Mind the Gap: How Neuropsychology Can Help Support Medically Complex Patients' Transition to Adulthood

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Workshop Objectives

- 1. Identify challenges associated with transition to adult care in medically complex populations.
- 2. Describe individual and systemic facilitators and barriers to successful transition to adulthood ______
- 3. Create a framework for program development of neuropsychology-informed transition to adulthood services using a quality improvement paradigm

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Workshop Outline

- Transition frameworks and guidelines
- Transition supports across patient populations
- Application of transition program for patients with sickle cell disease
- Neuropsychology consults for transition to adulthood in multidisciplinary care
- QI methodology to build and implement a transition program

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Transition Frameworks and Guidelines

- Defining transition
- Frameworks for assessing transition readiness
- Transition readiness scales
- Transition guidelines
- Role of neuropsychology

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Transition Frameworks and Guidelines

Defining transition



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Transition to Adulthood

- Events often associated with the transition to adulthood:
- Completing school
 Completing school
 Entering the labor force
 Leaving home
 Marriage
 Parenthood

- Personal conceptions on transition:
 Accepting responsibility for one's actions
 Deciding on values and beliefs
 Establishing equal relationship with parents
 Financial independence
- countries

Furstenberg, 2015, American journal of orthopsychiatry Arnett, 2001, Journal of adult development

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Health Care Transition

- Process of moving from a child/family-centered model of health care to an adult/patient-centered model of health care, with or without transferring to a new clinician.
- It involves planning, transfer, and integration into adult-centered health care.

McManus et al., 2015, Journal of pediatric nursing

The goals of health care transition are:
 To improve the ability of youth and young adults with and without special health care needs to manage their own health care and effectively use health services
 To ensure an organized process in pediatric and adult health care practices to facilitate transition preparation, transfer of care, and integration into adult-centered health care.

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Transition "Success" • Developmental, career, interpersonal: • Completing school • Entering the labor force • Lawing home • Marriage • Marriage • Parenthood • Healthcare • Building first adult appointment • Percentage of appointments attended within X months or years • Building a trusting relationship with adult provider • Satisfaction with care

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Transition Frameworks and Guidelines

• Defining transition

Frameworks for assessing transition readiness

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Transition Readiness Frameworks

- Operationalize and assess transition
- Program evaluation
- Identify targets of intervention
- · Displays the multisystemic nature of transiti







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Transition Readiness

- Multiple levels: Individual

 - Family
 Healthcare system
 Environment
- Pre-existing and modifiable factors routinely assessed as part of a neuropsychological evaluation

- Neurocognitive difficulties may not be regarded or recognized by patients
 Discrepancies in ratings of importance
 May be framed in relation to knowledge / health literacy

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Transition Frameworks and Guidelines

• Defining transition

- Frameworks for assessing transition readiness
- Transition readiness scales

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Transition Readiness Scales

- Recommended by most transition guidelines
- Suggested to select a readiness-assessment tool that can be "modified for specific patient situations"

-Indata

- Common domains assessed:
 Skills
 Knowledge
 Self-management
 Readiness for change

Disease Neutral and Specific Readiness Scales

- Disease neutral Transition Readiness Assessment Questionnaire (TRAQ 6.0)¹ Self-Management and Transition to Adulthood with the Rx (STARx)² UNC TRXANSITION Scale³
- Disease specific
 Transition Readiness Inventory item pool TRI Cancer⁴
 Transition Intervention Program Readiness for Transition TIP-RFT Sickle Cell Disease⁵
 CHD Readiness transition Assessment Congenital Heart Disease⁶

Johnson et al., 2021, Journal of pediatric nursing Ferris et al., 2015, Journal of pediatric nursing Ferris et al., 2012, Renal failute Schwartz, 2017, Journal of Pediatric Psychology Treadwell et al., 2016, International Journal of Adolescent Medicine and Health Stewart et al., 2017, Pediatric Cardiology

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Development Development - Derived from stages of change trans-theoretical model - Updated multiple times - Most recent version utilized item response theory - Eliminated low-discrimination items - Added high difficulty items

Transition Readiness Assessment Questionnaire (TRAQ v 6.0)

- Structure

 Four domains: managing medications, keeping appointments, tracking health issues, talking with providers

