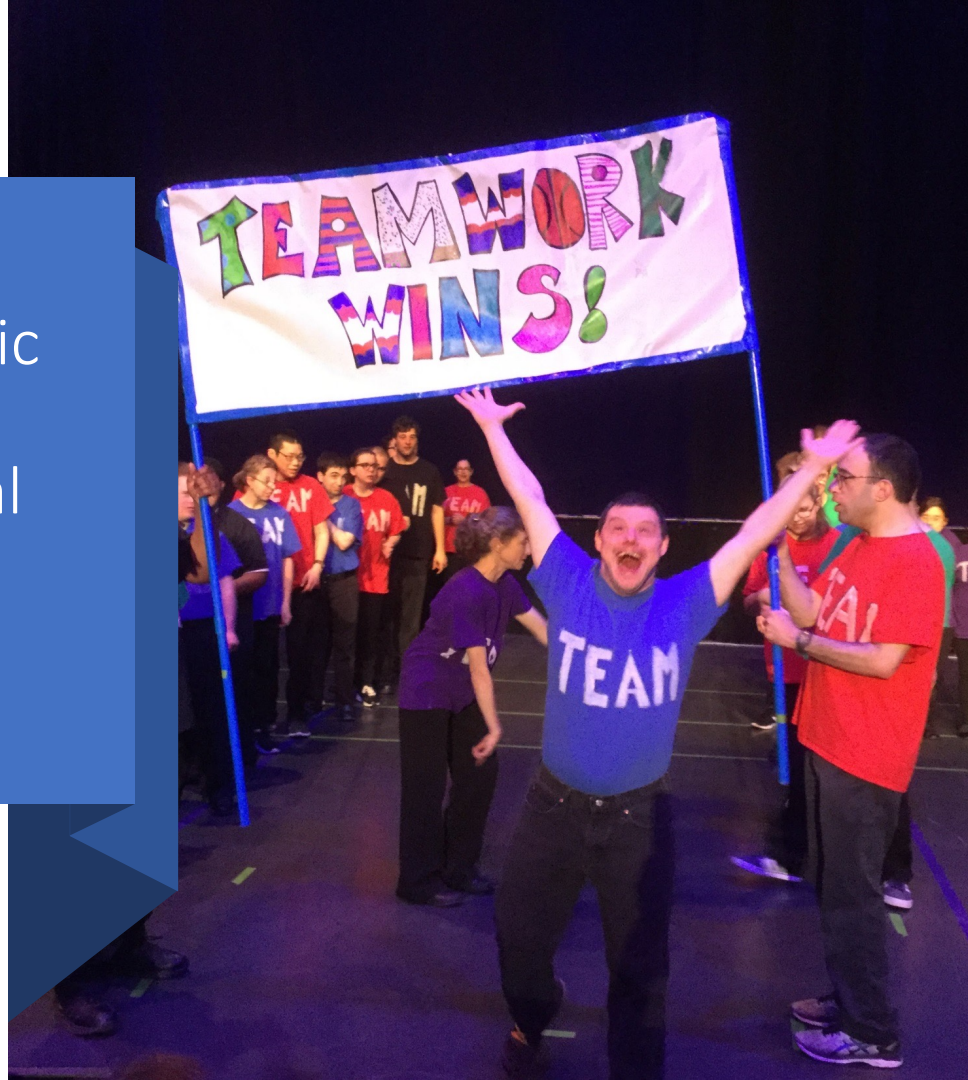
Transitioning from Pediatric to Adult Healthcare for People with Intellectual and/or Developmental Disabilities (I/DD)



Jessica Solomon Sanders, MD

Neurodevelopmental Disabilities

University of Colorado

April 28, 2021

Learning Objectives

Define	Define transition, and define transfer
Discuss	Discuss healthcare disparities patients with I/DD experience as they age.
Review	Review research about healthcare for adults with IDD.
Outline	Outline the process of an ideal healthcare transition. •(Wait a minute, there is no ideal! It should all be tailored to each patient and family's unique situation and timeline.)
Understand	Understand the perspective of a patient/family who has undergone transition from pediatric to adult healthcare.

What is health care transition?

