2024
CHILD NEUROLOGY SOCIETY
53rd ANNUAL MEETING
Nov. 11-14, 2024 • San Diego, CA

Epilepsy & **N**eurology **T**ransition **R**esources for **Y**outh **T**o **R**eady **A**dult **C**are: **ENTRY TRAC**

Preparing for Transition of Care

CNF Symposium: Caring for Children with Medical Complexity

Monday, November 11, 2024

Ahmed Abdelmoity, MD, MBA, MS, FAAP, FAES
J.B. Le Pichon, MD, PhD, FAAP
Division of Neurology University of Missouri at Kansas City

Disclosures

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- Dr. Le Pichon does ad hoc medical expertise.
- Dr. Abdelmoity: Speaker Bureau:
  - Livanova Inc.
  - Jazz Pharmacutical Inc.
  - UCB Inc.
  - Nurelis Inc.

Current State/Needs Assessment

- Annually, 1.1 million children with epilepsy become adults [1,2].
- Adolescence, an important stage for physical and psychological development.
- Young persons with epilepsy (YPE) often have extra difficulties such as social stigma, mental health and neurodevelopmental issues, isolation, and perceived lack of independence [3–5].
- Even in pharmacoresponsive epilepsy syndromes associated with intelligence quotients (IQ) within the normal range [6,7].
- Modifiable risk factors during adolescence which influence psychosocial outcome in adulthood are: high seizure frequency, unsupportive and unstable family environment, and polypharmacy [7,8].
- It is, therefore, important that YPE receive optimal care during adolescence and are adequately prepared for the subsequent transition to adult care [9].

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[2] WHO. 2022 [Available from: https://population.un.org/wpp/DataQuery/.
[3] Healy SA, Fantaneanu TA, Whiting S. The importance of mental health in improving quality of life in transition-aged patients with epilepsy. Epilepsy Behav 2020;112:107324.
[4] MacLeod JS, Austin JK. Stigma in the lives of adolescents with epilepsy: a review of the literature. Epilepsy Behav 2003;4(2):112–7.
[5] Geerlings RPJ, Gotmer-Welschen LMC, Machielse JEM, de Louw AJA, Aldenkamp AP. Failed transition to independence in young adults with epilepsy: The role of loneliness. Seizure 2019;69:207–12.
[6] Nickels K. Seizure and Psychosocial Outcomes of Childhood and Juvenile Onset Generalized Epilepsies: Wolf in Sheep's Clothing, or Well-Dressed Wolf? Epilepsy Curr 2015;15(3):114–7.
[7] Valova V, Kochen A, Werry B, John R, Prager C, Schmeder J, et al. Early onset, long illness duration, epilepsy type, and polypharmacy have an adverse effect on psychosocial outcome in children with epilepsy. Neuropediatrics 2020;51(2): 164–9.
[8] Geerlings RP, Aldenkamp AP, Gotmer-Welschen LM, de With PH, Zinger S, van Stas AL, et al. Developing from child to adult: risk factors for poor psychosocial outcome in adolescents and young adults with epilepsy. Epilepsy Behav 2015;51: 182–90.
[9] Dewinsky O. Transition to adult care for children with epilepsy–a call for action.

YES of Transition Age

CMKC Measures	2019-2021	2022-2023
Eligible for Discussion	789	626
Completed Readiness Survey	392 (50%)	342 (55%)
Documented Discussions	116 (15%)	149 (24%)
Orders for Transition to Adult Care	19	11
Missed Discussion Opportunities	673 (85%)	477 (76%)
Paired Readiness Assessment with Transition Discussion	88 (11.15%)	119 (19.01%)

Gender	CMKC YES	CMKC Neuro
Total Population of CSHCN	1,750	**20, 024**
Female	836 (47.8%)	10, 942 (54.6%)
Male	913 (52.2%)	9,075 (45.3%)
Unknown	1	7 (0.1%)

Insurance/ Economic Status	CMKC YES	CMKC Neuro
Uninsured Children	52 (3%)	373
Public Insurance	767 (42.8%)	9,139
Private Insurance	931 (53.2%)	10,512