 20 items

 Good construct validity

- Target specific domains
 Use repeatedly as part of motivational interviewing
- Managing medications Down that a previous if you need to? Do you how what to do if you are having a had naction to your medications? Do you explain any medications before the yrun ond? Do you explain any medication (same and dose) you are taking to headhcare provide with the planmaid about drug interactions or other con-cessin reflect oo you medication? Appointment keeping: Do you call the doctor's office to make an appointment? Do you follow-up on referrals for tests or direck-ups or labs: Do you arrange for your ride to medical appointments? Do you call the doctor about unusual dranges in your health (I Allervic machines).

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Weaknesses of Transition Readiness Scales

- Minimal criterion validity Validity typically based off: Other transition readiness tools Self-efficacy Medication knowledge Medication knowledge
 Age
 No clear definition of a successful transition
 Longitudinal studies of transition outcomes
 Attending adult care visits
 Retention in adult care
 Minimal to no associations with transition readiness scales
 Response bias
 Many studies exclude patients with cognitive deficits
 Primarily focused on health-care transition
 Need to be tested in culturally diverse settings

Utility of Transition Readiness Scales

- Understand patient, caregiver, and provider perspectives
- Facilitate communication
- Target modifiable behaviors
- Track patient progress
- Predictive of certain healthcare outcome
- Helps to identify program gaps

hang, L. F., Ho, J. S., & Kennedy, S. E, 2014, BMC Pediatri

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Transition Frameworks and Guidelines

• Defining transition

- Frameworks for assessing transition readiness
- Transition readiness scales
- Transition guidelines

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Transition Frameworks and Guidelines

• Defining transition

- Frameworks for assessing transition readiness
- Transition readiness scales
- Transition guidelines
- Role of neuropsychology

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	Transition Guideline	Role of Neuropsychology
	1. Systematically incorporate neuropsychological evaluation and	Perform a targeted neuropsychological evaluation beginning at age 14 focused on transition barriers and needs
	intervention	Complete yearly follow-up consultations throughout the transition process
		Update a Transition Rubric to monitor patient progress with multidisciplinary support
Role of	2. Support transitions through	Convey evaluation results to the medical team
	multidisciplinary input	Assist in determining the level of involvement needed across various providers (e.g., social work)
Neuropsychology	 Promote the patient's functional independence 	Assess the level of independence appropriate for a patient, particularly adaptive skills (e.g. activities of daily living)
for Pediatric Brain	ain	Determine potential barriers to transition and assist in obtaining post-secondary educational or employment accommodation
Tumor Patients		Connect patients with adult neuropsychologists who can monitor and track their functioning
	4. Actively incorporate and utilize familial	Increase familial awareness of potential transition barriers
	resources	Develop a plan to address these barriers with familial support
	5. Seek patient input in transition care	Inform the patient's role in decision-making and how to appropriately communicate information to the patient
		Assist in reconciling patient-caregiver conflict regarding transition goals
	6. Advocate for patients in the community	Convey test results to a patient's school
		Teach patient self-advocacy skills

Domain	Assessment	Transition Objective	Process
	(what is the status)	(behavioral goal)	(how to improve status)
Neurologic/sensory deficits: hearing, vision, motor			
Ongoing medical care: shunts, seizures, andocrine			
Ongoing medical risks: stroke, second nalignancy, recurrence			
Behavioral health: anxiety, depression, coping			
Neurocognitive deficits: processing speed, memory, executive functioning, attention, cognitive rehab			
Educational: post high school education/training			
Living arrangements: with parents, semi- independent, fully independent			
Employment: part time, full time, vocational rehab			
Social: engagement, intimacy			
Recreation: sports, interest groups			



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Future Directions

- Integrate neuropsychology into transition programs
 Determine the appropriate types of assessments to fit pressure to
 - Further refine understanding of transition "success"
- Examine neurocognitive skills associated with transition outcomes
- Systematically evaluate the benefits of neuropsychological services on transition

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Targeted Transition Evaluations











nsition Assessment: Clinical Interview		
Family History		
Birth & Developmental History		
Medical History		
Current Functioning		
School & Work History		
Social, Emotional & Behavioral History		