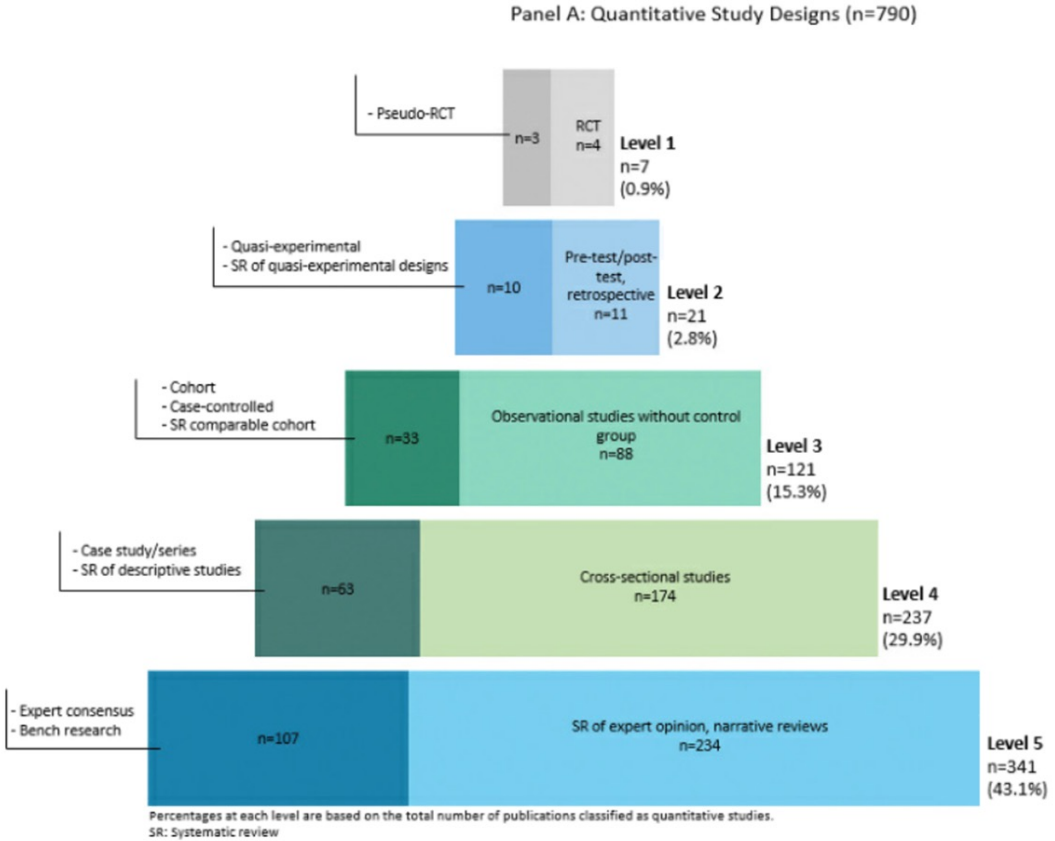
- A dynamic ***process*** of moving from pediatric to adult health care system
  - Prepare youth to receive care within the adult health care system.
    - Includes caregivers
  - Transition should be:
    - Patient centered
    - Developmentally appropriate
    - Comprehensive, uninterrupted

Blum, R.W., et al. (2002).

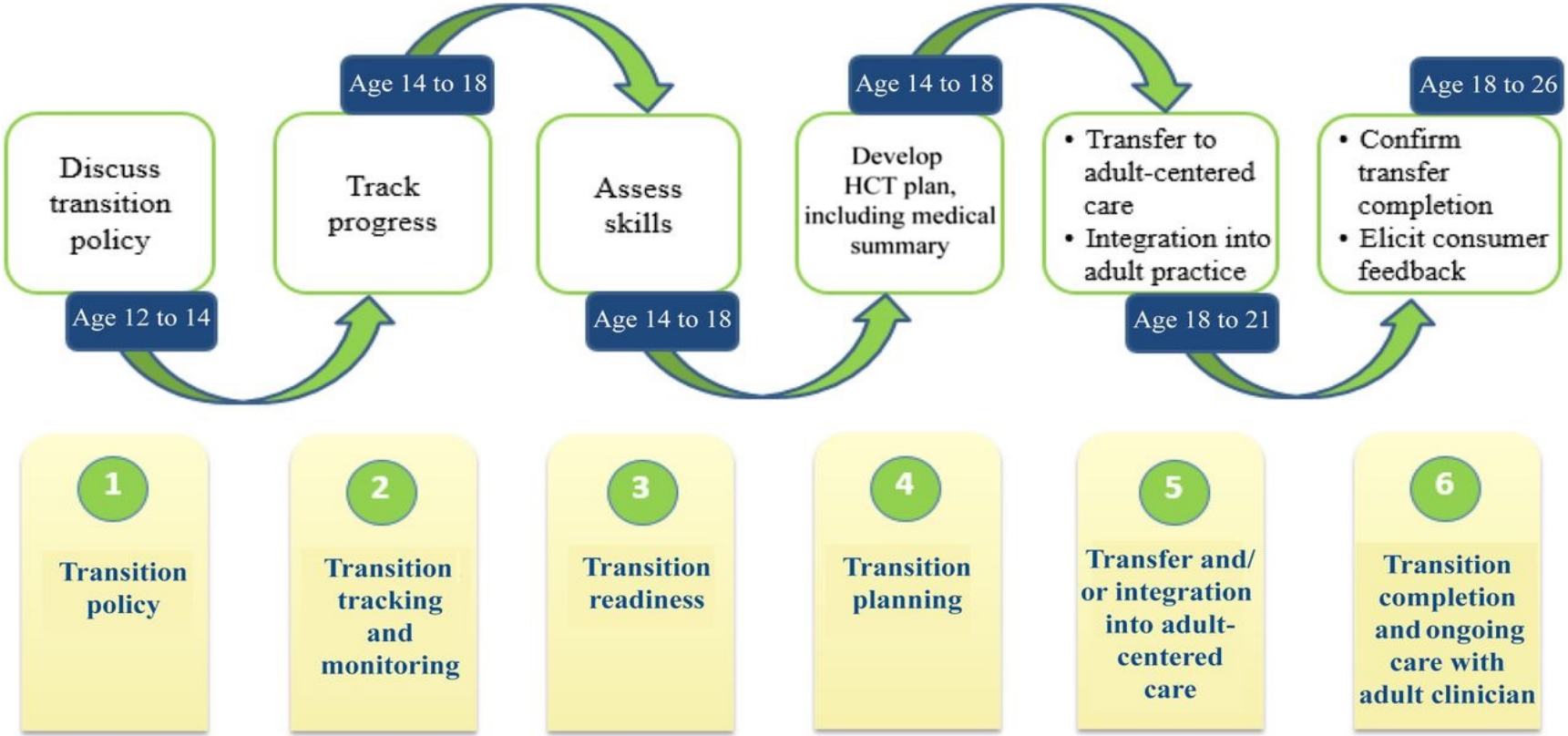
State of evidence-based practices in transition