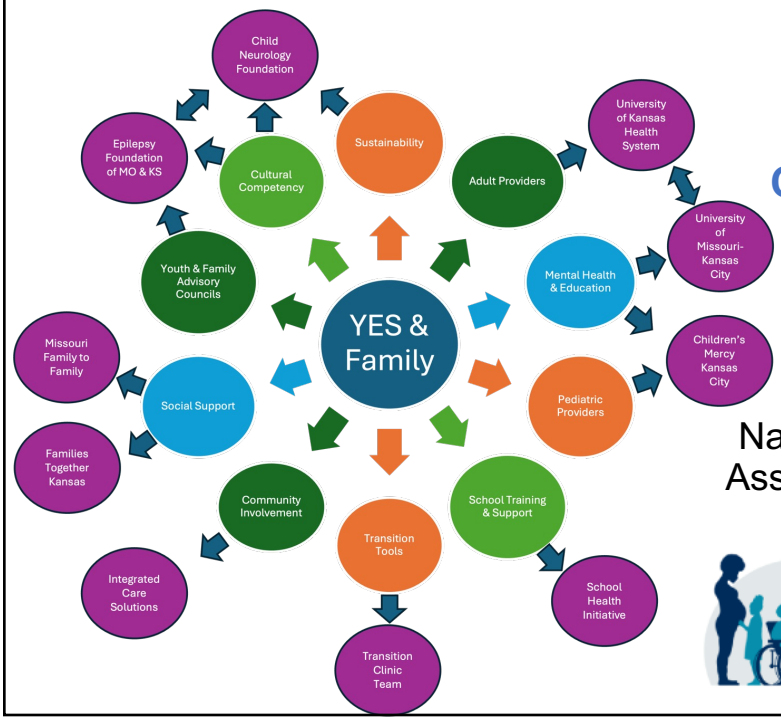
Age and Race/Ethnicity	CMKC YES	CMKC Neuro
YES 13-21	**1,750**	4064
White	1,244	14,469
Black	184	1,595
American Indian/Alaskan Native	3	76
Asian/ Native Hawaiian/Other Pacific Islander	32	315
Multiple races	98	1,321
Hispanic/Latino	161	1,565
Other	12	308
Declined	10	265
Unknown	6	110
Language other than English	72 (4.1%)	874 (4.3%)

Sources:
https://www.childhealthdata.org/browse/survey/results?q=10025&r=18&r2=27&q=1076, https://www.childhealthdata.org/browse/survey/results?q=10025&r=18&r2=27&q=1076, https://www.kff.org/other/state-indicator/children-by-raceethnicity/?dataView=0&currentTimeframe=0&selectedRows=%7B%22states%22:%7B%22kansas%22:%7B%7D,%22missouri%22:%7B%7D%7D%7D&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D
https://www.countyhealthrankings.org/explore-health-rankings/kansas?year=2023
https://www.kff.org/other/state-indicator/children-018/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D

Partners in Transition



- CMKC:
  - Partnership with School Health Initiative
    - ADAM Heart Safe Schools
    - School Nurse Advisory Council (SNAC): Represent regional school districts, ~130K students
  - Transition of Care Team: established in 2015, hospital wide initiative.
  - Integrated Care Solutions (ICS): Facilitate relations with families and integrated care across disciplines.
- Child Neurology Foundation
- Epilepsy Foundation of Missouri and Kansas: Youth Advisory and Parent/Family Advisory Councils.
- Families Together, Inc.
  - Kansas
  - Missouri
- University of Kansas Medical Center
- University of Missouri Kansas City



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Create a framework with existing structures to support the child and their family

National Coordinating Center: Association of Maternal & Child Health Programs

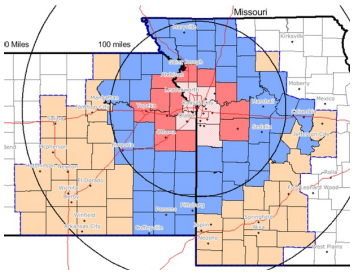


AMCHP
ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

Set Clear and Achievable Goals With an Emphasis on Sustainability

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- Educate (Year 1)
  - Lanscape analysis
  - Establish networks: YAC & PFAC
  - Define core competencies for patients, families, and providers
  - Develop/implement educational resources
  - Develop toolkits that will support transition of care.
- Implement (Years 2-5)
  - Reinforce support networks
  - Implement transition in clinic starting at 13
  - Warm handoff
  - Track and monitor
- Sustain (Years 3-5)
  - Measure outcomes and set evolving targets
  - Maximize productivity
  - Minimize health disparities
  - Increase family and provider satisfaction
  - Adopt sustainable index metrics



Aim 1: EDUCATE: Collaboratively improve transition of care for YES, families, providers, and community engagement across all life domains through the implementation of a comprehensive educational program.