Objective Measurement: Performance Based Measures				
Individuals with IDD seeking gov't services	Individuals seeking college accommodations			
Measure of intellectual ability				
Language: Receptive/Expressive				
Validity*				
Functional academics				
 Factors impacting iADLS¹ 				
Memory				
Attention				
Executive function				
 Problem solving / reasoning 				
 Organization / planning 				
Functional Living 1. Bruderer-Hofstetter, Sikkes, & Munzer, 2020				

Objective Measurement: Performance Based Measures				
Individuals with IDD seeking gov't services	Individuals seeking college accommodations			
	Check for institution specific requirements ²			
	Adult Norms			
	Often looking for specific diagnosis to back up rationale (ICD-10 or DSM-5-TR)			
	• SLD:			
	Aptitude			
	Academic Achievement			
	Information Processing			
	• TBI			
	Aptitude			
	 Nonverbal and Verbal/Language 			
	Information & Memory processing 2 Lindstrom Nelson Foels 2015			

Objective Measure	ment: Rating Scales
Caregiver & Self-report*	 Emotional & behavioral function Attention & executive functions Adaptive functions
Transition Specific	 Ability level vs confidence Transition general rating scales Diagnosis specific scales

















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Resources:

- Let Me Do It Phone App: Letmedoit.org
- CPR Supported Decision Making: supported decisions.org
- National Resource Center for Supported Decision Making: https://supporteddecisionmaking.org/in-your-state/
- Jump\$tart: https://www.jumpstart.org/
- GreenLight: <u>www.greenlight.com</u>
 Acorns Early: <u>https://www.acorns.com/early/</u>
- Centers for Independent Living: https://ncil.org/about/find-your-cil/
- Apprenticeship USA: https://www.apprenticeship.gov/ https://thinkcollege.net/

- Teaching Sexual health: https://teachingsexualhealth.ca
 YAI: https://www.yai.org/knowledge/sexuality-rights-expression-and-advocacy-people-idd
 Vanderbit Healthy Body Toolkit: https://vkc.vumc.org/vkc/resources/healthdevelopment/

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Supporting transition planning for patients with sickle cell disease

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SCD transition guidelines Formal discussion about transition and the policy/practice of the institution should begin at age 12 All patients should have written transition plan by age 14 Developed collaboratively and updated annually Periodic neuropsychological evaluations to identify deficits that may impact disease management skills and academic/vocational and transition planning Bryant et al., 2015, Jour Ped Hemr/Onc Nur



Special considerations with SCD

Strong attachment to pediatric centers

Hesitancy and reluctance to transition

Insulated from stigmatization, discrimination

Wraparound services fade after transition







Cognition supports transition

Higher estimated IQ (PRI & VCI) and verbal comprehension associated with shorter transition $^{\rm 1}$

Inattention predicts transition to adult care For every 1-point decrease in Omission errors, the odds of fulfilling an adult care visit within 6 months increased by 324 ²

Saulsberry et al., 2021, Br Jr Haem; 2 Ali et al., 2020, Ped Bld Can













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Recommendations in report &

Sharing results with medical teams at transition rounds









Strategies to support verbal comprehensionUtilizing apps or other technologiesPractice vocabulary buildingDaily reading at home (15-20 min/day)Practice with reading comprehensionImage: Daily comprehension</t





Supporting attention

Children with SCD less likely to receive ADHD diagnosis ¹ If possible, diagnosis or rule-out ADHD

Psychoeducation on evidence-based treatments, including medication and environmental supports

Using visual aids and reminders Calendar and Notes app Step-by-step instructions EHR, insurance, and disease centered apps



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C-READY Intervention Program

Cognitive-Remediation of Executive and Adaptive Deficits in Youth

3 components: individual therapy, parent training, and skill practice at home

SCD-focused pilot (n=12) Telehealth Improved medication management and communication with healthcare providers Improved inhibition and switching



t al., 2021*Jr Clin Tr*

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Psychoeducation on selecting adult care center

Familiarize with options in the local community or area where patient is anticipated to live

Does the clinic accept your insurance? What will the co-pay be per visit?

Does the clinic have a transition program for young adults?

Is the clinic location convenient to home, school, or work?

