The Next Frontier in the Transition of Care

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What is Transition?

"The purposeful, planned and timely transition from child and family-centered pediatric health care to patient-centered adult-oriented health care."

Society for Adolescent Medicine, 1993

- "Transition" is the process the patient/family undergoes from one life-stage to the next, of which adult care transfer is just one part.
- "Transfer" to adult facility is a medical handoff that has its own challenges, risks, requirements and idiosyncrasies

- Failure to recognize and plan transition may result in patients dropping out of care
- Poor transition processes are recognized to have a significant negative effect on morbidity and mortality in young adults with chronic health needs

Why is transition of care important?

Non-adherence

Worsening Disease

More:

- **ED visits**
- **Surgeries**
- **Hospitalizations**

Treatment Dropout

Death

Aligning Goals

got transition

6 Core Elements

1. Transition Policy
2. Transition Tracking & Monitoring
3. Transition Readiness
4. Transition Planning
5. Transfer of Care
6. Transfer Completion

Child Neurology FOUNDATION
Creating a Community of Support

8 Common Principles to Assist with the Transition of Care

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

Recommended Health Care Transition Timeline

1. Transition Policy

Updating

Providing

Creating

2. Transition Tracking & Monitoring

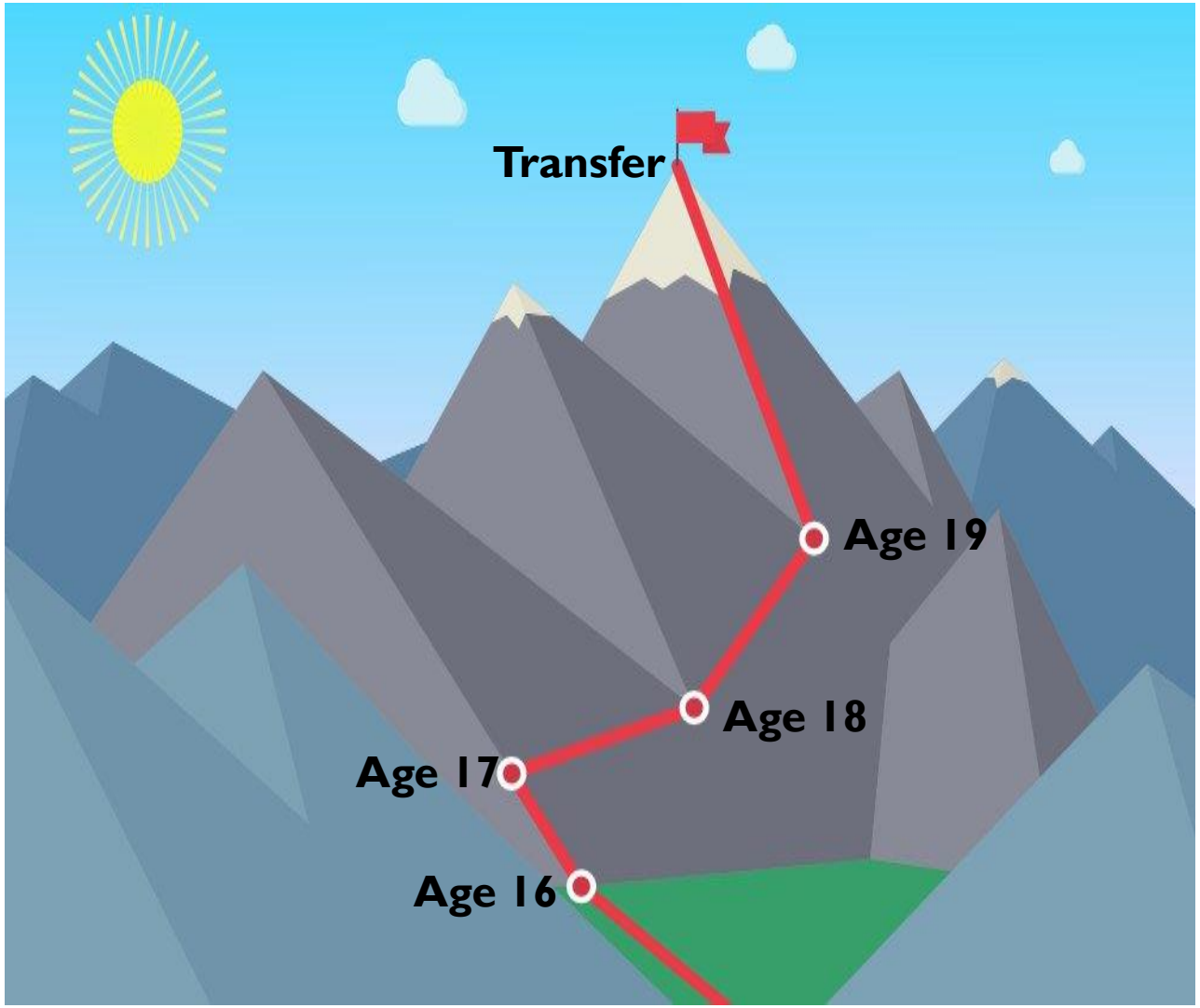
Patient data

