16th Annual Health Care Transition Research Consortium Research Symposium

October 9, 2024

Agenda

7:15 AM	**Registration/Breakfast**
8:00 AM	**Opening Remarks** *Cecily L. Betz, PhD, RN, FAAN; Megumi J. Okumura, MD, MAS* *HCTRC Research Symposium Co-Chairs* *Albert C. Hergneroeder, MD* *Baylor College of Medicine, Texas Children's Hospital*
8:20 AM	**Keynote Presentation: Transitional care- a bridge or a goal? Lessons from Europe and UK** *Swaran Singh, MBBS, MD, FRC, Psych, DM*
9:00 AM	**Platform Session 1: Continuous Quality Improvement/Self-Management** Moderator: *Nancy Cheak-Zamora, PhD*
Abstract listed on page 9	**Platform #1:** Institutional Financial Incentive Supporting Provider Participation in a Pediatric to Adult Transition Program. *Stephanie Pratt MSW, LMSW, Michelle Bozarth, Timothy E. Corden MD*
Abstract listed on pages 9-10	**Platform #2:** A Quality Improvement Initiative to Simplify Transition to Adult Neurology Care *Madeline Chiujdea, BA, CPHQ, CLSSGB; Natalie Mann, BSE; Mary Heins, MSN, RN, CPN; Julia Laurino, BA; Susan Shanske, LICSW; Tuba Rashid-Khan, MD; Sarah Spence, MD, PhD; Regina Laine, MSN, PNP-BC, CNRN*
Abstract listed on pages 10-11	**Platform #3:** Building Bridges: Development and Implementation of a Transition to Adult Care Program for Youth with Multi-Morbidity at a Canadian Children's Hospital *Sara Santos, BKin, MHI; Eryn Vandepoele, BScN, MHSc, MN; Julia Orkin, MD, MSc, FRCPC; Eyal Cohen, MD, MSc, FRCPC; Megan Henze, MScOT; Jessica Teicher, MD); Kimberly Colapinto, BScN, MN; Robyn Lippett, MSW); Susan Miranda, BScN; Karla Wentzel, BScN, MN, NP; Joanna Soscia, BScN, MEd, MN; Tomisin John, BScN, MPH; Darryl Yates, RN, MHSc, CHE; Brooke Allemang, MSW, PhD; Dara Abells, MD; Donna Thomson; Alène Toulany, MD, MSc, FRCPC*
Abstract listed on page 11	**Platform #4:** Primary Care Transition Assistance Program for Adults with Childhood Onset Medical Conditions: A Retrospective Evaluation of Program Effectiveness *Patrick Burke, MD, MHCDS; Raul Ayala, MD, MHCM; Tracy Gong, RN, BSN*
10:00 AM	**Break**