Does the clinic take walk-ins and are they affiliated with a local hospital system and/or Emergency Department?

Special considerations

Caregivers may have cognitive difficulties Approachable communication

Health literacy skills may be underdeveloped

Require combination of comprehension, reasoning, and arithmetic Simplified messaging Prioritizing verbal feedback can be helpful Checking for comprehension

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Cognitive impairment and health care agents

Patients with medical conditions are at increased risk for cognitive disorders

Comprehension and reasoning support capacity Some patients will require assistance navigating adult care

Neurocognitive evaluations can identify patients at-risk Enhances planning

Minimizes last minute requests for consults as patients reach age of majority



Challenges with capacity questions

Discrepancy between neuropsychological information and the medical team and/or caregivers experiences Team may feel a patient is more impaired

Sometimes there are limited options for appropriate surrogates for medical decision making

Caregivers may have cognitive limitations

Challenging to predict capacity for some patients 1-2 years in advance of age 18 $\,$

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Key points

Neuropsychology well-positioned to support patients with SCD in transition from pediatric to adult care Cognitive skills support successful transitions

Leverage systematic clinical programs to support transition readiness Transition is high-stakes and mortality risk increases two-fold

Recommendations for practical medical management skills, supporting comprehension and attention

Consider caregiver cognition and health literacy skills, and patient capacity

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Patients and families



Increasing independence: Neuropsychologically informed care for pediatric spina bifida

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Spina Bifida (SB):

 Most common CNS congenital 	Physical	Orthopedic	Neurologic	Cognitive
	Paraplegia	Scoliosis / Kyphosis	Hydrocephalus	Visual spatial deficits
birth defect in the U.S.	Neurogenic bowel	Club foot	WM tract changes	FM impairment
Neural tube	Neurogenic bladder	LE contractures	Shunt / revisions	Attention/EF deficits
defect with multisystem	Pressure sores	Hip dysplasia	Chiari II malformation	High
involvement	Infection risk (wound, UTI)	Rotation/torsion	Dysgenesis / Agenesis of CC	Hig ADH

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SB: At a glance



Medical advances = longer life expectancy
 85% of individuals born with SB will live past 18 years (Tennant et al., 2010)
 Estimated more adults than children living with SB (Briggs, 2020)

Lower rates of achieving adult milestones (zukerman et al., 2011; Holmbeck & Kritikos, 2022)



Neuropsychologically Informed Care



Neuropsychologically Informed Care

Strengths	Challenges
Vocabulary	Attention (shifting)
1emory	Executive functioning skills (initiation, pro solving)
Social	Information processing
arly academic skills (word reading, spelling, nath facts)	Visual spatial reasoning
	Motor (fine and gross)
	Applied academics (word problems, readi comprehension)



Neuropsychologically Informed Care, cont.

 Spina Bifida Association (SBA) Neuropsychological Care Guidelines for the Care of People with Spina Bifida (2020) recommend neuropsychological assessment and monitoring throughout the lifespan Early elementary
Transition to adulthood



- Expertise at the intersection of biopsychosocial and neurodevelopment
- Opportunity to focus results and recommendations into targeted recommendations for independence skills (Bradstreet et al., 2022)



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Neuropsychology and Interdisciplinary Care

- · Majority of neuropsychologists specialize in outpatient assessment (Jordan et al., 2025) Few neuropsychologists are embedded within interdisciplinary clinic settings
- Integrated vs Embedded care Integrated vs Enhoedded care
 Integrated: Interdisciplinary collaboration <u>across</u> settings (Baum et al., 2017; Festa, 2018; Kubu et al., 2018; Schaefer et al., 2024; Scotti-Degnan et al., 2024)
 Embedded: Interdisciplinary care <u>within</u> clinic context (Bernat et al., 2024; Mietchen et al., 2021; Tannahill Glen et al., 2019; Turner et al. Wolfe et al., 2022)



Neuropsychology and Interdisciplinary Care

Advantages of Embedded Care

• Care continuity: More frequent follow up times

• Direct check ins

Emerging concerns
 Ensure linkage to supports
 Appropriate referrals

• Improve efficiency of care

- Reduce waitlists
 Brief screening/triage methods to determine care (Bernat et al., 2024; Hardy et al., 2017; Mietchen et al., 2021; Wolfe et al., 2022)



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Interdisciplinary Clinic Care, cont.