(Mora et al., J. Adol Health, 2019)

- Over 19,000 articles = > 952 reviewed
- Countries represented
  - US, Canada, UK
- 7 Randomized Controlled Trials
- Focused on specialty populations
- Varied quality, consistency



Got Transition 6 Core Elements of Transition



Slide from Dr. Miya Asato's grand rounds

8 Common Principles of Transition

1. Expectation of Transition
2. Yearly Self-Management Assessment
3. Annual Discussion of Medical Condition and Age-Appropriate Concerns
4. Evaluation of Legal Competency
5. Annual Review of Transition Plan of Care
6. Child Neurology Team Responsibilities
7. Identification of Adult Provider
8. Transfer Complete

Child Neurology FOUNDATION
Creating a Community of Support

Goals of Transition

- MEDICAL
- SCHOOL/EMPLOYMENT
- LEGAL

Medical Transition

- There are major differences between the **pediatric** model and the **adult** model of care
  - Paternalistic vs. independent
  - Holistic vs. symptom based
  - Level of comfort with developmental and behavioral issues

Goals of Health Care Transition:

- Maximize lifelong functioning and potential
  - Promote self-advocacy, teach self-management skills
- Prevent “bridge to no where”
  - Good communication and uninterrupted services

Slide content from TSC Conference 2017, Dr. Schultz

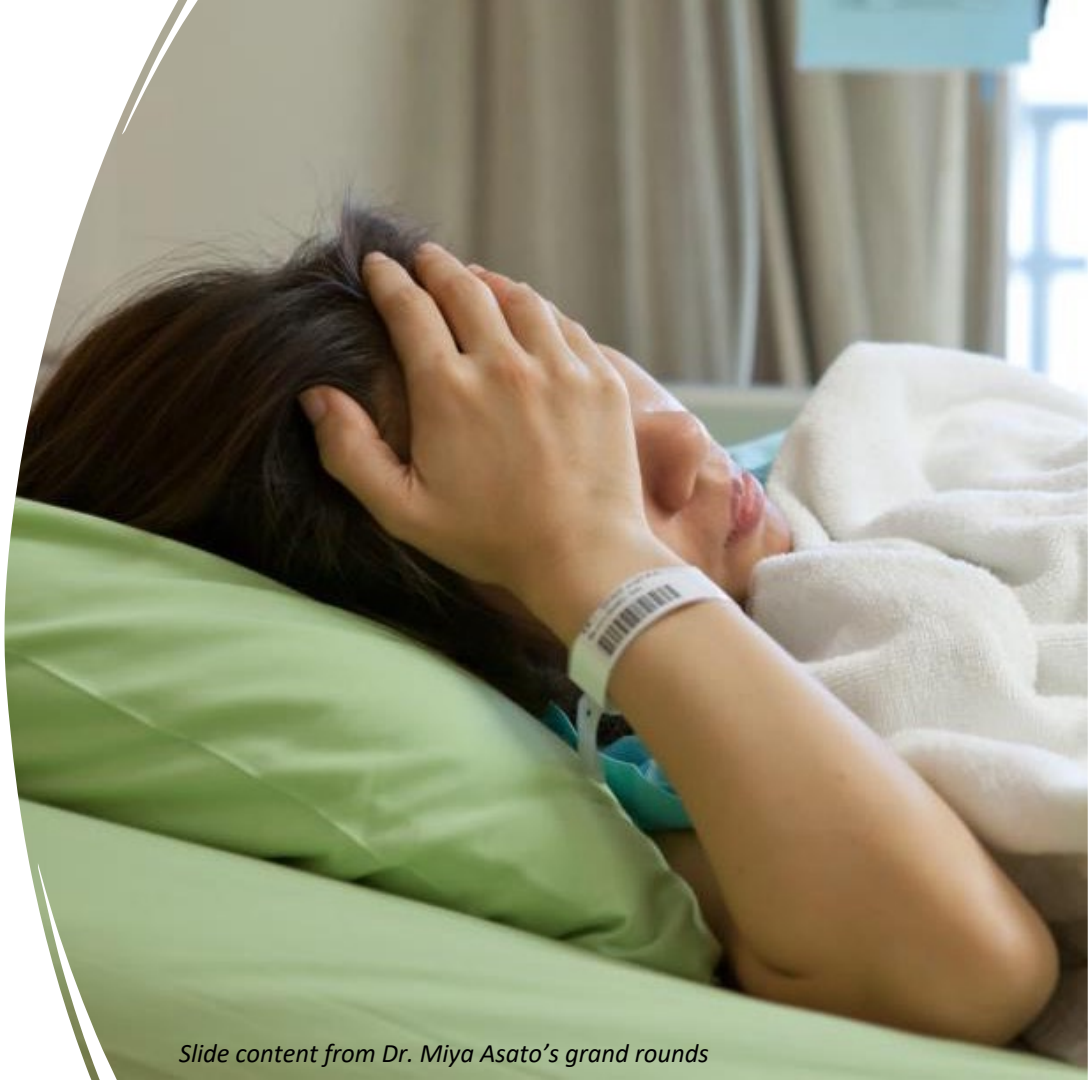
Successful transition leads to

- Continuity of care
  - Fewer gaps in clinical follow up
  - Improved access to care
    - Decreased financial barriers to care
- Improved adherence
  - Better disease (for example, seizure) control
  - Fewer emergencies
- Improved quality of life