Physician Platform

Transition Registry

3. Transition Readiness

4. Transition Planning



Transformation Journey to Adult Health Care

DRAFT

12 – 14 Years Old

15 – 17 Years Old

- Know your condition and medications and why you take medicine
- Meet alone with your doctor for part of the visit
- Know what to do in an emergency and how to stay safe
- Learn about healthy lifestyle habits
- Learn about reproductive health
- Learn about the impact of drugs and alcohol
- Lean on friends for support & connect with others like you
- Speak Up and Ask Questions
- Explain your Condition /
- Name your medications
- Know names and purposes of tests conducted
- Know when and how to contact your medical team
- Take your medication & order refills on your own
- Plan for your future educational & career goals
- Book your own medical appointments and check yourself in
- Know your medical history and fill out medical forms with help
- Advocate for your medical needs
- Carry your insurance card and learn about health insurance and finances
- Understand your legal rights and what changes when you turn 18
- Consider basic needs and learn independent living skills
- Consent for your own medical treatment
- Choose who participates in your health care
- Understand differences between pediatric and adult care
- Identify an adult PCP (and adult specialists, if needed)

Start at 12!

SUPPORT ← ***KNOWLEDGE***

CONFIDENCE → ***INDEPENDENCE***

18 Years Old

19 - 21 Years Old

Congratulations on Graduating to Adult Health Care!