10:15 AM	**Poster Session 1**
Abstract listed on pages 11-12	**Poster #1** Adult Retention Rates within Pediatric Specialty Care Practices: Developing Models using Historical Data *Adam Greenberg MSN, CRNP; Evan Fieldston MD, MSHP; Dava Szalda MD, MSHP*
Abstract listed on pages 12-13	**Poster #2** Differences in Sub-specialty Care Utilization Before and After Transfer to Adult Health Care among Autistic Youth *Laura Hart MD, MPH: Joseph Sirrianni PhD; Steve Rust PhD; Chris Hanks, MD*
Abstract listed on page 13	**Poster #3** Pilot testing of PREPARE for Autistic Adults: An Adult Autism Training for Resident Physicians Designed with Autistic Adults and Family Members *Brittany Hand, PhD; Daniel Gilmore, MS, RDN; J Madison Hyer, MS; Holden DeVassie, BS; Deondray Radford; Lisa Juckett, PhD; Christopher Hanks, MD; Susan Havercamp, PhD; Daniel Coury, MD*
Abstract listed on pages 13-14	**Poster #4** A System-Wide Healthcare Transition Consult Service: Reflections After Our First Year *Chelsea Ghena, DNP, APRN, CPNP-PC; Carolyn Reynolds, MSN, APRN; Aileen Casas; Camille Reay; Stephanie Sund, MSN, RN, HWC*
Abstract listed on pages 14-15	**Poster #5** Parents report High Likelihood of Recommending a Transitional Readiness Assessment (TRA) *Shannon Anderson, LOT; Jonathan Cohen, MOT, OTR/L, SIPT; Jennifer Helshoj, MOT*
Abstract listed on page 15	**Poster #6** Comparing Pediatric Care Transition Risk Predictors: BLSS and the TRxANSITION Index *Reny Partain, LCSW, MPH, Radha Nagarajan, PhD, Wendy Gray, PhD, Erin Benekos, FNP-C, Kenneth Grant, MD, Steven Martel, MD, Michael Weiss, DO*
Abstract listed on pages 15-16	**Poster #7** A Machine Learning Approach for Predicting Care Transition Risk *Reny Partain, LCSW, MPH; Radha Nagarajan, PhD; Wendy Gray, PhD; Erin Benekos, FNP-C; Kenneth Grant, MD; Steven Martel, MD; Michael Weiss, DO*
Abstract listed on pages 16-17	**Poster #8** Partnering Together to Elevate Health Care Transition in Special Education Transition Planning *Samhita Ilango, MSPH; Peggy McManus, MHS; Tim Markle, MA; Wendy Berghorst, MS, RN, PHN; Linda Starnes*
Abstract listed on page 17	**Poster #9** Supporting Outpatient Transition Preparation Through an Inpatient Med-Peds Hospital Medicine Consult Service *Jennifer Disabato, DNP, CPNP-PC, AC; W. Aaron Manning, MD; William C. Anderson III, MD*
Abstract listed on pages 17-18	**Poster #10** Screen and Intervene: An Approach to Health Care Transition (HCT) Utilizing Inpatient Care Coordinators *Luke Coffman BS; Ashley McCool MHA; Tanika Middleton RN, BSN, CCM; Emily Nations Bufkin, MD*
Abstract listed on pages 18-19	**Poster #11** Co-Developing a Terms of Reference for Patient Engagement in Transition Research

	Sarah Munce, MSc, PhD; Tomisin John, RN, MPH; Dorothy Luong, MSc; Sarah Mooney, Lisa Stromquist, Alene Toulany, MD, MSc.
Abstract listed on pages 19-20	**Poster #12** Patient, caregiver and other knowledge user engagement in consensus-building healthcare initiatives *Sarah Munce, MSc, PhD; Elliott Wong; Dorothy Luong, MSc; Justin Rao; Jessie Cunningham; Katherine Bailey, BSc; Tomisin John, RN, MPH; Claire E.H. Barber, MD, PhD; Michelle Batthish, MD, MSc; Kyle Chambers; Kristin Cleverley, RN, PhD; Marilyn Crabtree, MD; Sanober Diaz, MHSc; Gina Dimitropoulos, MSW, PhD; Jan Willem Gorter, MD, PhD; Danijela Grahovac; Ruth Grimes, MD; Beverly Guttman, MSW, RSW; Michèle L. Hébert, PhD, OT; Megan Henze, OT; Amanda Higgins; Dmitry Khodyakov, PhD, MA; Elaine Li; Lisha Lo. MPH; Laura MacGregor, PhD, MA, MSc, BScOT; Sarah Mooney; Samadhi Mora Severino, MA, HBA; Geetha Mukerji, MD, MSc; Melanie Penner, MD, MSc; Jacklynn Pidduck, MSW; Rayzel Shulman, MD, PhD; Lisa Stromquist; Patricia Trbovich, PhD; Michelle Wan; Laura Williams; Darryl Yates, RN, MHSc; Alène Toulany, MD, MSc*
Abstract listed on page 20	**Poster #13** Protocol for a Consensus-Building Multistakeholder Initiative to Establish Quality Indicators for Transition to Adult Care *Alene Toulany, MD, MSc; Katherine Bailey, BSc; Claire Barber, MD, PhD; Michelle Batthish, MD, MSc; Kristin Cleverley, RN, PhD; Gina Dimitropoulos, MSW, PhD; Jan Willem Gorter, MD, PhD; Danijela Grahovac, Ruth Grimes, MD; Beverly Guttman, MSW, RSW; Michèle L. Hébert , PhD, OT; Tomisin John, RN, MPH; Dmitry Khodyakov, PhD, MA; Lisha Lo, MPH; Dorothy Luong, MSc; Laura MacGregor, PhD, MA, MSc, BScOT; Sarah Mooney; Geetha Mukerji, MD, MSc; Jacklynn Pidduck, MSW; Rayzel Shulman, MD, PhD; Lisa Stromquist, Patricia Trbovich, PhD; Sarah Munce, MSc, PhD*
Abstract listed on page 20-21	**Poster #14** Integrating primary care and transition support into survivorship care *Emma Wilcox, BA; Roma Bhuta, DO, MPH; Amanda Bellamy, MSN, RN, FNP-C; Jennifer Welch, MD; Suzanne McLaughlin, MD, MSc*
Abstract listed on pages 21- 22	**Poster #15** Self-Perceived Importance and Confidence Scoring for Adolescents and Young Adults Transitioning to Adult Care *Lisa Lestishock DNP, RN, CPNP-PC; Carrie Cuomo DNP, RN, CPNP-PC/AC; Teresa Hickam MSW, LSCSW, CCM; Tisa Johnson-Hooper MD, FAAP; Michele Maddux PhD; Evan Muzzall PhD; Margaret McManus, MHS; Patience White, MD, MA FAAP*
Abstract listed on page 22	**Poster #16** Understanding the needs of youth living with spina bifida during transition to adult care: a quality improvement initiative *Laurence Veilleux, MSc, NP, RN; Kimberly Anganu; Nadine Korah MDCM, MSc, FRCPC; Sara Long-Gagné MD, MSc, FRCPC*
Abstract listed on pages 22-23	**Poster #17** Adaptation of Patient XLH Toolkit into Interactive Mobile Website that Incorporates Six Core Elements of Health Care Transition (HCT) *Amber Parson, BA; Carolyn M. Macica, MS, PhD*
Abstract listed on pages 23-24	**Poster #18** Inclusion of Individuals with Intellectual and Developmental Disabilities into Research: A Process for Informed Consent *Caren Steinway, MPH, LMSW; Jason Woodward, MD, MS; Charmaine Wright, MD, MSHP; Sophia Jan, MD, MSHP*

