Transitioning Care:

THE STANFORD CLINICS
NOVEMBER 3, 2018

Jacinda Sampson MD PhD
Associate Professor of Neurology
Neuromuscular and Neurogenetics

Many thanks to:
Michileen Oberst, ALCSW
Transitioning your clinic

Lucile Packard Children’s Hospital
Mary L Johnson Specialty clinic
730 Welch Rd.

Stanford University Hospitals and clinics
Stanford Neurosciences Health Center
213 Quarry Rd.
Transitioning your team- old and new faces

LPCH

John Day MD PhD

Carolina Tesi-Rocha MD PhD

Jenna Klotz MD

Jacinda Sampson MD PhD

Karolina Watson NP

SNHC

John Day MD PhD

Jacinda Sampson MD PhD

Yuen So MD

Neelam Goyal MD

Connie Wolford NP

Stanford University
Transitioning your multidisciplinary team

Cardiology
Beth Kaufman MD
Matthew Wheeler MD
Marco Perez MD
David Liang MD

Pulmonology
MyMy Buu MD
Michelle Cao MD
Transitioning your therapists

PHYSICAL THERAPY

Richard Gee PT  Tina Duong PT  Sally Dunaway-Young PT  Chelsea MacPherson PT

OCCUPATIONAL THERAPY

Janis Kitsua-Lowe PT  Julie Muccini PT
More familiar faces

Carly Siskind, Licensed Genetic Counselor

Michileen Oberst, Social Work

Jennifer Fisher, Community Outreach Liaison
Transitioning to adult care

When?
   This may depend on your clinic, your individual doctors, and your insurance.

Why?
   Clinics, hospitals, emergency rooms may have maximum ages they will follow someone

   Adult doctors for adult issues

How?
   Does not need to be all at once
Taking charge— your body, your health

Your diagnosis:
  Do you have questions?
  Are there things your family and team assume you know, but you aren’t sure?

Your medications:
  Do you know your doses?
  Do you know what it is for?
  What side effects should you be aware of?

Your care team:
  What do each of them do, and how to contact them?
  How often should your appointments be?

Your input:
  Are you involved in discussing decisions about your medical care with your family?
Transitions- treating you as an adult

• Adolescence and adulthood
  • Autonomy and independence
  • Hormonal changes
  • Bone health
  • Dating and sex
A Transition Toolkit for Duchenne Muscular Dystrophy: Supplementary Materials

Duchenne Muscular Dystrophy
Pediatric to Adult Care
Transition Tools:

Supplementary Material 1

Transition Readiness Assessment for Young Adults with Duchenne Muscular Dystrophy

Please fill out this form to help us see what you already know about your health, how to use health care and the areas you need to learn more about. If you need help completing this form, please ask your parent/caregiver. Then we’ll review the form together to develop a plan.

<table>
<thead>
<tr>
<th>Date: _______________</th>
<th>Participants in today’s discussion:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name: _______________</td>
<td></td>
</tr>
<tr>
<td>DOB: _______________ Age: __________</td>
<td></td>
</tr>
</tbody>
</table>

Transition Importance and Confidence

On a scale of 0 to 10, circle the number that best describes how you feel right now

<table>
<thead>
<tr>
<th>How important is it to you to prepare for/change to an adult doctor before age 22?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 (not)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How confident do you feel about your ability to prepare for/change to an adult doctor?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 (not)</td>
</tr>
</tbody>
</table>

My Health and Using Healthcare

Please check the box that applies to you right now:

<table>
<thead>
<tr>
<th>I know my medical needs and can tell others about my needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, I know this</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I know my symptoms, including ones that need medical care quickly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, I know this</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I know what to do if I have a medical emergency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, I know this</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I know my medications, what they are for, and take them without reminders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, I know this</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I carry important health information with me every day (e.g., insurance card,</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, I know this</td>
</tr>
</tbody>
</table>
Health Insurance – It’s complicated
Health Insurance planning
Transitioning from Pediatrics to adult care

When and how to plan –

1. Start to learn & gather facts around age 17 – there is a lot to consider – everyone has to renew their health insurance annually and you need to know YOUR unique circumstances to make the BEST decision

2. Know your current benefits & their limitations – e.g. your parents can keep you on their policy ‘til age 26, but their employer can extend that if you have a qualifying disability. Talk to your HR (human resource) Department.

3. Changing from Pediatrics to Adult care means changing providers and it often means changing who accepts your insurance.