Slide content from TSC Conference 2017, Dr. Schultz

Consequences of poor transition

- Risk for medical complications
- Problems with treatments and medical adherence
- Discontinuity of care
- Higher acute care utilization and costs (Fortuna et al., 2010)



Slide content from Dr. Miya Asato's grand rounds

The need for transition services

Women with ID/DD are less likely to

- Have cervical and breast cancer screenings
- Have ever visited a gynecologist

Adults with ID/DD are less likely to

- Visit the dentist regularly
- Get eye and hearing tests
- Receive vaccines

Lower income households experienced even greater disparities.

Patients with Sickle cell disease have increased risk of mortality during transition.

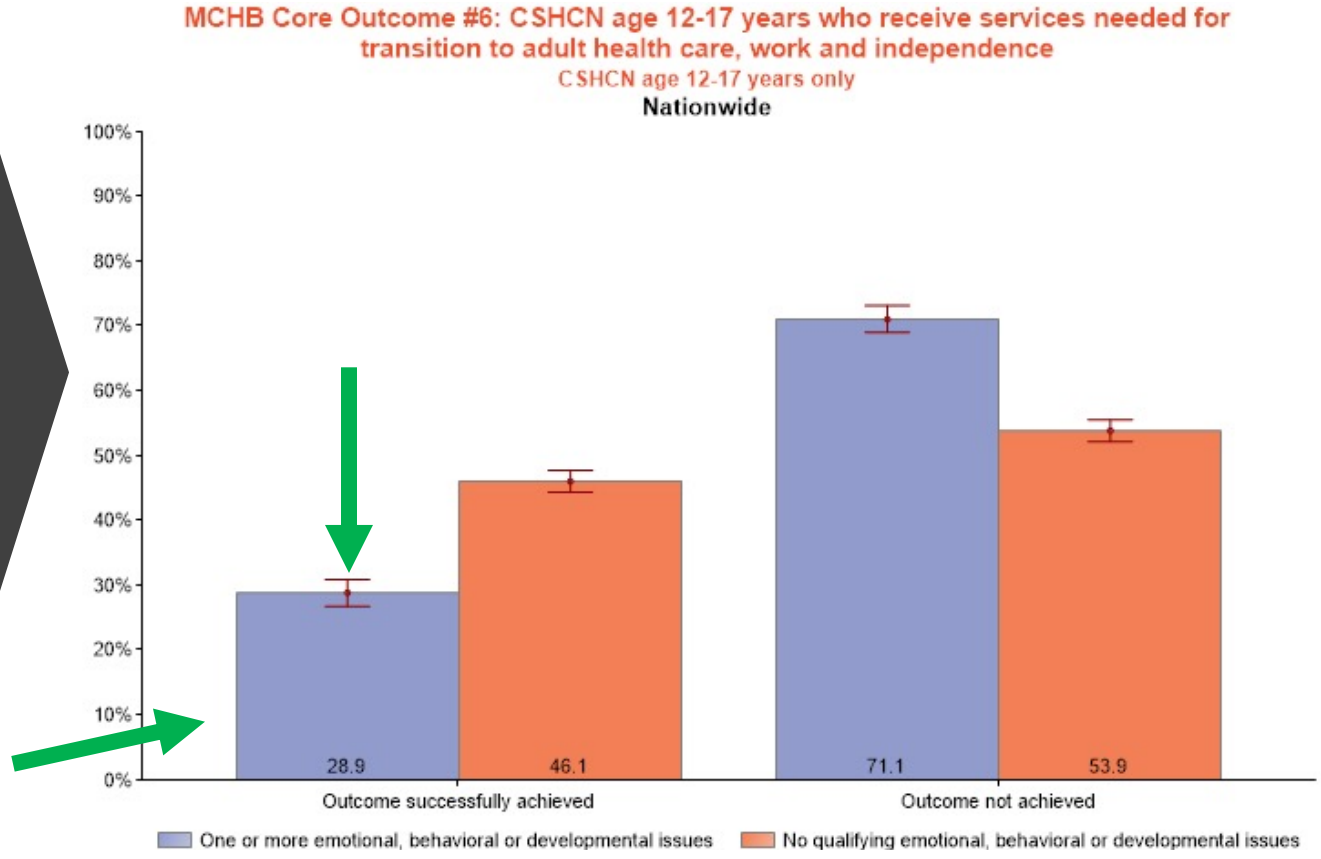
National core indicators (NCI) data- collaboration of state developmental services agencies
http://www.nationalcoreindicators.org/upload/presentation/FINAL_NASDDDS_2014_Health_Disparities.pdf

Figure 1.
"Cascade of Disparities" leading to poor health outcomes in adults with intellectual disabilities.