NCH Myelomeningocele Clinic • SBA Clinical Care Partner

- Large patient cohort
- High retention rate of patients (>90%)

• Lifespan clinic

Comprehensive interdisciplinary team





Interdisciplinary Clinic Care, cont.

Role of Neuropsychology

Staffed by Neuropsychology fellow

- See all patients (4 to 18 years)
- Two types of consultation visits
 Annual psychosocial check ins (typically 20-30 min)
 Focused consult (time varies based on reason)

• Billing: H&B codes (96167, 96168)













Rationale

Broader care needs





Independence Skill Assessment, cont.

- Need identified: No systematic screening for independence skills for youth with SB
- Quality Improvement methodology (Backhouse & Ogunlayi, 2020)
 - Identify gap in care Use of data driven system change to improve patient experience and
 - outcomes
 - Introduce incremental and iterative change Assess intervention effectiveness over time



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Independence Skill Assessment, cont.

Kennedy Krieger Independence Scales – Spina Bifida (KKIS-SB) (Jacobson et al., 2013)

• Parent report

- Normed against other individuals with SB
- Two factor scale

Prospective Memory
Initiation of Routine

Items explore parent perception of youth ability to handle typical and SB specific care tasks



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KKIS-SB



Independence Skill Assessment, cont.

- Part of annual Neuropsychology assessment
 Interview with parent/caregiver and patient
 Independence with medical cares
 Activities of daily living (ADLs) adaptive skills
 Instrumental ADLs managing money, transportation, meal prep, laundry)
 School/Vocational plans
- KKIS-SB iPad administration
 KKIS-SB scored and feedback shared with family during consult visit
- Important to consider cultural context What are typical expectations for the family? Culture?
 What are family goals? What does the patient want to achieve?



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- January 2021 April 2024
 Q1 2021-Q2 2022: 60.7%
 Q3 2022: 92.7%
- KKIS –SB completion by insurance
 Lower rates of completion for public health insurance (81.6%) vs commercial insurance (92.2%) (p >.05)
- Most common reason for completion
 Clinic time constraint
 Family decline screen

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Independence Skill Assessment, cont.

- 134 KKIS administrations (100 unique administrations)
- KKIS-SB respondent: 77.4% mothers
- Predominantly White, Non-Hispanic / Latino
- No significant differences between KKIS completion and non-completion groups

Age					
Gender					
			66.1%		
Race					
			87.5%		
or African American					
Other Race					
		101	-		
Ethnicity		7	-	-	
Hispanic/Latino	12.5%	-	1		
n Hispanic/Latino	17.1%		(F		
Payor			Er.		
Medicaid	20.9%		1	A	
Commercial	13.4%		Ba - C	5	
	 	- 1	120		

Independence Skill Assessment, cont.



- Majority of individuals with SB performing at or above age expectations
- Notable subset of individuals who are below age expectations
- Potential for referral for interventions / future supports

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Independence Skill Assessment, cont.

Limitations & Future Considerations

- KKIS currently administered to only English-speaking families
 Not available in other languages
- Rely on verbal interview for non-English speaking families
- Not administering to adults
- Considering developmental context
 - What does independence look like at 12 vs 17?
 - Earlier developmental time frames to teach independence?





Case Study (L): 14 yo multicultural female Image: Study (L): 14 yo multicultural fema

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- Ambulatory
 Does not like to wear AFOs
 Can cath independently
- Takes a long time to complete
 Bowel routine with parent assistance
- Low motivation for physical therapy exercises



 Social and friendly; Experiences bullying and teasing at school
 Low social awareness - impulsive behaviors, weak boundaries and easily believes others giving personal information strangers



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Case Study, cont. (L)

• Based on 2021 neuropsychological evaluation, recommendations for treatment provider:

- Chunk information
- Reduce memory demand
- Use visuals
- Offer short breaks during therapy sessions
- Give prompts to help remember information
- Use teach back strategies
- Teach goal setting strategies (break into smaller steps)
- Tools to help with self-monitoring and timing task completion





