Planning for Transition to Adult Care & Living

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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

AGE:	12	14	16	18	18-22	23-26
	Make youth and family aware of transition policy	Initiate health care transition planning	Prepare youth and parents for adult model of care and discuss transfer	Transition to adult model of care	Transfer care to adult medical home and/or specialists with transfer package	Integrate young adults into adult care

  – 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

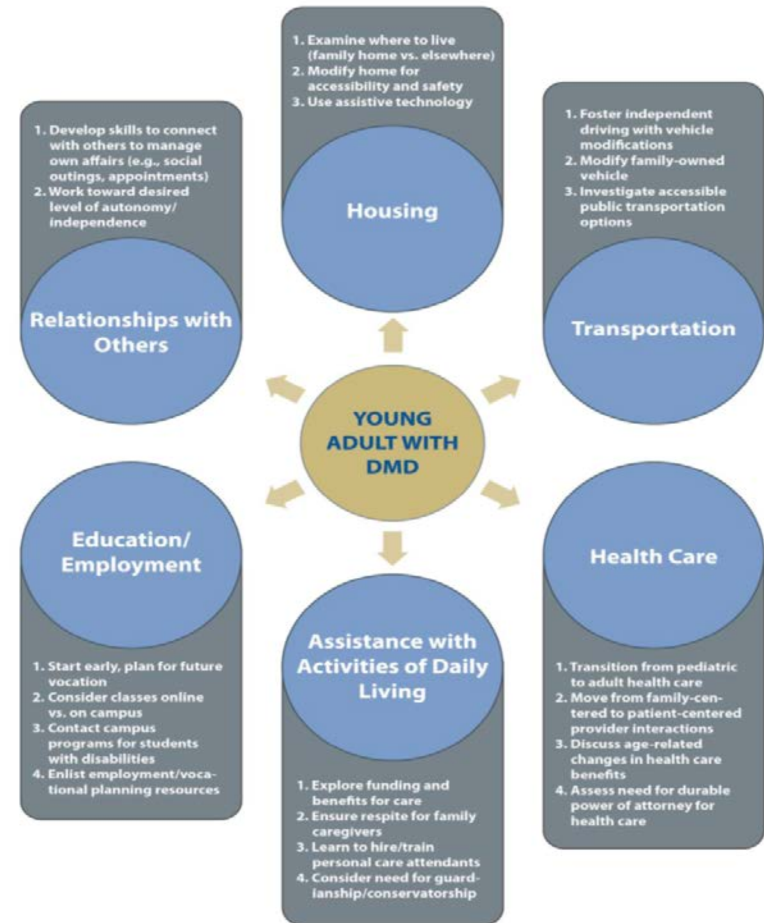
- From the team – someone designated to -
  - Lead discussions
  - Provide guidance – break it into smaller tasks
  - Monitor progress – keep momentum moving along
  - Celebrate achievements

- 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

1. Explore funding and benefits for care
2. Ensure respite for family caregivers
3. Learn to hire/train personal care attendants
4. Consider need for guard-ianship/conservatorship

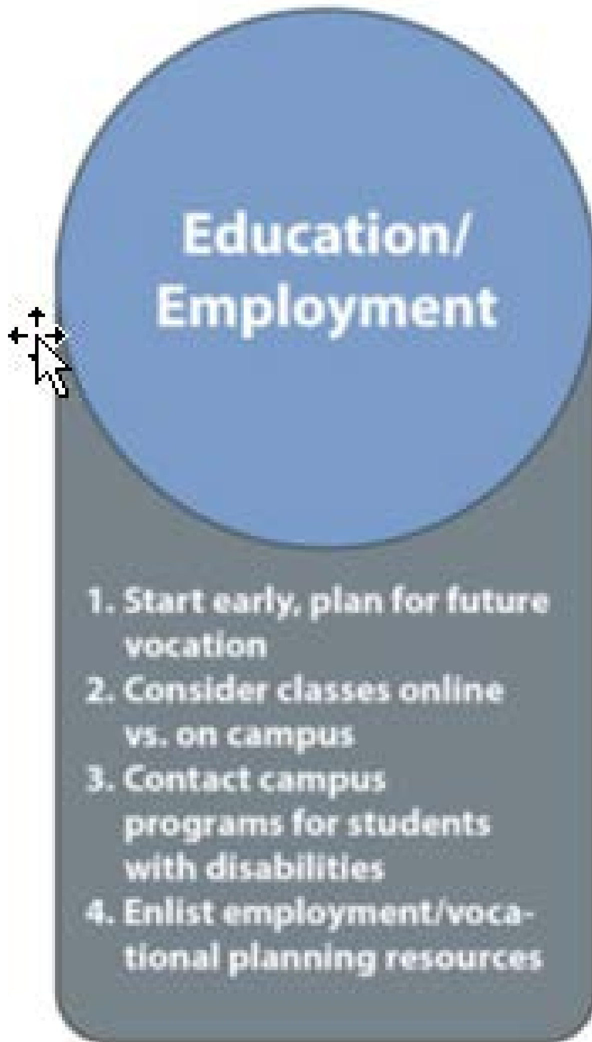
- Action Items!
  - Find & finance attendant care
    - Insurance –therapy & skilled nursing
    - Public – may support ADLs care
    - Often funding changes with age, employment & education!
  - Learn to hire/train care assistants
    - Direct own cares, often at school
    - Communicate needs, teach 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