4. Be sure to know your Social Security Disability benefits and how they work with your health insurance. E.g. if you receive SSI then you have MediCal; if you start working and receive SSDI you may qualify for Medicare: https://www.ssa.gov/
Critical insurance questions to ask:

1. What doctors or hospitals have contracts with my insurance?
2. Will I need pre-authorizations for appointments or treatments?
3. Have I considered applying for straight MediCal versus a MediCal HMO?
4. Who can I talk with to further explore my health care options?

Resources:
- Hospital Financial Counselor & Social Worker
- Parents, families with similar circumstances (support groups)
- Insurance Web Sites: HICAP Healthcare Insurance Counseling Advocate Program
  - www.healthcareoptions.dhcs.ca.gov/
  - https://www.nolo.com/about/about.html
California Children Services
State funded & County managed

**ELIGIBILITY:**
- Age – Birth up to age 21
- Eligible Diagnosis (see State website)
- Income - = < $40,000 or out-of-pocket exceed 20% of household income
- Be resident of county in which application is made
- Recertified annually

**MTU – Medical Therapy Unit**
- Age – ‘til age 21
- Eligible Diagnosis
- No income eligibility
- County Resident
- Prescription for PT/OT
California Medi-cal

MEDICAL PLAN ENROLLMENT (HMO)

Full Medi-Cal benefits assigned to a county managed care program

Patient needs a pre-authorization to receive services from a non-contracted provider – no authorization needed for CCS special care centers

STRAIGHT MEDICAL EXEMPTION FROM PLAN

Full Medi-Cal benefits

Has no other health insurance coverage

You have a complex medical condition

No pre-authorization required

https://www.healthcareoptions.dhcs.ca.gov/
Education: What is Transition Planning?

Future planning for adolescent from school to:
   A) Post-secondary education
   B) Vocational training
   C) Work/Supported Employment
   D) Independent Living
Individuals with Disabilities Education Act (IDEA)

Federal Law – 1975, 2004
Formal process assess children with disabilities
Provides specialized programs & services
Guarantees free, appropriate education (FAPE)
Least restrictive environment (LRE)
13 eligibility categories – Other Health Impaired (OHI)
IDEA ‘04 defines Transition Services as . . .
Coordinated set of activities with a result-oriented process focusing on academics and functional achievement to facilitate movement from school to postsecondary education, vocational education, employment with consideration of the child’s needs, taking into consideration the child’s strengths, preferences and interests.
Support students throughout the process . . . Talk early and often!

Review IEP Transition process including legal mandates and best practices
College & Vocational Resources for Students with Disabilities

**Three important resources:**
1. Secondary Transition Planning: The Basics
2. Disability Benefits 101
   &
3. California State Vocational Rehabilitation
   plus “Talent Knows No Limits”
IEP Mandates

COURSE OF STUDY & TRANSITION SERVICES:

- Review Annually
- 1st IEP meeting by age 14
- Course work reflects secondary goal
- Measurable statement of achievement leaving high school
- What will be worked on this year to achieve outcome

INVITE TO AGENCIES INVOLVED IN TRANSITION PLAN. WHY?

- Delays in Service
- Lack of Coordination
- Lack of Adequate Information

1st IEP meeting by age 14
GOALS ARE BASED ON AGE

APPROPRIATE ASSESSMENT:

9th & 10th grade receive career exploration assessment
11th & 12th grade receive vocational skills assessment

MEASURABLE POST-SECONDARY GOALS:

Enroll at a community college or university
Enroll in vocational training
Enroll in adult education
WHAT SHOULD SCHOOL OFFER TO TRANSITION STUDENTS?

Certificate of completion or Diploma
Formal and informal assessments on post-secondary goals
Career education
Job instruction at school
Work experience/related activities

TYPES OF ACTIVITIES TO SUPPORT POSTSECONDARY GOALS:

Explore careers that match interests/abilities
Career counseling
Work experience
Field trip to local colleges
Help in filling out college application forms
Transition can mean . . .

1. Don’t automatically receive accommodations
2. Services governed by different federal laws & regulations
3. Students have to apply and request on own
4. High school documentation not sufficient sometimes, e.g. guidelines, dates
### College/University Disability Resource Centers (DRC)
**Rehabilitation Act of 1973 in Section 504**

<table>
<thead>
<tr>
<th>Counselor’s Role</th>
<th>Student’s Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Provide accommodations &amp; assistance to students to achieve theirs educational goals</td>
<td>1. Schedule appointment with DRC counselor</td>
</tr>
<tr>
<td>2. Provide equal access to all programs &amp; services</td>
<td>2. Bring documentation of your disability and copy of high school IEP</td>
</tr>
<tr>
<td>3. Protect integrity of the college’s programs and services</td>
<td>3. Have request for accommodations arranged and documented</td>
</tr>
</tbody>
</table>
What is an Accommodation?