Abstract listed on page 24	**Poster #19** Preliminary Findings of a Peer Navigator Health Care Transition Planning Employment Pathway Program *Cecily L. Betz, PhD, RN, FAAN; Christine Mirzaian, MD, MPH, IBCLC; Rowan Smith, MPH*
Abstract listed on pages 24-25	**Poster #20** Modifying the Transition Readiness Assessment to better meet the needs of families of Children with Medical Complexity. *Stephanie Pratt MSW, LMSW; Leslee Throckmorton Belzer PhD; Emily J Goodwin MD; Timothy E. Corden MD, MS*
Abstract listed on pages 25-26	**Poster #21** Comprehensive Assessment of Lived Experience and Burnout in Caregivers of Transitioning Young Adults with Childhood Medical Complexity in Alabama: A Mixed Methods Approach *Raksha Ramdas, BS; Heather Johnson, DrPH, MPH, Carlie Somerville, MD, Madeline Eckenrode, MD, Betsy Hopson, MSHA*
Abstract listed on page 26	**Poster #22** A Multidisciplinary Clinic for Adults with Medical Complexity: Understanding the Challenges of Hospital Courses for Patients Navigating Healthcare Transition *Margaret Rosenthal, BS; Madeline Eckenrode, MD; Betsy Hopson, MSHA; Carlie Stein Somerville, MD*
Abstract listed on page 27	**Poster #23** A Contextual Analysis of a Swiss Model of Transition from Pediatric to Adult Rheumatology as Part of the Heroes (Rheumatology Transition for Young People in Switzerland) Study *Séverine Soiron, MSN; Sandra Staudacher, PhD; Natalie Tarr, PhD; Marlis Matter, BSN; Andreas Wörner, MD; Thomas Daikeler, MD; Mary-Louise Daly, Msc; Lut Berben, PhD, RN*
11:45 AM	**Lunch**
12:15 PM	**Breakout Sessions**
Abstract listed on pages 27-28	**Breakout Session #1** Policy and Program Recommendations to Reduce Disruptions and Disparities Among Youth with Disabilities Aging Out of Public Programs (Moderator: Lynn Davidson, MD, FAAP) *Margaret McManus, MHS; Samhita Ilango, MSPH; Annie Schmidt, MPH; Patience White, MD, MA*
Abstract listed on pages 28-29	**Breakout Session #2** Using Project ECHO to Build a Statewide Health Care Transition Learning Collaborative (Moderator: Megumi Okumura, MD, MAS) *Rhonda Cady, PhD, RN; Tori Bahr, MD; Patience White, MD, MA, MACP, FAAP; Peggy McManus, MHS; Wendy Berghorst, MS, RN, PHN; Megan Lutz, MPH; Katie Stangl; Alyssa Green, LPCC; Maria Medina, MPH; Debbi Harris MS, MA, GCAS*
Abstract listed on page 29	**Breakout Session #3** Educating the Next Generation: How can you champion education in healthcare transition and the care of individuals with IDD at your institution? (Moderator: Jason Woodward, MD, MS) *Jordan Kemere, MD MS FACP; Priya Chandan MD, MPH, PhD; Elisha Acosta MD*
1:00 PM	**Platform Session 2: Health Care Transition Outcomes and Readiness Measures (Moderator: Thomas Davis, MD)**

