

leading the way
together



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12TH INTERNATIONAL CONFERENCE



Building Bridges and Navigating Adult-based Healthcare for Individuals with Developmental Disabilities

John Berens, MD | July 12th, 2024

Baylor College of Medicine

Financial disclosures

- None



Objectives

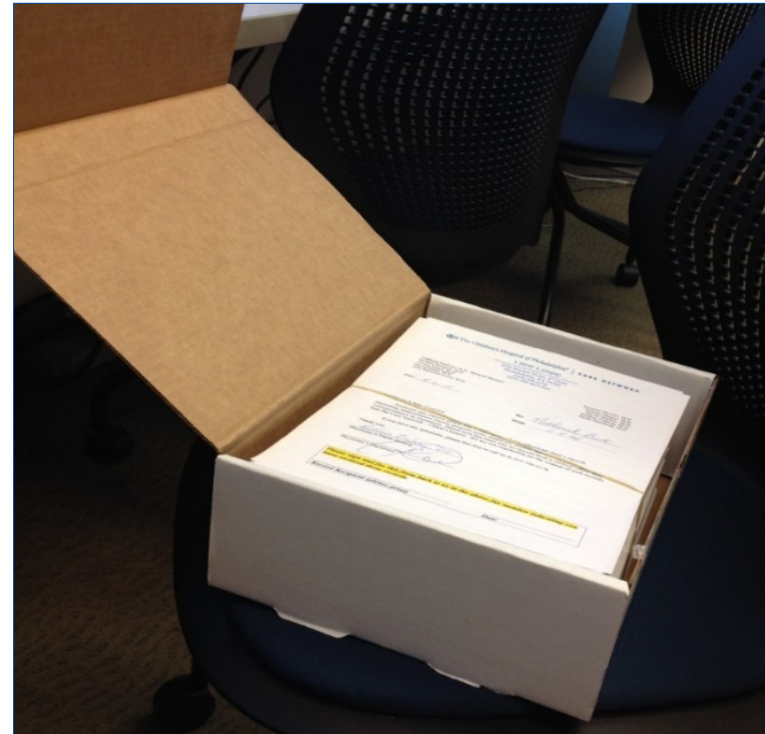
- **Review** the challenges faced by many emerging adults during the transition from pediatric to adult-based healthcare, particularly those with intellectual/developmental disabilities (IDD).
- **Describe** the experience of one primary care clinic that serves adults with IDD.
- **Develop** a framework for the healthcare transition process that will highlight the key pieces at each stage.
- **Discuss** the unique health and life considerations for individuals with IDD as they reach young adulthood and beyond.





Healthcare transition (HCT) is difficult

- Points of view:
 - Family/patient
 - Pediatrician
 - Internist
- Emerging adulthood
- Change in supports
- IDD considerations



How are we doing?

- ...Not good, on the whole
- National Survey of Children's Health, 3 questions:
 - Discuss shift to adult care?
 - Talk to doctor independently?
 - Work on self-care skills or health care changes?
- ~20% say yes
 - Maybe ↑ ? Maybe better for more severe disease?
- Outcome measures:
 - 1) Patient/family experience
 - 2) Health outcomes
 - 3) Good value



Transition Medicine Clinic

- Primary care medical home
- Patient population
- Faculty/staff
- Team-based
- Enhanced support
- Mission to teach
- Transition processes
- Research