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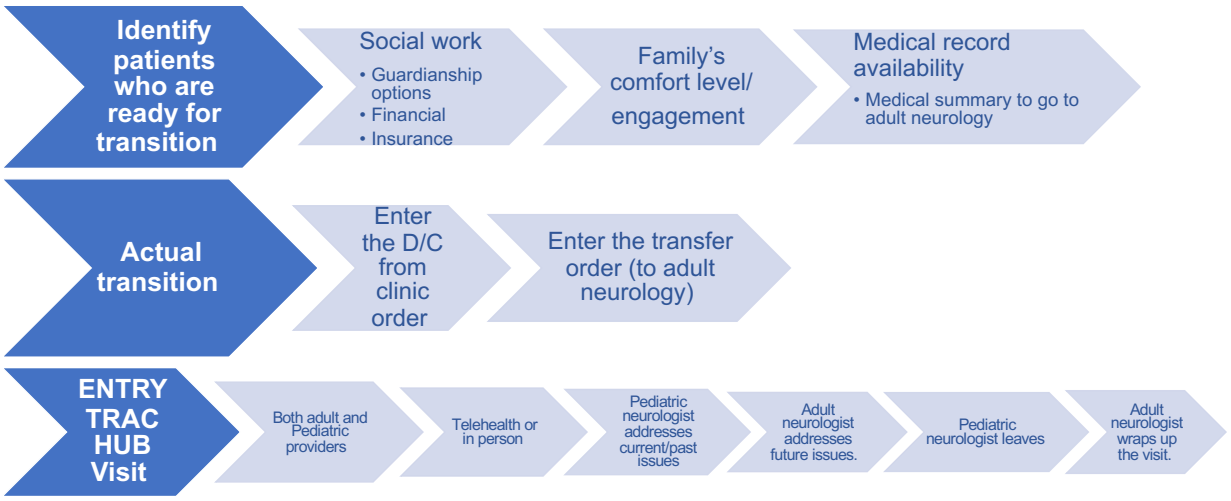
1. Analyze existing processes and barriers to TOC from the perspective of all key stakeholders by conducting an extensive landscape analysis.
2. Establish a YAC and PFAC to connect families to each other, foster peer support and information sharing.
3. Identify and define critical competencies for both YES and their parents, as well as key competencies for healthcare providers, to facilitate and manage the successful TOC.
4. Develop and implement educational resources for YES for TOC.
5. Develop an inclusive educational toolkit that equips community stakeholders to support successful TOC.

Aim 2: IMPLEMENT: Implement the ENTRY TRAC framework to increase the quality of life for YES and their families in all life domains by 50% within five years.

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1. Implement "warm handoff" visits between pediatric and adult providers for all patients ready for TOC.
2. Track and monitor all YES using a transition readiness assessment tool starting at 13 years old.
3. Recognize and respond effectively to mental health concerns in YES and their families, facilitating timely and appropriate referrals and interventions.
4. Establish formal partnerships with key community partners to offer community resources for YES and their families to support transition to adulthood.

Transition process



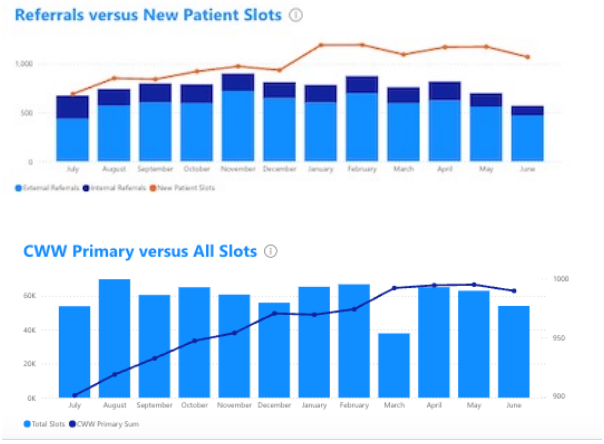
Aim 3: SUSTAIN: Optimize the long-term sustainability of transition of care for YES and their families by demonstrating improvements in population health outcomes, patient experience, and cost-effectiveness.

1	2	3	4	5	6
Increase YES and family self-efficacy scores on a transition readiness scale by 25% each year through educational resources, patient support groups and individualized goal planning.	Measure efficacy of treatment monitoring medication adherence, seizure frequency and severity	Increase patient satisfaction scores for transition of care visits by 10% within six months.	Reduce health disparities by 20% within the next five years for YES and their families, ensuring equitable access to healthcare services and resources regardless of socioeconomic status or geographic location.	Maximize clinic productivity by optimizing Relative Value Units (RVUs) and the overall effectiveness of the transition clinic.	Develop a comprehensive index of metrics, incorporating transition-related drivers to facilitate seamless transferability of the framework to any healthcare system.

Access Index

Measure	Desired Direction	Current Performance	Goal Thresholds		
			Baseline	Target	Stretch
NewAppt_14	UP	77%	75%	76%	77%
Prod-Physician	UP	82	37	50	55
Prod-Staff	DOWN	1.7	1.4	1.25	1.06
Timeliness	UP	60%	57%	59%	60%
Unfilled_Slots	DOWN	13%	10%	15%	13%





Questions? Comments?

