Planning for Transition to Adult Care & Living

Christina Trout, MSN, RN
Neuromuscular Program
University of Iowa - Stead Family Children’s Hospital
CDC Care Considerations: Transitions NEW!

- **CDC Care Considerations** *(Lancet, 3 parts)*
  - Important to be future-directed from an early age
  - Address the common physical and psychosocial elements impacting planning for the future.

- **DMD Transition Toolkit** — *(Pediatrics, Spring 2018)*
  - intended to provide guidance and a toolkit for:
    - individuals with DMD,
    - Healthcare providers,
    - families
    - those who work with students with DMD
Transitions CDC Panel Members
(December 2014 – Current)

- Christina Trout, chair (Peds & Adult NM)
- Annie Kennedy, chair (Advocacy/PPMD)
- Paula Clemmons (Adult NM)
- Garey Noritz (Primary Care)
- Kathryn Wagner (Adult NM)
- Laura Case (PT)
- Elizabeth Vroom (son w/DMD, dentist, Advocacy)
- Marie Ritzo (social work)
- Ben Dupree (adult w/DMD)
- Alex McArthur (adult w/LGMD/Advocacy)
- OVERLAP with Psychosocial Panel
  - Kathi Kinnett, Molly Colvin, James Poysky
Guiding Principles – Fall 2015

- **Transition process is supported in the literature**
  - (AAP, AAFP, ACP-ASIM)
  - Transitions are part of normal, healthy development and occur across the lifespan
  - Cohesive approach with communication & care coordination is desirable
  - Transition should be patient-centered

- **DMD - a high risk population for difficulties in transition**
  - Medically complex, physically challenged, possible neurocognitive involvement
  - Needs increase through adolescence, but growing physical dependency & limited resources available
  - Not just healthcare, but education, vocation, adult living
    - (autonomy, independence in personal & social life)
Timing of Transition Planning

• **Process – not a single event**

  ![Recommended Health Care Transition Timeline](image)

  – Reference: Got Transition (gottransition.org)

• **Precursors to Transition years**

  – Be [future oriented](#) from the start (at diagnosis)
  – Set [high expectations](#) & remain optimistic
  – Promote age-appropriate [independence](#) and social development
  – Engage [youth](#) as key participants
Care Coordination & Social Work

• **Transition Team** – all will participate in discussions…
  – Nurses, social workers, therapists, doctors
  – teachers & guidance counselors

• From the team – **someone designated** to -
  – Lead discussions
  – Provide guidance – break it into smaller tasks
  – Monitor progress – keep momentum moving along
  – Celebrate achievements

• Typically – Care Coordinator and/or Social Worker
  – Anticipatory guidance – what to expect
  – Communicate across settings – consent, exchange information
    • (within healthcare teams, school, community)
  – Identify resources, services & funding options
  – Provide support & encouragement
Care Considerations: Transitions

Six Domains of Transition Content:
Health care
Assistance with ADLs
Education/Employment
Housing
Transportation
Relationships/Social life
Transitions: Health Care

• Action Items!
  – Have time alone with providers
    • Increase focus on teen involvement
    • Teen learns to direct care
  – Identify & plan for new providers
    • Ensure records or notes shared
    • Medical summary at handoff
  – Medical care plan (urgent care)
    • Communicate goals of care to others; Advance directives when appropriate
    • Phone apps & emergency cards
  – Determine level of decision making supports
  – Discuss benefits & know policies
Transitions: Activities of Daily Living

• Action Items!
  – Find & finance attendant care
    • Insurance – therapy & skilled nursing
    • Public – may support ADLs care
    • Often funding changes with age, employment & education!
  – Learn to hire/train care assistants
    • Direct own cares, often at school
    • Communicate needs, teach others
  – Provide respite for family caregivers
    • Ensure social ties are maintained
  – Maximize independence
    • referrals to OT/PT or AT specialists
  – Consider longer need for support
    • guardianship, conservatorship
“Transition in benefits”

- **Disability Benefits**: Requires a financial aptitude that is above and beyond that required of those without disabilities due to the complex and often-fragmented nature of disability benefits systems.