Abstract listed on pages 29-30	**Platform #1** Challenges and Inequities Facing Youth and Young Adults with Disabilities Aging Out of Public Programs *Samhita Ilango, MSPH; Peggy McManus, MHS; Annie Schmidt, MPH; Patience White, MD, MA*
Abstract listed on page 30	**Platform #2** Utilizing Electronic Health Record Data to Improve Patient Follow-up in the Transition Medicine Clinic *Erin E Brown FNP, Robin Spidell, John Berens MD*
Abstract listed on page 31	**Platform #3** The Association Between Parental Nativity and the Use of Healthcare Transition Services for Youth with Intellectual and Developmental Disabilities *Catherine A. Harwood, MSSW PhD Student; Pei-Chiang Lee, MSW PhD Student; Sandra B. Vanegas, PhD,*
Abstract listed on page 31-32	**Platform #4** The Impact of a Patient Navigator on Readiness Assessment Scores in Youth Transitioning to Adult Health Care in Alberta *Megan Patton, MSc; Cassandra Chisholm, MBA; Zoya Punjwani, MPH; Andrew S. Mackie, MD; Scott Patten; Daniella San-Martin Feeney, MSc; Samantha J. Anthony, PhD, MSW; Gina Dimitropoulos, PhD, MSW; Susan Samuel, MD*
2:00 PM	**Poster Session 2**
Abstract listed on pages 32-33	**Poster #1** Assessing Healthcare Transition Readiness at a Multidisciplinary Neurodevelopmental Clinic in a Large County Hospital *Ruchita Iyer; Rishi Shah FACHE, Lauren Tardo, MD*
Abstract listed on page 33	**Poster #2** Mental Health Transition Practices in College Students with and without Previous Suicide Attempts: An Exploratory Analysis *Nani Kim, BSN, RN, PhD student, Cara C. Young, PhD, APRN, FNP-C, FAANP, FAAN, Susan Calloway, PhD, FNP-BC, PMHNP-BC, FAANP*
Abstract listed on pages 33-34	**Poster #3** Workshops to Support Transition-Age Patients Co-designed and Developed with Adolescent and Young Adult Advisory Council *Rachel Cuevas, BS, BA; Martha Mendoza Orozco, MPH; Emozino Ayetuoma, MPH; Brianna Capers, AA; Jesus Covarrubias; Soha Ghavami; Danissa Maroquin, MS; Monica Mejia; Adan Santiago; Asma Sodager, BS; Dalen Thomas, BA; Daron Wong; Courtney Porter, MPH, CPHQ*
Abstract listed on pages 34-35	**Poster #4** Massachusetts Statewide NDD Transition Summit 2023: Deepening Engagement with Stakeholders *Susan Shanske, MSW, BRIDGES; Lindsay MacAuley, MPH; Tuba Rashid Khan MD, MPH, Ed.M; Sarah Spence, MD, PhD*
Abstract listed on page 35	**Poster #5** Who Decides? Improving Documentation of Decision Makers for Adults in the Pediatric Setting *Salihah Hanson, LICSW; Susan Shanske, LICSW; Lindsey McMahon, MPH; Kristina Taylor, BSN, RN; Ahmet Uluer, DO, MPH*
Abstract listed on page 36	**Poster #6** Multidisciplinary Pilot Program to Transfer Young Adults with Enteral Tube Needs to Adult Care