Final Thoughts

- Embedded neuropsychology can serve a unique role for continuity of care and supporting independence skill assessment
- Potential for neuropsychologically informed interventions
 Integrate neurocognitive profiles to inform recommendations
- Provide education around expectations
 TOPS, C-READY, CO-OP

Collaborate with interdisciplinary teams to provide highest level of

• Flexible application of specialty skillset



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Disclosures

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Agenda Items

1. Neuropsychology's Role in Transition Programming

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- 2. Understanding the Need for a Transition Program
- 3. Program Design and Framework
- 4. Key Components of the Transition Program
- 5. Implementation Strategies
- 6. Measuring Success and Outcomes
- 7. Improving Existing Programs
- 8. Research and Best Practices

Neuropsychology's **Role in Transition** Programming

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Pediatric neuropsychologists are uniquely suited to lead transition-to-adulthood programs at pediatric hospitals for several reasons:

- Expertise in Cognitive and Functional Capacities
- Addressing Psychosocial Barriers
 Family-Centered and Multidisciplinary Approach
- Holistic Understanding of Developmental Transitions
 Promoting Independence and Responsibility

By leveraging their expertise in these areas, pediatric neuropsychologists can play a pivotal role in developing and leading transition-to-adulthood programs that support the unique needs of young patients at pediatric hospitals.

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Understanding the Need for a Transition Program



Challenges Faced by Pediatric Patients Transitioning to Adult Care

Health Literacy Gaps Many policitric patients lack the necessary health literacy to navigate adult healthcare systems effectively, leading to confusion and potential miscommunication. For example, they may be expected to be familiar with their medical condition, medications, and treatments.

Urfamiliarity with Adult Care Transitioning pacliatric patients often struggle with the unfamiliarity of adult healthcare systems, which can create barriers to accessing needed services. Adult health care systems are byically much more hands-oft than pediatric systems, which can be streadult of patients and families nev to adult care.

Anxiety About New Providers The anxiety of meeting new healthcare providers can hinder pediatric patients' willingeness to engage in their own health management during the transition. In addition, it may be difficult to find medical providers for patients transitioning to addithcod, especially if they have complex medical conditions.

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Importance of **Continuous Care**

Health Maintenance Continuous care is essential for pediatric patients to ensure their overall health and wellbeing is consistently monitored and maintained.

Transition of Care

Disruptions in care during patient transitions can negatively impact health outcomes, leading to complications and increased hospital visits.

ing Hospitalizations Effective continuous care strategies can significantly reduce unne hospitalizations and promote better health outcomes for children. ssary







Current Gaps in

the System

Insufficient Communication Insufficient Communication Lack of effective communication between care teams leads to misunderstandings and inadequate patient care during transitions.

Lack of Transition Programs The absence of structured transition programs contribu to inconsistent patient outcomes and fragmented care experiences for patients.



In a nutshell...

Transition to adulthood is stressful for most young people and even more so when there is a chronic illness to contend with.

- Hurdles to transition often include: • Understanding and communicating about their medical condition
- Managing medical appointments

Transportation to medical appointments
 Managing medications

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Laying the Groundwork

Identify your institute's policies and procedures for facilitating transitions.

- Identify systems for monitoring patients' progress through the transition process.
- Evaluate patients' readiness for transitioning to adult care.
- Develop individualized plans for the patient's future.
- Identify adult providers to ensure a smooth and coordinated transfer of care.
- Establish a system for monitoring patients' progress and providing ongoing support following transition.

UNC Chapel Hill Behavioral Health Springboard at the School of Social Work





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Creating a Patient-Centered **Care Plan**



Understanding Individual Needs Considering the unique needs of each pediatric patient is crucial for creating effective care plans that promote better outcomes.



Collaboration with Families nvolving families in the care plan process strengthens support systems and ensures that the patient's preferences are honored.

Don't rush it!

Most of my patients are not ready for transition at the same time as their neurotypical peers. • But also, start early.



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Educational Resources for Patients and Families

Empowering Patients Educational resources empower patients by providing essential information that helps them understand their healthcare options.

Family Involvement Involving families in the educational process ensures they are equipped to support the patient's transition to adult care.

Navigating Adult Care Understanding the transition process is crucial for patients and families to effectively navigate adult care systems.