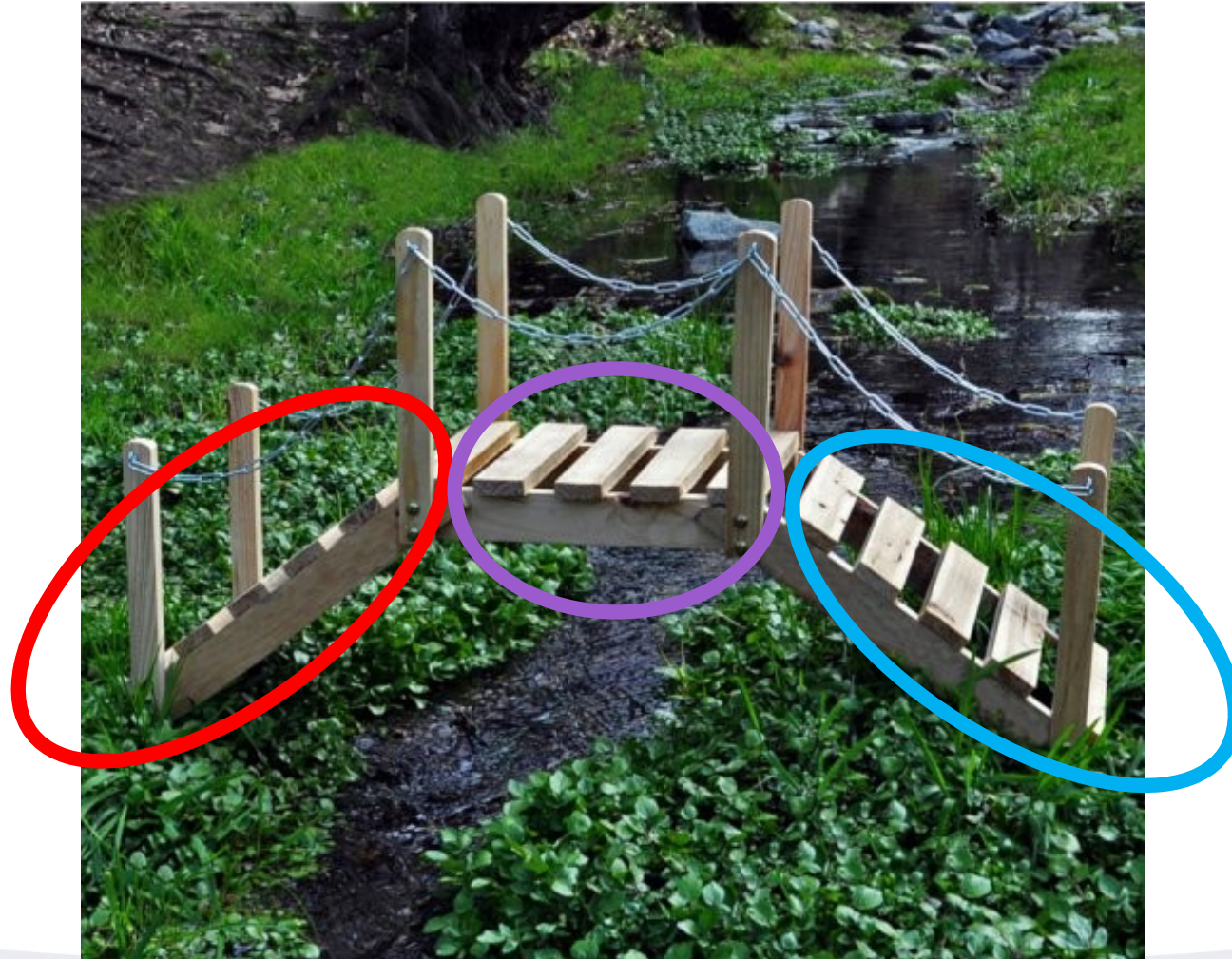
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Building our own bridges

- 1) Preparation
(pediatric)
- 2) Transfer
(pediatric ☾
adult)
- 3) Integration (adult)



Preparation

- Discuss transition timing with each doctor
 - Strict or flexible?
 - Confirm policy/accepted insurance plans
 - Adult MD recommendations?
 - Start early!
- Discuss “big picture” with each doctor
 - Easy vs. complicated
 - Window of opportunity



Preparation, cont.