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>What disability benefits is one eligible for and at what age does eligibility begin/end?</td>
</tr>
<tr>
<td>Is there an income threshold for eligibility?</td>
</tr>
<tr>
<td>Is that threshold impacted by:</td>
</tr>
<tr>
<td>- Individual’s marital status?</td>
</tr>
<tr>
<td>- Whether the individual’s parents are living?</td>
</tr>
<tr>
<td>- Whether the individual is a homeowner or has valuable possessions in his name (i.e. car)?</td>
</tr>
<tr>
<td>What Special Needs Trusts exist and how can funds be accessed?</td>
</tr>
<tr>
<td>- Who is the Executor of this account?</td>
</tr>
<tr>
<td>Has an ABLE account been established and in which state?</td>
</tr>
<tr>
<td>Does the individual with Duchenne have a credit card and established a line of credit?</td>
</tr>
<tr>
<td>- i.e. making small purchases to be paid off monthly</td>
</tr>
<tr>
<td>Has the individual registered to vote?</td>
</tr>
</tbody>
</table>
Education (Eventually Employment)

• Action Items!
  – Ensure written plan at school!
    • 504 Plan or IEP
      – Teen should attend meetings
      – input: nurse, PT/OT, aides, family advocates
  – Identify strengths & interests
    • How do these apply to the future?
    • Neurocognitive testing?
  – Acquire resources & technology
    • Vocational Rehabilitation
    • Consult with PT/OT, AT experts
    • Advocacy groups offer peer-to-peer advice, chats, blogs, forums, support networks
Education (Eventually Employment)

- Action Items: College 101!
  - Start 1-2 years BEFORE actual start date!
    - Visit the campus
    - Meet with office of students with disabilities
  - Plan for:
    - Housing
    - Attendant care
    - Academic planning
    - accommodations
Transitions in Education, Pursuit of Vocations and Future Planning

• Not all persons with DMD will seek education beyond high school
• **Similar amount of planning & goal setting** are needed for attendant care for staying in the home

• Identify and explore ways to participate in planned, meaningful activities that utilize strengths, talents and opportunities to contribute
  
  – Enlist the same set of participants
  – Continue to have patient-centered discussion & planning

• **Set of questions regardless of trajectory:**
  
  – What do you want to do each day?
    What personal skill sets will be maximized?
    What financial resources will be needed?
    What community, state, federal resources are available?
    What educational/vocational planning resources are available?
    What equipment or technology might be needed?
    What caregiving might be needed?
Housing: Transition to **Autonomy** & Desired Levels of **Independence**

- **Action Items!**
- **Where to live…**
  - the family home,
  - on a campus during college/university,
  - in a community setting such as group home or organized facility, or
  - In a home or apartment with or without a roommate.
- **Home Modifications Enlist:**
  - OT & PT experts!
  - Architects & vendors
  - Laws to protect disabled when accessing housing/community
  - Grants, loans, and financial incentives
  - Assistive technology to expand access to environmental controls, dwelling entrances, and more
Transitions: Transportation

- **Action Items!**
  - Driver evaluation – OT/PT
  - Vehicle modifications
  - Public transportation
    - Practice getting around with or without a caregiver (when appropriate)
    - Planning for long distance travel, i.e. flights
Transitions: Relationships with Others

• Action Items!
  – Make & keep social connections
    • Seek opportunities to interact
    • Connect with psychologists & counselors
      – Strategies for socialization
      – Strategies to overcome anxiety
  • Make referrals to psychiatrists for medical treatment of anxiety/OCD
Transitions: Relationships with Others

- **Dating, Intimacy and Sexuality**
  - **Timing of discussions**
    - High school health classes: topics on reproduction & relationships
      - Offer a forum to discuss health concerns about acts of intimacy or self pleasure
    - Good time to review genetic counseling, inheritance & family pedigree
      - Identify sibling carriers
      - Review XLR inheritance
      - Introduce concepts of family planning & prenatal/preimplantation genetic diagnosis
      - With family planning, discuss parenting with a disability
  - **Referrals outside the clinic setting**
    - Pros and cons about social media and online dating
    - Introduce to safe teen/adult social groups (online groups for DMD adults)
    - Make referrals to relationship counselors
    - Assistance with intimacy
      - guidance on talking w/personal care attendant
      - Identify resources e.g. books about sex with physical disability, or finding sex therapists
DMD Transition Toolkit is Coming…

• Assessment of Readiness
  – Gages readiness to participate
  – Identifies areas where instruction is needed

• Transition Checklist
  – Identified needs for information – very detailed!
  – Charts progress in areas of transition

• A Medical Summary
  – Useful information for anyone who is “new” to the team
    • Medical diagnosis (past & recent medical results)
    • Urgent care needs
    • List of providers, agencies, vendors (contact info)
    • Equipment & other healthcare/home care supplies
    • School/work information
Not all centers transition their healthcare from one provider to the next, but the discussions should still occur.

Limited research showing differences between those who have a formal transition process vs. those who do not.

Limited research looking at factors that influence “successful” transition:
- Example: parenting style, personality characteristics, personal resources, etc.

Variable resources available to facilitate transition based on where you live, payer type and who is involved...