Skills Training for Independent Living

Importance of Skills Training Skills training is crucial for empowering individuals to manage their own lives and health effectively.

Self-Management Techniques Teaching self-management techniques helps individuals to take control of their health and make informed decisions.

Preparation for Independence Effective skills training prepares patients for the challenges of independe living and enhances their confidence.

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Mental Health and Emotional Support

Importance of Mental Health Mental health plays a vital role in managing transitions effectively and maintaining overall well-being.

Access to Counseling Services Access to counseling services can provide essential support for indi coping with changes during transitions.

Coping with Changes Emotional support helps individuals develop coping strategies for t challenges they face during transitions.



Pilot Program and Feedback Mechanisms



Program Refinement Using feedback to refine the program allows for adjustments that improve overall effectiveness and user satisfaction.

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Importance of Staff Training Training staff is essential to ensure they are well-equipped to handle the complexities of pediatric patient care.



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Integrating Technology and Innovative Tools

ng Transition Pro Utilizing technology can significantly improve the transition process for patients, ensuring smoother experiences.

Resource Accessibility Innovative tools can provide essential resources, helping patients and families navigate their healthcare journey effectively.

Support for Patients and Families Leveraging technology ensures ongoing support for both patients and their families throughout their healthcare experience.

Gathering Data, Setting Goals



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Developing KPIs

- 1. Understand Your Strategic Goals and Critical Success Areas
- Example: Transition outcomes
- 2. Identify Key Metrics and Processes
- Example: Patient satisfaction with transition process
- 3. Define KPIs
- Example: Number of transition patients successfully moved to adult provider's care in the last year
- 4. Involve Stakeholders
- Example: Include medical team, family, and patient

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Patient and Family Satisfaction Surveys

Purpose of Surveys Surveys are designed to colli informing healthcare improv

Importance of Feedback Feedback from patients and families is crucial for identifying areas of improvement in the transition program.

tinuous Improvement zing survey results is essential for ongoing enhance satisfaction. ents to patient care

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Long-Term Tracking and Follow-Up

Patient Support Continuity Long-term tracking helps maintain support for patients transitioning to adult care, ensuring their ongoing health needs are met.

Importance of Follow-Up Regular follow-ups are crucial for monitoring patient progress and making necessary adjustments to their care plans.

Transition to Adult Care Effective tracking ensures a smooth transition from pediatric to adult care, minimizing disruptions in patient support.

Improving Existing Programs

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Key Driver Diagram (KDD)

Identifying Key Factors

- Setting Clear Goals
- Developing Strategies
- Monitoring Progress
 Collaborative Approach
- https://www.ihi.org/sites/default/files/QfToolkit_DriverDiagram.pdf
 https://testingchange.com/2020/07/22/how-to-use-key-driver-diagrams/





Research and Best Practices

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Successful Transition Programs: What Does Research Tell Us?

- Education and Skill Building
- Continuity of Care
- Patient-Centered Approach
 Family Involvement
- Family involvement
- Interdisciplinary CollaborationMonitoring and Evaluation
- Tionitoring and Evaluation

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Lessons Learned and Improvements

Avoiding Common Pitfalls

Lack of preparedness
Lack of seamless care
Limited access to specialists
Poor communication



Adapting Best Practices to Our Hospital's Context

Understanding Best Practices

Foster Self-advocacy
Promote independence
Comprehensive planning

Tailoring to Pediatric Needs It's crucial to customize these practices to ensure they align with the specific needs of our pediatric patients.

Following-up Creating opportunities for check-ins to manage hurdles that arise during the transition process is key to success.

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Importance of Transition Prog

Careful Planning Collaborati Healthcare Continuous Evalu

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Helpful links

Got Transition® Tools https://nhpcc.org/wp-content/uploads/NHPCC-National-QI-Project-Transition-Resources_June-2024-Load

Primary Care Provider Toolkit https://www.massgeneral.org/assets/mgh/pdf/heart-center/primary-care-provider-toolkit-for-supporting-transition-of-youth-from-pediatric-to-adult-health-care.pdf

Quality Indicators for Youth Transitioning to Adult Care onina-to

University of North Carolina at Chapel Hill Complex MH and IDD

Thank you!

Questions?