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

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

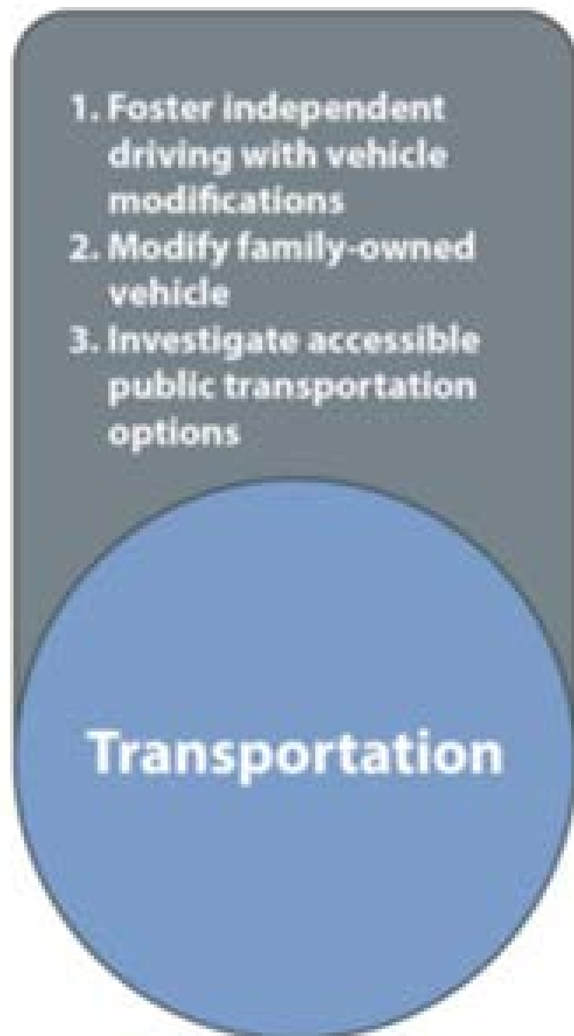
- Identify and explore ways to participate in planned, meaningful activities that utilize strengths, talents and opportunities to contribute
  - Enlist the same set of participants
  - Continue to have patient-centered discussion & planning

- **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

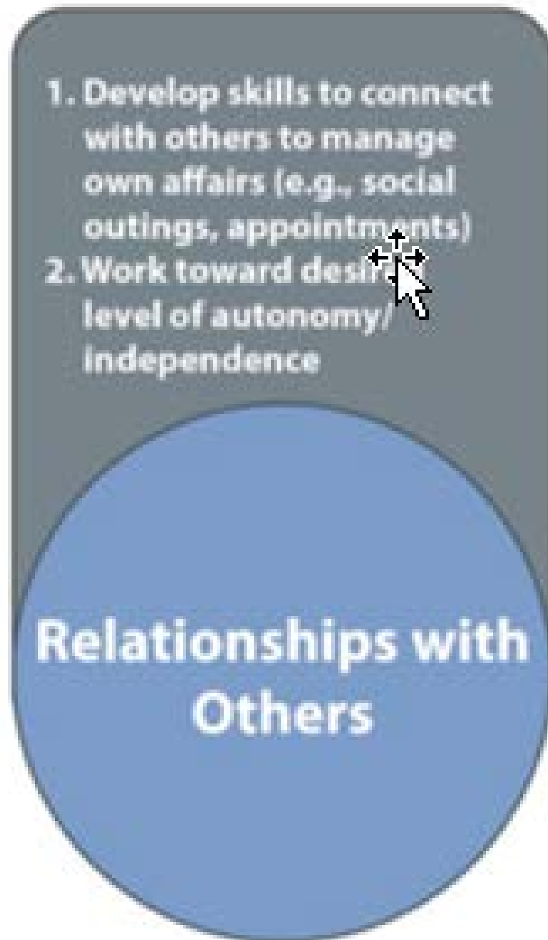
- Action Items!
- Where to live…
  - the family home,
  - on a campus during college/university,
  - in a community setting such as group home or organized facility, or
  - In a home or apartment with or without a roommate.
- Home Modifications Enlist:
  - OT & PT experts!
  - Architects & vendors
  - 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

“Clinical Controversies”

- 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…