Take Care of YOUR Health with Support, Knowledge, Independence, and Confidence

5. Transfer of Care

Strengthen relationships

Support

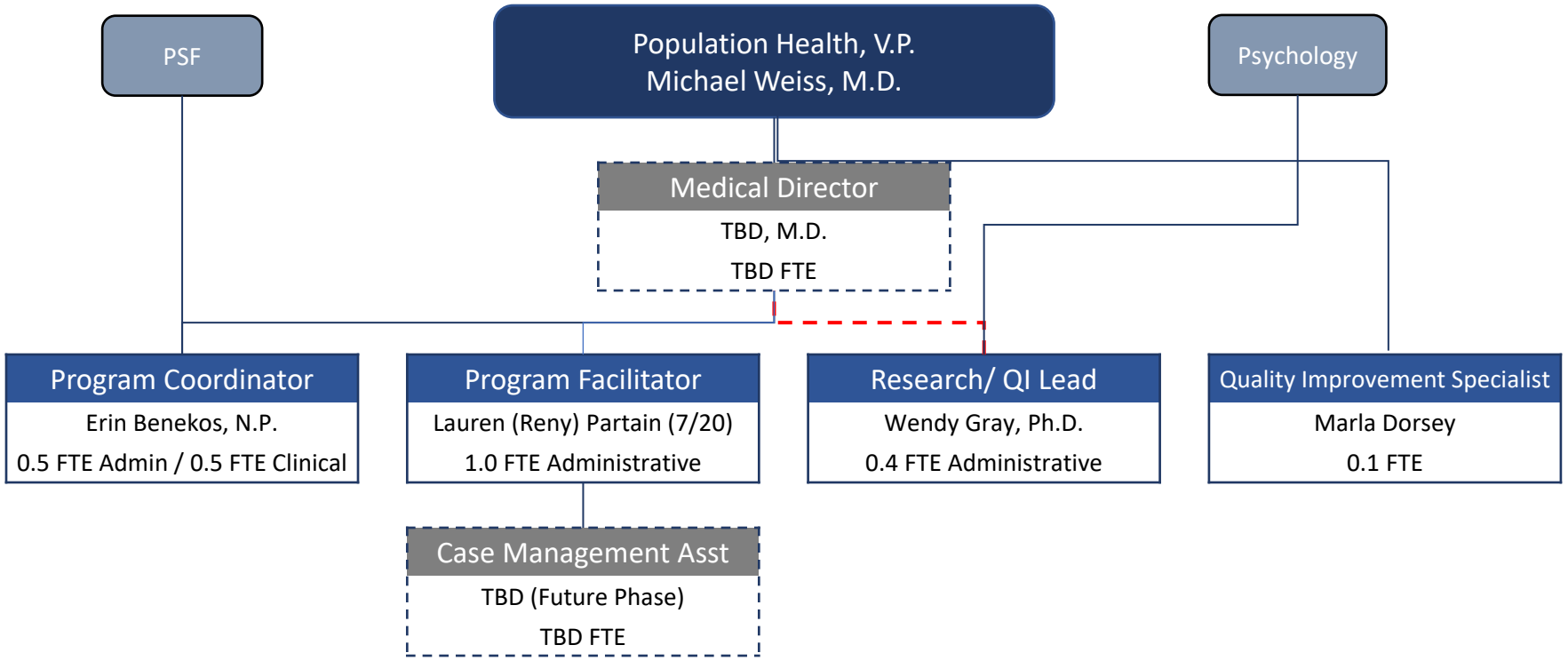
Streamlined process

6. Transfer Completion

Approach

- Build the Team
- Inventory Current State
  - Division-specific programs
  - Community providers
  - Patients/Families
  - Partner Medical Groups/Health Systems
- Build EMR Systems/Registry/Forms/Surveys
- Design and Implement Training Program
- Pilot in Neurology and Gastroenterology
- Learn and Spread

Organizational Chart – Pediatric to Adult Care Transition Program



Pediatric to Adult Health Care Transition - Stakeholders

Executive Sponsor
Michael Weiss, M.D.

Project Support
Hanae Kim

Steering Committee		
Erin Benekos, N.P. Anne Carpinelli, M.D. Marla Dorsey William Feaster, M.D.	Kenneth Grant, M.D. Wendy Gray, Ph.D. Erika Jewell, LCSW Michelle Kennedy	Rhonda Long Kristen Rogers Michael Weiss, M.D. Mary Zupanc, M.D.

WORKGROUPS

Program Design	Adult Provider Engagement	Education	Communications
Erin Benekos, N..P. Wendy Gray, Ph.D. – Lead Erika Jewell, LCSW – Lead Anne Carpinelli, M.D. – Lead	Kenneth Grant, M.D. – Lead Mary Zupanc, M.D. – Lead Wendy Gray, Ph.D.	Erin Benekos, N.P. Wendy Gray, Ph.D. – Lead Erika Jewell, LCSW – Lead Anne Carpinelli, M.D. – Lead	Michael Weiss, M.D. – Lead

Health System Engagement	Technology / Data	Research / Quality Improvement	Patient / Family Engagement
Michael Weiss, M.D. – Lead	Bill Feaster, M.D. – Lead Kenneth Grant, M.D. – Lead	Wendy Gray, Ph.D. – Lead Marla Dorsey, QIA	Kristen Rogers

Ad-Hoc Members	
Megan Beckerle Dan Cooper Rebecca Hernandez Heather Huszti, Ph.D. Rhonda Long Sara Marchese, M.D.	Alexandra Roche, M.D. Lisa Stofko Amanda Thyden Lilibeth Torno, M.D. Terez Yonan, M.D.

