Navigating the Journey: The Transition to Adulthood

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so this is the part where i'm supposed to tell you it's not scary.
well, it is.
but fear is natural, fear is good— it just means you're growing.

http://quotesgram.com/growing-up-quotes-and-sayings/
What Makes a Good Life?

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- Relationships
- Community Participation
- Independence/Autonomy
- Hopes for the Future

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Many pieces to the puzzle--

1) Health Care Financing
2) Medical Home - Primary Care and Subspecialty Care -
3) Community Care Coordination
4) Education and Employment
5) Family and Caregiver Support
6) Transportation
7) Behavior and Mental Health
8) Health Habits
9) Self-Management
10) Recreation and Social Activity
11) Independent Decision-Making and Legal Issues

(Center for Youth and Adults with Chronic Conditions of Childhood, Eskenazi Health)
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Healthy Habits to support success

Physical Activity

- Physical benefits may include:
  - Decreased obesity/improved body composition
  - Improved strength and balance
  - Increased cardiovascular fitness
  - Improved bone density
  - Reduced inflammation
Healthy Habits to support success

Physical Activity

- Cognitive benefits may include:
  - Motor dexterity
  - Executive function
Healthy Habits to support success

Diet

- Nutrient deficiencies
  - Iron, vitamin D, may also include zinc and vitamin A
- Obesity rates significantly increased
  Interacts with: physical activity/mental health/physical health/social participation
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Health Factors impacting function

Behavior and Mental Health

- Adolescence is filled with new challenges for all kids
- Unique issues for adolescents with DS/ID
- Mental Health issues may present differently than for peers
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Healthcare Transition

“Health Care Transition” is a process that begins in early adolescence and supports young person in:

- Participating more actively in his/her own health care and medical decision making
- Transitioning from pediatric to adult care
  - May include changing from pediatric care to new adult clinicians
  - May mean transitioning to a more active/mature role in decision-making with the same clinic
Healthcare Transition

Special considerations for the person with DS:

- Adults with Down Syndrome have unique health care issues: Can sometimes be difficult to identify adult primary care and specialty providers with experience and expertise in care of people with DS

- Currently no “Adult Healthcare Guidelines”

- Increased life expectancy in recent years means many who provide adult healthcare have had limited preparation

- Supporting optimal participation in decision-making

- Accessing a true “Medical Home”
Choosing an adult clinician

- Information that you might want to find out includes:
  - Experience with Down syndrome
  - Whether there is a commitment to highest quality of life for the young person
  - Office hours
  - Availability for extra time for appointments
  - Young person’s comfort level with the clinician
  - Whether the clinician respects the young person and communicates with him/her directly
  - Coverage when primary clinician is away
  - Medical insurance accepted
  - Hospital affiliations
  - Availability of same day appointments
  - Ease of referral to specialists
  - Willingness to partner with caregivers in addition to family members
  - Office location and accessibility via public transportation

(Simons, *Down Syndrome Transition Handbook*)
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Healthcare Transition

- Special considerations for the person with DS:
  - At age 18, a person is no longer a minor and is entitled to right and responsibilities to make legal choices as an adult
    - Most individuals with DS continue to require some support with decision making as adults due to intellectual disability
  - If conscious efforts are not made to support transition, person with DS may be bystander in his/her healthcare, rather than an active participant
Decision Making for young adults:

- Decision Making is a skill that needs to be developed over time; can’t wait until adulthood to start
  - Lack of practice/experience with decision-making may lead to impression of incapacity

- Range of options for supported decision-making exist, even within guardianship
Ways to support participation in health care for adolescents:

- Learn to name and describe each of his/her health conditions.
- Learn names of medication he/she takes and purpose of those medications.
- Carry info regarding medical conditions and medications in his/her wallet.
- Prepare list of questions prior to medical visits and ask those questions at the visit.
- Spend time 1:1 with health care providers to ask questions.
- Gradually increase participation in medical decision making.
Healthcare Transition

Resources:

http://www.gottransition.org/resourceGet.cfm?id=17
Other Transition Resources

Resources:
- Down Syndrome Transition Handbook
- Health Transition Wisconsin Website http://healthtransitionwi.org/
What is your Dream?

- Define the goals/dreams for the future
- What are the skills/supports needed to achieve those dreams?
- Start early!