Kahn and Fox, J Appl Res Intellect Disabil. 2014 September ; 27(5): 431–446. doi:10.1111/jar.12067

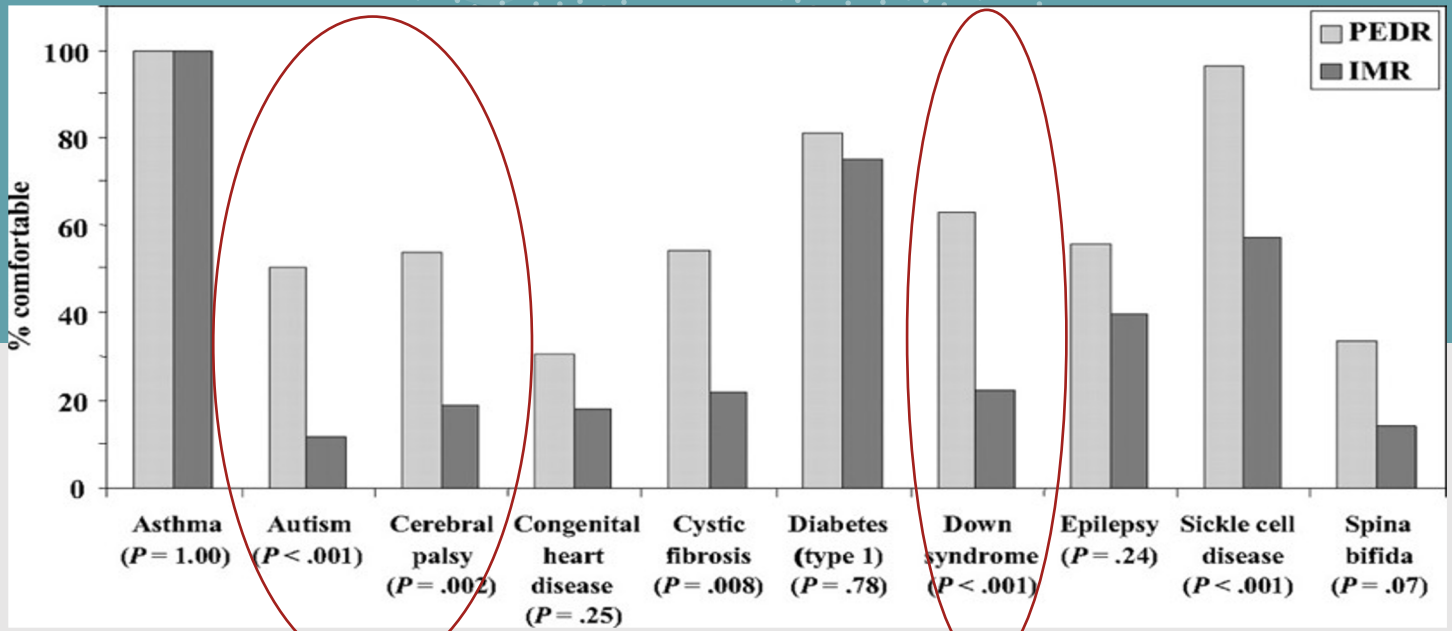
Transition:

More difficult for youth with chronic conditions/developmental disabilities



National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 05/07/18 from www.childhealthdata.org.

Resident Comfort with Outpatients



Patel MS and O'Hare K. Residency Training in Transition of Youth with Childhood-Onset Chronic Disease. Pediatrics 2010; 126 S3:S190-3.

90% of children with chronic conditions, including ID/DD, survive to become adults

SURVEY OF RESIDENTS

- N=412 Residents
- 96% treated a patient with IDD
- 24% received formal education about IDD during their training

- How comfortable are you treating patients with IDD?
  - **Just over half say they feel COMFORTABLE treating patients with IDD…**
    - Very uncomfortable 2%
    - Somewhat uncomfortable 15%
    - A little uncomfortable 26%
    - **A little comfortable 24%**
    - **Somewhat comfortable 29%**
    - **Very comfortable 5%**

Transition takes

- Time
  - Locate resources
  - Learn new information
- Advocacy
- Tenacity

#1 Start Early

- Begin discussion at 12-13 years of age
  - Ask your doctor when you will have to transfer to adult care?
    - 18 years
    - 21 years
    - Never
  - Will they help you with this process? How?

- Begin to set goals and expectations
  - Obtain optimal independence

Slide content from TSC Conference 2017, Dr. Schultz

#2 Self-Care Assessment

My Health — *Please check the box that applies to your child right now*	*Yes, he/she knows this*	*He/she needs to learn*	*Someone needs to do this… Who?*
My child knows his/her medical needs.	☐	☐	☐
My child can explain his/her medical needs to others.	☐	☐	☐
My child knows his/her symptoms including ones that he/she quickly needs to see a doctor for.	☐	☐	☐
My child knows what to do in case he/she has a medical emergency.	☐	☐	☐
My child knows his/her own medicines, what they are for, and when he/she needs to take them.	☐	☐	☐
My child knows his/her allergies to medicines and medicines he/she should not take.	☐	☐	☐
My child carries important health information with him/her every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).	☐	☐	☐
My child knows he/she can see a doctor alone as I wait in the waiting room.	☐	☐	☐
My child understands how health care privacy changes at age 18.	☐	☐	☐
My child can explain to others how his/her customs and beliefs affect health care decisions and medical treatment.	☐	☐	☐

Make emergency plan

- Medical Alert bracelet/necklace or tag
- Wallet card
  - Diagnoses, seizure type
  - Medications
  - Allergies
  - Emergency contact information
  - Medical contact information

Slide content from TSC Conference 2017, Dr. Schultz

#3 Annually Discuss Medical Condition and Age-Appropriate Concerns:

Discuss:

- The youth's **medical condition**
- Current **medications** and potential side effects
- Signs and symptoms of concern
- **Genetic counseling** and reproductive implications of the condition
- Issues of **puberty** and **sexuality**
- Driving, alcohol and substance use, and other risks
- **Emotional/psychological** concerns and **wellness**.