Transition Program Project Progress

Program Design

- ✓ Determined **Staffing Model**
  - ✓ Hired Nurse Practitioner and Program Facilitator (LCSW)
  - ❑ Recruiting Medical Director
- ✓ Identified **Transition Assessment Measurement Tools**
  - ✓ UNC TRxANSITION – validated tool used by Providers to assess patient's transition readiness
  - ✓ STARx – Patients/families assess their own transition readiness
  - ✓ Disease Knowledge Questionnaires (will vary by specialty)
- ✓ Developed Drafts of **Transition Program Policies**
- ✓ Implementing **Pilot Programs** for Epilepsy and IBD patients starting mid-June 2020

Education

- ✓ Determined **Core and Specialty Education Topics** by Age Range
- ❑ Gather existing/available educational materials and resources
- ❑ Determine new modules and modes of Education

Technology

- ✓ Developing **Cerner Powerform** for UNC TRxANSITION tool
- ✓ Working on integrating Patient/Family-facing Transition surveys and tools with **HealthGrid** initiative
- ❑ Develop Transition **Dashboard**
- ❑ Develop Transition **Registry** (future goal)

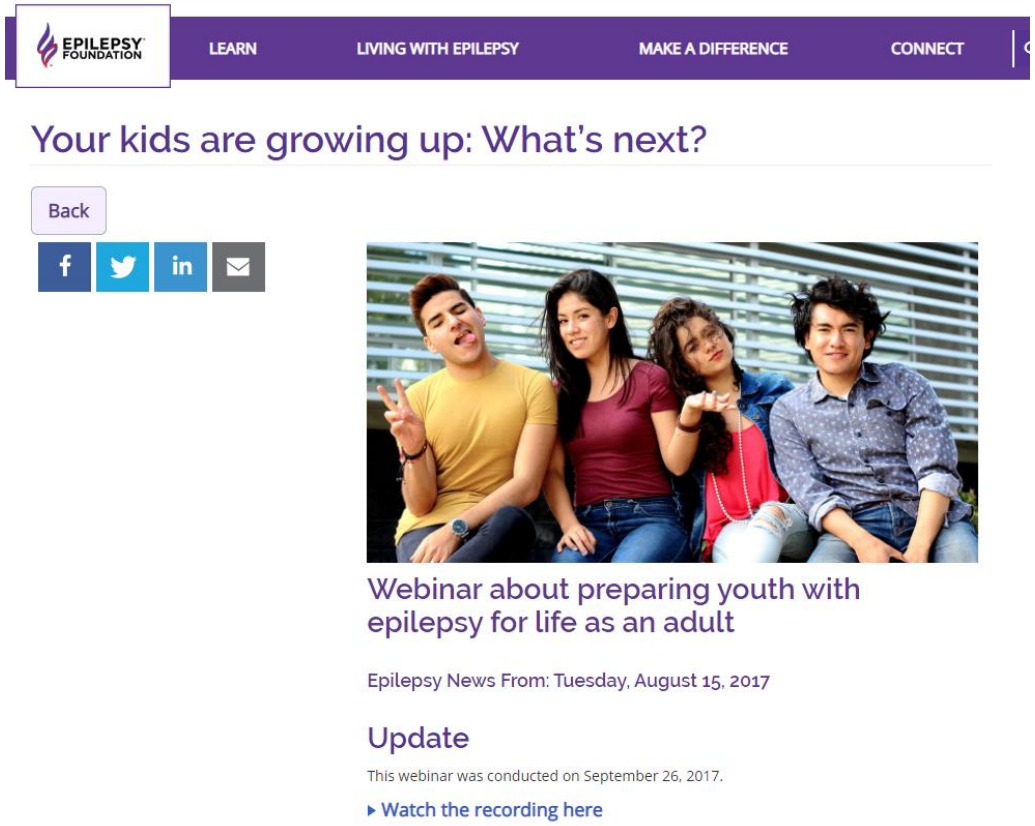
Community Engagement

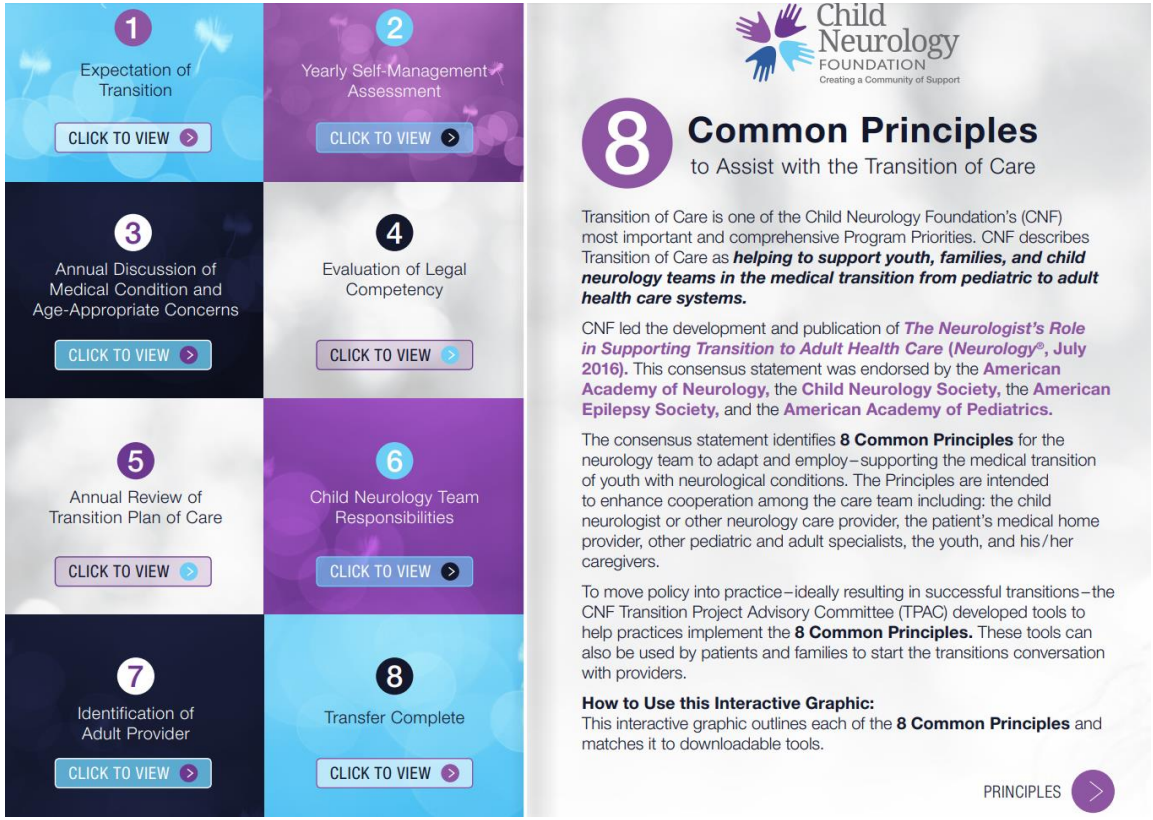
- ❑ Conducting an **Adult Provider Focus Group** (estimated timeframe: June – July)
- ❑ Plan for a **Patient and Family Focus Group**

Research / QI

- ✓ Defined **Transition Registry Data Elements**
- ❑ Determine Program **Quality Improvement and Success Measures**

Moving Policy into Practice





In Summary

- The importance of successful transition has been well established
- Increased risk of morbidity and mortality during this delicate time
- Focus on creating protocols starting at an early age
- Incorporate transition elements and common principles to ensure successful transition
- Communication is essential

"Support for the medical transition of youth living with neurological conditions is a critical acknowledgment that youth should not simply survive to adulthood... they should thrive as adults!"

Transitions Project Advisory Committee (TPAC)
https://www.childneurologyfoundation.org/transitions/