	Ahmet Uluer, MD; Kristina Taylor, BSN, RN; Susan Shanske, MSW; Jennifer Lawlor, RN, BSN, CPN; Lori-Parker Hartigan, ND, RN, CPN; Tara McCarthy MS, RDN/LDN; Elizabeth Hait, MD MPH
Abstract listed on pages 36-37	**Poster #7** Assisting Teens and Young Adults Transition to Adulthood Through Short Educational Videos *Salihah Hanson, LISCW; Susan Shanske LISCW; Catherine Melnick; Nancy Easter LISCW; Alex Sullivan; Kristina Taylo RN; Colleen Huysman LISC; Ahmet Uluer, DO MPH*
Abstract listed on pages 37-38	**Poster #8** Management of the mental health needs of autistic adults: A description of a psychiatric and primary care collaborative approach *Kristin Cooper, MD, Christopher Hanks, MD, and Ashley Byrd, MD*
Abstract listed on page 38	**Poster #9** Qualitative Study Examining the Experiences of CHWs in the Management of Care Transitions for Emerging Adults with Sickle Cell Disease (COMETS) Trial *Brahadesh Sivakumar; Sadie Butcher; Caren Steinway, LMSW MPH; Tanisha Belton, DrPH; Symme Trachtenberg, MSW; Desiree Williford PhD; Kim Smith-Whitley, MD; Sophia Jan, MD MSHP*
Abstract listed on pages 38-39	**Poster #10** Community Health Worker and Mobile Health for Emerging Adults Transitioning Sickle Cell Disease Care (COMETS Trial): Patient-Reported Outcomes at 6 Months *Sophia Jan, MD, MSHP; Caren Steinway, MPH, LMSW; Tanisha Belton, MPH, DrPH; Justine Shults, PhD; Laura Bennett; Heather Griffis, MS, PhD; Banu Aygun, MD; Abena Appiah-Kubi, MD, MPH; Nataly Apollonsky, MD; Donna Boruchov, MD; Omar Niss, MD; Lisa Schwarz, PhD; Lori Crosby, PsyD; Lamia Barakat, PhD; Biree Andemariam, MD); David Rubin; Kim Smith-Whitley*
Abstract listed on pages 39-40	**Poster #11** Pre-Clinical Medical Students Piloting Transition *Elisha Acosta MD, Vaishnavi Sankar BS, and Jordan Kemere, MD, MS*
Abstract listed on page 40	**Poster #12** Healthcare Insights from a Neurodiverse Community Advisory Board *Ashley Smith; Kylie Cullinan, MD; Emily Nations Bufkin, MD*
Abstract listed on pages 40-41	**Poster #13** Predictors of the Transition from Pediatric to Adult Epilepsy Care *Jasmine Sondhi MD; Esraa Ali MBBS; Krishna Trivedi, MD; Stephanie DeCarvalho, DO; Traci M. Kazmerski, MD, MS: Laura Kirkpatrick, MD*
Abstract listed on page 41	**Poster #14** The Role of Social Work Leadership in Healthcare Transition Programs *Angela Berger, MSW; Terri Hickam, MSW, CCM; Reny Partain, MSW, MPH; Susan Shanske, MSW; Symme Trachtenberg, MSW*
Abstract listed on page 42	**Poster #15** Mixed-Methods Evaluation of the Clients of the Adolescent and Young Adult Health Care Transition Clinic *Hannah Chew BS; Kemberlee Bonnet MA; David Schlundt PhD; Nina Hill MD; Leslie Pierce MPH; Aima Ahonkhai MD, MPH; Neerav Desai MD*
Abstract listed on pages 42-43	**Poster #16** A Novel Healthcare Transition Structure for Adult Patients with Medical Complexity *Kathleen Irby, MD FAAP; Kira Watson, MD MPH FAAP*