- Determined on an **individual basis**
- Supported by appropriate **medical documentation**
- Doesn’t compromise **academic standards**

Types of accommodations:
1. Notetaking
2. Audio Record Lectures
3. Breaks in Class
4. Furniture placement
5. Testing Accommodations – extra time
Student & Professor Communication

1. Student receives accommodation letter from Counselor at Disability Resource Center (DRC)
2. Student provides letter to each of their professors
3. Professor only needs to know that student is registered at DRC and what their accommodations are
Valuable Websites for Transition Planning
Transitions to College

- What would you like to study?
- Where would you like to attend?
- Are you applying for scholarships?
- What accommodations will you need?
- Timeline and schedule?
- Contact Office of Accessible Education, obtain an advisor

https://www.mda.org/young-adults/education
Transitions to Work

- What would you like to do?
- Resources: clinic social worker!
- State department of vocational rehabilitation
- Writing a curriculum vitae, practicing interview skills
- Full time? Part time?
- Transportation/commuting?
- Stepping stones to employment
  - Internships
  - Volunteering
  - Working from home, online employment
- Requesting accommodations
  - JAN (Job Accommodation network)
  - Americans with Disabilities Act

https://www.mda.org/young-adults/employment
Things Are About To Change
### Talent Knows No Limits

A California public education resource for the employment of people with disabilities

**“I hired David because**
- He has great customer service
- He’s dependable and helpful
- And you should see him bag groceries!

### For Job Seekers

- **The Best Jobs for People with Disabilities**
  *Forbes Nov. 4, 2014*
  A sampling of some of the best jobs that people with disabilities are likely to get and perform with relative ease. These jobs also pay well and the outlook for growth is high, according to the Bureau of Labor Statistics. Read article and see slideshow

- **Federal Government Enhances Job Opportunities for People with Disabilities**
  The Workforce Innovation and Opportunities Act (WIOA) strengthens commitment to person-centered planning. The Workforce Innovation and Opportunity Act (WIOA) was signed into law by President Barack Obama on July 22, 2014. "Every person deserves opportunities to gain skills training and to fulfill their potential. Read more
  Social Security now has a mobile site

### For Employees

- **Using Employee Resource Groups**
  Using their perspective to deliver solutions beneficial to the company’s bottom line, the efforts of ERGs for People with Disabilities have paid large dividends for a number of major U.S. companies. Read more

- **Free webinar series offers skill building opportunities for businesses**
  The Essential Workplace Skills Webinar Series offers proven techniques to help HR staff acquire and maintain employment of people with disabilities. Learn more

### For Service Providers

- **The Workforce Innovation and Opportunities Act Strengthens Commitment to Person-Centered Planning**
  The Workforce Innovation and Opportunity Act (WIOA) was signed into law by President Barack Obama on July 22, 2014. "Members of Congress took a significant step forward in modernizing the workforce development system." Read more

### News and Notable

- **Best Jobs for the Disabled**
  Healthcare’s growing importance in the American economy has particular impact for job seekers with disabilities. Organizations specializing in job placement for the disabled find that healthcare employers often extend access to careers at a better rate than for any other industry in the nation. For an overview of the best jobs for candidates with disabilities, read more,

- **Assistant Labor Secretary Kathy Martinez on how disabled former workers can find employment again**

### Educational Resources

- **I Can Work**
  See More Videos
  Trainings
  Disability in the News
  Job Seekers Toolkit
  Webinars

### Youth Transition Toolkit

- **All of the resources that young people with disabilities need to make good decisions as they transition into adulthood are in this guide. Visit website.**
Personal Care Assistants

In-Home Supportive Services Program (IHSS)
- provides funding for a personal care assistant (PCA)
- assistance in self-care (dressing, bathing, bathroom)
- assistance in travel
- assistance at school or work

- this could be a family member, or hired outside the home
- Interview candidates, make sure they understand what you need

- http://tknl.sdsu.edu/Toolkit/assistance.html
Planning your financial future

CalAble
Allows tax-free savings up to $15,000/hr without counting as income in SSI eligibility
www.treasurer.ca.gov/able