#4 Discuss Legal Competency

- Medical and Financial Power of Attorney
- Proxy Decision Maker
- Supported Decision-Making
- Guardianship Alliance of Colorado offers classes to discuss each option in detail and help families decide what is best. http://www.abilityconnectioncolorado.org/guardianshipallianceofcolorado/

- Full guardianship means having the court appoint a guardian; individual is then considered “adjudicated.”
- Can be a difficult decision

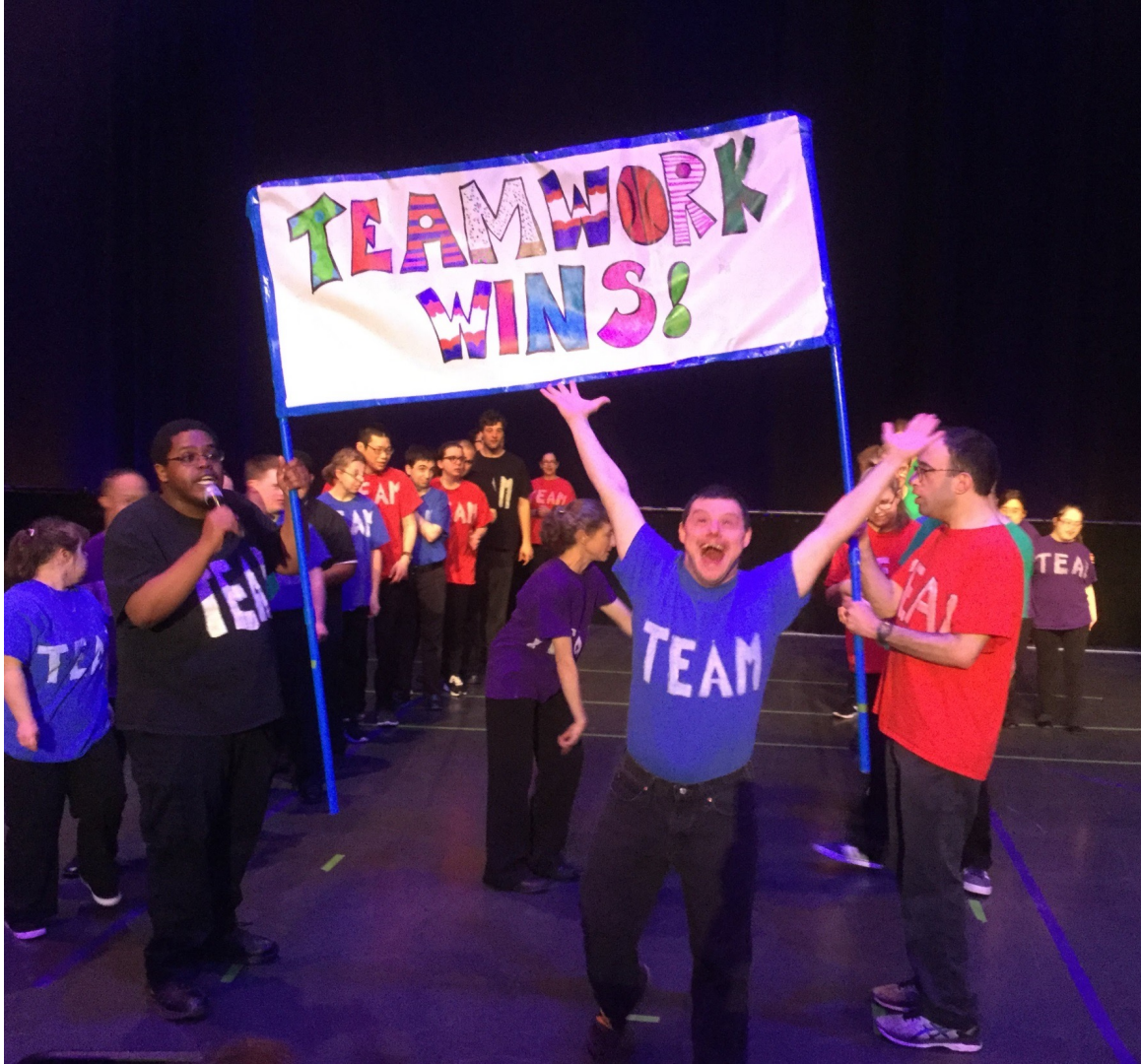
#5 Annual Review of Transition Plan of Care

Developed in collaboration with youth, health, school, and vocational professionals.

Should address:

- Health care finance and legal concerns
- Primary care
- Other specialty care
- Education to employment
- Housing
- Community services

#6
Define Responsibilities of team members



7

Identify Adult Provider(s)

- How can we help our patients access adult providers?

- Give adult providers tools to feel confident accepting the transition-age patient:
  - Provide plan of care
  - Provide information about the condition
  - Provide prior records, for example, imaging or genetic testing

8

Transfer to Adult Provider

Transition Clinic

- Occurs monthly
- Held within Developmental Pediatrics
- Patients age 14-26
- 2 hour visit:
  - 1 hour with MD
  - 1 hour with social work

Children's Hospital Colorado
Here, it's different.