- Insurance
 - Medicaid: ages, changes, options
 - Private/Medicare
- Waivers
- Build knowledge/independence



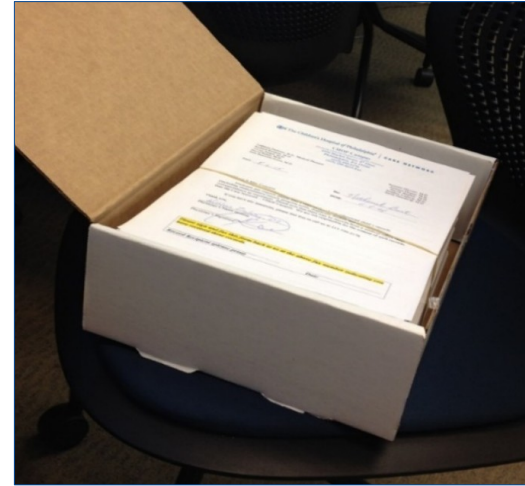
Transfer

- Before first appointment
 - Visit location
 - Clinic accommodations
 - Transfer records
- At first appointment
 - Bring medications
 - List of doctors
 - ~1 page summary



Transfer summary

- Care team
- Meds/allergies
- Medical conditions
- Prior surgeries
- Communication/function
- Family/caregiver support
- Durable medical equipment/supplies (details)
- +/- Recent hospitalizations



Integration

- First adult appointments:
 - Reason for visit
 - Good (adequate) fit?
 - Bring summary– include info about SMS
- Continue building knowledge/independence
- Reimagine possibilities



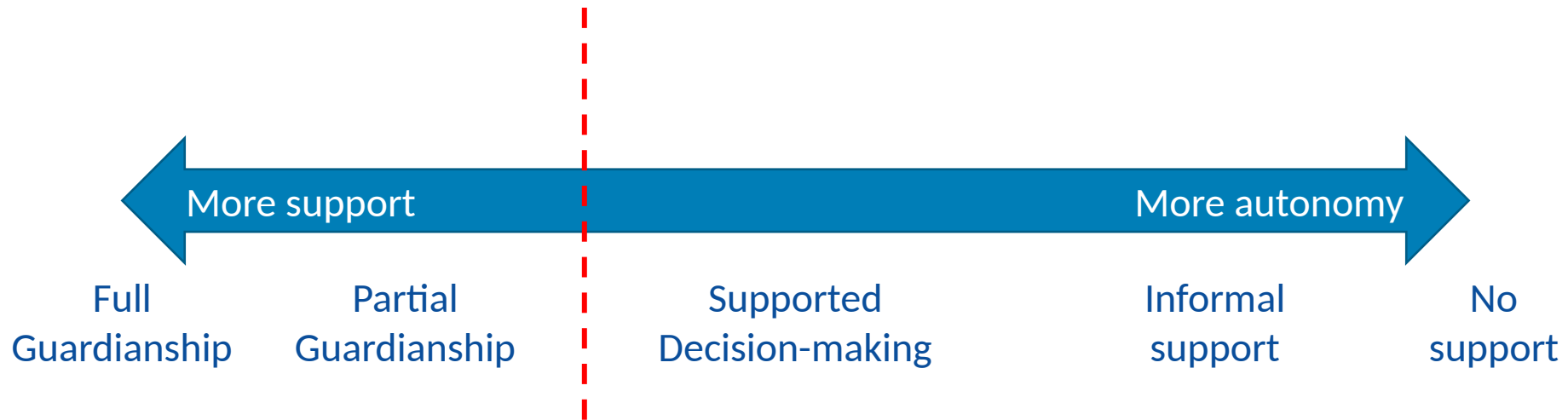
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Medical Decision-Making

- Fluidity of capacity
- Autonomy vs support
- What does guardianship mean?



Long Term Care Planning

- Definition, domains
- Barriers
- Opportunities



Misc. “wisdom”

- Everyone is constipated
- Know your baselines
- Behavior is communication
- Put your mask on first
- Build your team: medical, insurance, social support, etc.



The Way Forward

- The current reality
- Finding “the good ones”
- The future looks brighter
- Use our collective voices



Key Points

- Healthcare (transition) is tough
 - There is a lot we can do to smooth the process
- Build your own team
 - Utilize available supports
 - Advocate for the rest
- Build/support independence
 - May involve “unlearning”
- Don’t stop dreaming of (and working toward) a better future



Resources/contact info

- Got Transition Tool Kit:
<https://www.gottransition.org/resource/?hct-family-toolkit>
- Supported Decision-Making:
<http://www.supporteddecisionmaking.org/>

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