Financial Planning and Trusts
<table>
<thead>
<tr>
<th>Stanford Comprehensive Neuromuscular Program</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Neurologists</strong></td>
</tr>
<tr>
<td>Charles Cho</td>
</tr>
<tr>
<td>John Day</td>
</tr>
<tr>
<td>Les Dorfman</td>
</tr>
<tr>
<td>Neelam Goyal</td>
</tr>
<tr>
<td>Safwan Jaradeh</td>
</tr>
<tr>
<td>Srikanth Muppidi</td>
</tr>
<tr>
<td>Carolina Tesi Rocha</td>
</tr>
<tr>
<td>Sarada Sakamuri</td>
</tr>
<tr>
<td>Jacinda Sampson</td>
</tr>
<tr>
<td>Yuen So</td>
</tr>
<tr>
<td><strong>Neuromuscular Pathologists</strong></td>
</tr>
<tr>
<td>Hannes Vogel</td>
</tr>
<tr>
<td>Don Born</td>
</tr>
<tr>
<td><strong>Advanced Care Providers</strong></td>
</tr>
<tr>
<td>Karolina Watson</td>
</tr>
<tr>
<td>Connie Wolford</td>
</tr>
<tr>
<td>Genetic Counselor</td>
</tr>
<tr>
<td>Carly Siskind</td>
</tr>
<tr>
<td><strong>Nurse Coordinators</strong></td>
</tr>
<tr>
<td>Jessica Guzman</td>
</tr>
<tr>
<td>Deborah Gilman</td>
</tr>
<tr>
<td>Liza Chong</td>
</tr>
<tr>
<td><strong>Medical Assistant</strong></td>
</tr>
<tr>
<td>Mediatrix Pia Vega</td>
</tr>
<tr>
<td><strong>Physical Therapists</strong></td>
</tr>
<tr>
<td>Tina Duong</td>
</tr>
<tr>
<td>Richard Gee</td>
</tr>
<tr>
<td>Chelsea MacPherson</td>
</tr>
<tr>
<td>Sally Dunaway-Young</td>
</tr>
<tr>
<td><strong>Occupational Therapists</strong></td>
</tr>
<tr>
<td>Julie Muccini</td>
</tr>
<tr>
<td>Janis Kitsuwa-Lowe</td>
</tr>
<tr>
<td><strong>Speech Therapist</strong></td>
</tr>
<tr>
<td>Sarah Stranberg</td>
</tr>
<tr>
<td><strong>Respiratory Therapists</strong></td>
</tr>
<tr>
<td>Susan Metcalfe</td>
</tr>
<tr>
<td><strong>Social Worker</strong></td>
</tr>
<tr>
<td><strong>EMG Technicians</strong></td>
</tr>
<tr>
<td>Tim Fassler</td>
</tr>
<tr>
<td>Rika Yamasaki</td>
</tr>
<tr>
<td>Ewa Fratczak</td>
</tr>
<tr>
<td><strong>Clinical Research</strong></td>
</tr>
<tr>
<td>Shirley Paulose</td>
</tr>
<tr>
<td>Lesly Welsh</td>
</tr>
<tr>
<td><strong>Laboratory Research</strong></td>
</tr>
<tr>
<td>Katharine</td>
</tr>
<tr>
<td>Hagerman</td>
</tr>
<tr>
<td>Sheela Crasta</td>
</tr>
<tr>
<td><strong>Administrators</strong></td>
</tr>
<tr>
<td>Gayla Weng</td>
</tr>
<tr>
<td>Angelica Martinez</td>
</tr>
<tr>
<td><strong>Community Liaison</strong></td>
</tr>
<tr>
<td>Jennifer Fisher</td>
</tr>
<tr>
<td><strong>EMG Technicians</strong></td>
</tr>
<tr>
<td>Tim Fassler</td>
</tr>
<tr>
<td>Rika Yamasaki</td>
</tr>
<tr>
<td>Ewa Fratczak</td>
</tr>
</tbody>
</table>

Stanford University
COURSE OF STUDY & TRANSITION SERVICES

Reviewed Annually

Course work must reflect post-secondary goal. No later than age 16, but often sooner!

What will be worked on this year to achieve outcome

Measurable statement of achievement leaving High School

INVITE TO AGENCIES INVOLVED IN TRANSITION PLAN. WHY?

Lack of coordination

Delays in service

Lack of adequate information
Things Are About To Change
Stanford University
Template for Microsoft Office PowerPoint

CHOOSING THE RIGHT PAGE LAYOUT