Portable Medical Summary

SPECIAL HEALTHCARE NEEDS (common emergency problems, communication, sensory triggers, procedures to avoid/adapt, important behaviors around health care, recommendations for exams, certain labs or procedures needed, etc)

CURRENT PROBLEM LIST (include date of onset, current status, provider managing)

CURRENT MEDICATIONS (dose, date started, targeted symptoms, positive and negative effects and prescribing provider)

MEDICAL SUMMARY AND EMERGENCY ACTION PLAN

LAST UPDATED:

PATIENT CONTACT INFORMATION

Name: Goes By:

Date of Birth:

Address:

Phone number:

Email:

Insurance:

EMERGENCY CONTACT

Name:

Phone number:

Relation to Patient:

Preferred emergency care location:

MEDICAL DECISION-MAKING

Can make own medical decisions? YES NO

Substitute decision-maker? YES NO

CONTACT INFORMATION OF DECISION-MAKER

Same as emergency contact? YES NO

Title (guardian, power of attorney):

Name: Goes by:

Address:

Phone number:

Relation to Patient:

ALLERGIES (Include type of reaction)

PRIMARY DIAGNOSES: (date of onset, etiology, current status)

After Visit Summary

- **Diagnoses:**
- **Plan:**
- Medical Transition Action Plan

Goals	Issues/Concerns	Actions	Person Responsible	Target Date

Transition Planning Roadmap for PCP

TRANSITION GUIDELINES FOR ADOLESCENTS WITH DEVELOPMENTAL DISABILIITES	12 years	14 years	16 years	17 years	18-26 years
Adaptive testing	X	*	*	*	*
Contact Community Center Board for adult services wait list		X	*	*	*
Share written practice policy on medical transition with family	X	*	*	*	*
Discuss school's transition plan		X	X	X	X
Assess medical transition readiness		X	X	X	X
Develop and place patient on office's medical transition registry		X	X	X	X
Develop brief portable medical summary				X	*
Discuss possible ACT/SAT testing accommodations			X	*	
Discuss driving/transportation options			X	*	*
Discuss applying for SSI if qualifies				X	*
Discuss guardianship, shared decision making, medical power of attorney				X	X
Discuss possible need for day programming				X	X
Share compiled list of adult primary and specialty care providers with an interest in patients with special needs				X	X
Send brief letter and portable medical summary to adult care provider				X	X

X = Recommended at this age

*** = If not already done, recommended at this age**

Transition clinic is a resource for patients with developmental disabilities to plan for the future in both **medical** and **non-medical** aspects of life, which will look different for everyone!

Adult Developmental Disabilities Clinic at UC Health

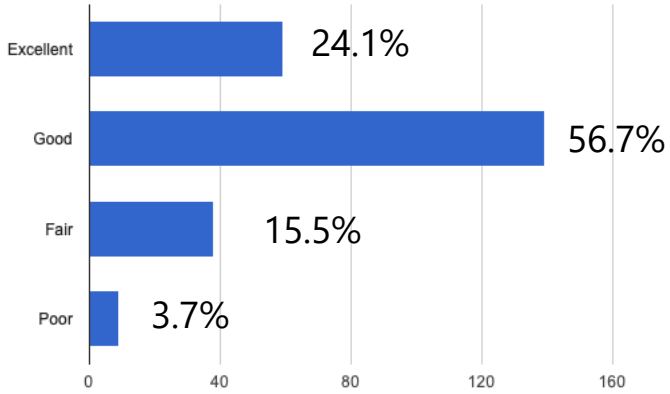
- Brand new clinic with Dr. Jessi Solomon Sanders
- Consultations for adults with Developmental Disabilities
- Within the Behavioral Neurology Clinic at UC Health
- **Phone:** 720-848-2080
- **Address:** UCHealth Central Park Medical Center
- 3055 Roslyn Street, Suite 120
- Denver, CO 80238

How are youth and adults faring in the pandemic?

Preliminary data suggests behavioral health challenges worsened

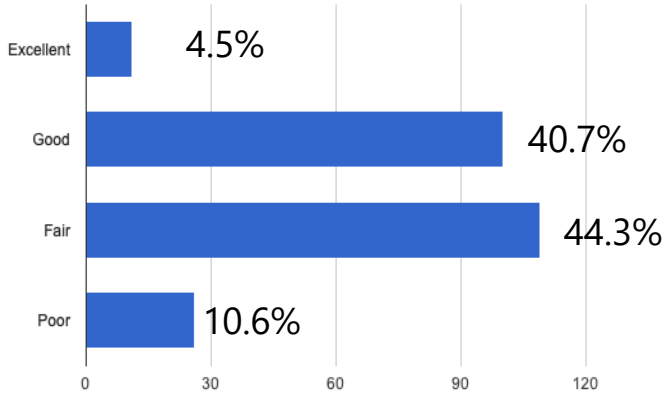
How would you rate your overall PHYSICAL health right now?

N = 245



How would you rate your overall MENTAL health right now?

