be referred to vocational training and for adaptive driving.
  - Maria and her mom make a list of things she needs help with during the day to discuss action plans.
Health Concerns: Changes in Function

- **Mobility**
  - Function may decline with age due to growth, obesity, contractures, skeletal deformities, or condition prognosis.
  - Adaptive aids may need to change.
  - Exercise and therapies can help function.

- **Pain**
  - May be due to muscle strain or neuropathic pain.
  - Physical therapy, positioning, and pain regimens are important for quality of life and function.

- **Bone health**
  - Disuse osteoporosis causes higher risk for fractures of long-bones (femur, humerus, tibia/fibula)
  - There is not consensus on diagnosis and treatment. Calcium and vitamin D may help as well as weight bearing exercises.
Health Concerns: Bowel

- **Transition Concerns**
  - Incontinence is a huge quality of life concern
  - Constipation can cause pain and further complications
  - Bowel regimens may need to change to provide better control and independence

- **Treatment Options:**
  - Oral medications, rectal stimulants, transanal irrigation systems, antegrade enemas
  - Know how various foods and menstrual cycle affects bowel regulation
  - Have a daily routine and management plan
  - Follow up with primary care, GI, or physical medicine doctor
Health Concerns: Bladder

- **Concerns**
  - Bladder dysfunction may progress with age
  - Incontinence is a quality of life concern
  - Prevent complications: kidney damage, stones, frequent infections, organ prolapse

- **Bladder Care Goals:**
  - monitor for complications
  - maximize regimen independence and continence
  - establish care with an adult urologist familiar with neurogenic bladder
Health Concerns: Sexual Health

- **Preventive care needs**
  - Same health checks apply to women with disabilities
  - May need evaluation for organ prolapse as well.
  - Talk about modifications needed for well woman exam.
  - Talk about menses, sexual health function, relationship safety, and child-bearing.
  - Referral for ob/gyn care

- **Education Resources**
  - [http://www.med.umich.edu/yourchild/topics/disabsex.htm](http://www.med.umich.edu/yourchild/topics/disabsex.htm)
  - [https://www.bcm.edu/research/centers/research-on-women-with-disabilities](https://www.bcm.edu/research/centers/research-on-women-with-disabilities)
Health Concerns: Menses and Contraception

- **Concern**
  - Menstrual problems: pain, hygiene, heavy flow
  - Contraception: options and discussion

- **Management**
  - Set expectations with teens and families regarding confidentiality
  - Pain management: NSAIDs, contraceptives
  - Flow management: long acting oral contraceptives, IUD, Implanon
  - Contraception: discuss effect of seizure meds, antibiotics, barrier methods
Health Concerns: Adult Health

- **Obesity**
  - May need to meet with a nutritionist to ensure adequate nutrients and correct calories for level of activity
  - Healthy weight is important for mobility, skin, lung function, pelvic floor health

- **Emerging adult health problems**
  - Screen for high blood pressure, diabetes, sleep apnea
Maria’s Physical Health

- Maria previously walked more with orthotics and crutches, she has noticed she is using her wheelchair more now.
  - Evaluate equipment, range of motion, skin
- Bladder- Maria has frequent leaking from the urethra
  - Evaluate cath regimen and previous bladder studies
- Bowel- Maria uses a MACE for her bowel regimen, but can’t set it up by herself
  - Consider OT assessment for independence in ADLs
- Sexual health- Maria is not sexually active, has heavy menses, and wonders about having children in the future
  - Discuss menses management and considerations about pregnancy for condition
- Maria has gained about 10 pounds in the last two years
  - Exercise and healthy eating goals
Health Concerns: Mental Health

- Many young adults with or without disabilities struggle with depression, anxiety, self-acceptance, and substance abuse.
- Concerns such as accepting condition and disability, dealing with health concerns, and adaptive living are unique to young adults with disabilities.
- Many changes are happening which can be stressful.
- Talk about mental health, seek-out peer groups and mentors, get counseling, and embrace adulthood.
Maria’s Mental Health

- Maria reports she was bullied in middle school about using a wheelchair and having incontinence. It is better now and her family and boyfriend are supportive.
- She has a lot of anxiety with meeting new people and trying new things.
- She feels mostly happy, but has had times of depression when she was sick in the hospital for several months.

What do you think can help Maria?

- Peer groups, camp
- Counseling
- Regular follow up
- Focus on the things she can do
- Goals and positive outlook
Keeping a Positive Perspective during Transition

- **Plan**
  - Get organized
  - Practice self-advocacy and self-management
  - Talk about changes

- **If you don’t know, ask**

- **Make wellness a routine**
  - Self-management
  - Sleep
  - Exercise
  - Healthy eating

- **Embrace Adulthood**
  - Family and friends
  - Maximize independence (freedoms and responsibilities)
  - Contribute to the world
If nothing ever changed, there'd be no butterflies.
~Author unknown