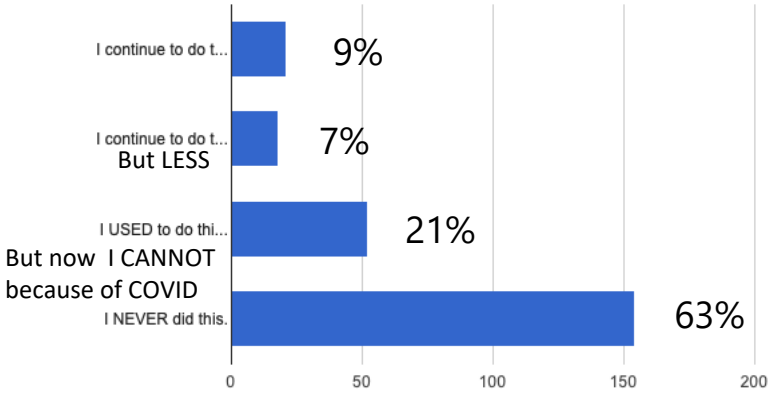
N = 245



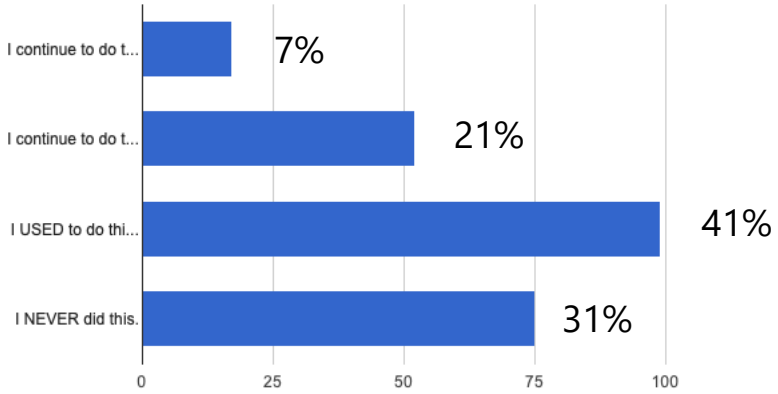
The importance of adult services

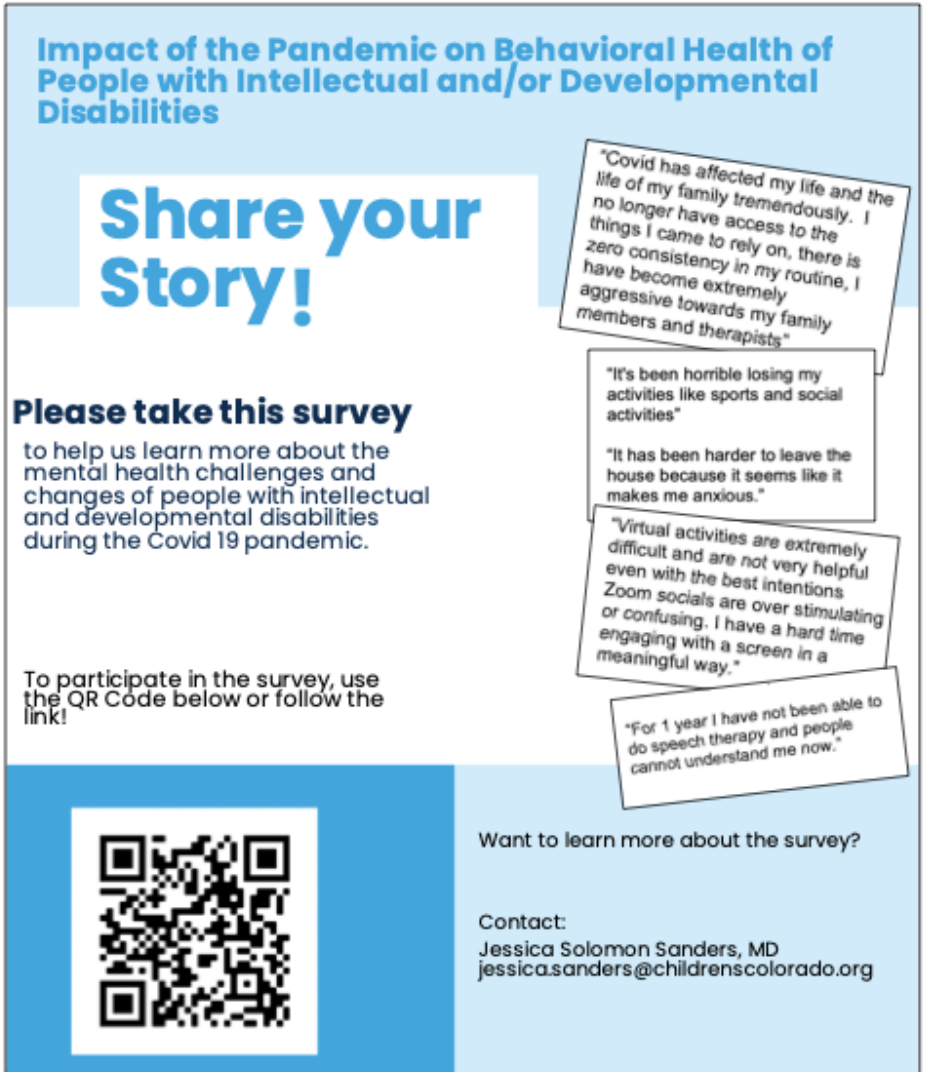
"Please tell us how your services/activities have CHANGED because of the COVID pandemic."

Paid Work/Employment



Day Programming/Supports in the Community





https://redcap.link/covidimpact

Questions?

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RESOURCES:

- https://www.childneurologyfoundation.org/transitions/
- GotTransition.org
- IDDtoolkit.org

Patient and Family Perspective