Abstract listed on page 43	**Poster #17** *8 Years of Successful Transition: A Description of an Adult Clinic's Transition Program* *Cybele Ghossein, MD; Laura Nishi, DScPAS, PA-C; Lauren Suchy Marzinelli, LCSW, MPH*
Abstract listed on pages 43-44	**Poster #18** Family-Centered PCP-led Transition of Medically Complex Youth with Intellectual Delay to Adult Care: All Grown Up! *Charu J Sehgal, DO; Heather C Moore, MD; Elizondo, MSN, RN*
Abstract listed on pages 44-45	**Poster #19** Educating Aspiring Healthcare Providers to Enhance Healthcare Delivery for Patients with Disabilities *Jonathan Tolentino, MD, MS-HPE; Anjali Saxena, MD; Rochelle Baer, MSW, LCSW; Jairo Arana; Jenna Tatavitto; Brady Wallace; Esther Cine; Ashley Falcon, PhD, MPH*
Abstract listed on pages 45-46	**Poster #20** Interdisciplinary Education in Transition for Internal Medicine-Pediatrics Residents *Erin Tully, MD: Brittany Glassberg, MD; Dava Szalda, MD MSHP*
Abstract listed on page 46	**Poster #21** Transitioning Adolescents/Young Adults to Adult Primary Care: A Resident-led Quality Improvement Initiative *Erin Tully, MD; Kevin Ackerman, MD; Madeline Chandra, MD; Swati Goel, MD; Dava Szalda, MD MSHP*
Abstract listed on pages 46-47	**Poster #22** Systematic Review of Support System Interventions for Solid Organ Transplant Patients Transitioning from Pediatric to Adult Healthcare *Anji Zhu BSN, MPH; Karim. G. Mina MD, MPH, Shea. O. Herlihy MPH, Samad. Siddiqui MPH, Zexuan Yu MPH, Renata. W. Yen PhD, MPH*
Abstract listed on pages 47-48	**Poster #23** Higher Transition Readiness Scores Associated with Higher Emergency Department Visits in Adolescents and Emerging Adults *Zoya Punjwani, PhD, MPH; Cassandra Chisholm, MD(c), MMgmt, BSc; Megan Patton, MSc; Laurel Ryan, MFA; Daniella San Martin-Feeney, MSc; Andrew Mackie, MD, SM; Gina Dimitropoulos, PhD, MSW; Susan Samuel, MD MSc*
Abstract listed on page 48	**Poster #24** A Multi-Site Study of Transition Improvement in Primary Care for Youth and Young Adults with Epilepsy (CYE) *Peter Corcoran, PhD; Patience White, MD, MA; Peggy McManus, MHS*
3:30 PM	**Platform Session 3: Educational Perspectives, Innovations and Policy Implications (Moderator: Parag Shah, MD)**
Abstract listed on page 48-49	**Platform #1:** Do You Have What It Takes to Transition? Association of Coping Strategies and Social Support on Transition Readiness Among Young Adults with Sickle Cell Disease *Apoorva Iyengar, MD; Tisheya C. Ward, BA; Tanisha D. Belton, DrPh, MPH; Banu Aygun, MD; Abena Appiah-Kubi, MD, MPH; Nataly Apollonsky, MD; Donna Boruchov, MD; Biree Andemariam, MD; Omar Niss, MD; Lori E. Crosby, PsyD; Lisa Schwartz, PhD; Lamia P. Barakat, PhD; Jack Chen, MBS; Kim Smith-Whitley, MD; Sophia Jan, MD, MSHP; Caren Steinway, LMSW MPH*

Abstract listed on pages 49-50	**Platform #2:** Association of Disease Specific-Worry on Pain-Related Quality of Life in Young Adults with Sickle Cell Disease *Apoorva Iyengar, MD; Tisheya C. Ward, BA; Tanisha D. Belton, DrPh, MPH; Banu Aygun, MD; Abena Appiah-Kubi, MD, MPH; Nataly Apollonsky, MD; Donna Boruchov, MD; Biree Andemariam, MD; Omar Niss, MD; Lori E. Crosby, PsyD; Lisa Schwartz, PhD; Lamia P. Barakat, PhD; Jack Chen, MBS;* *Kim Smith-Whitley, MD; Sophia Jan, MD, MSHP; Caren Steinway, LMSW MPH*
Abstract listed on pages 50-51	**Platform #3***:* Enhancing Education in Primary Care for Youth and Adults with IDD through Project ECHO® *Ellen Fremion, MD; K. Jordan Kemere, MD; Nital Appelbaum, PhD*
Abstract listed on page 51	**Platform #4:** The Feasibility, Acceptability, and Efficacy of an Intervention (IPACT) to Improve Provider Behavior in Promoting Autonomy and Competence in Transition-Aged Youth *Jordyn Babla, BS; Constance M Wiemann, PhD; Blanca Sanchez-Fournier, BA; Beth H. Garland, PhD; Cortney Zimmerman, PhD; Marietta M. de Guzman, MD; Seema Walsh, MD; Kimberly Houck, MD; Mary Majumder, JD, PhD; Albert C. Hergenroeder, MD*
4:30 PM	**Wrap-Up** *Cecily L. Betz, PhD, RN, FAAN; Megumi J. Okumura, MD, MAS* *HCTRC Research Symposium Co-Chairs*

	HCTRC Research Symposium Abstracts
	Platform Session 1: Continuous Quality Improvement/Self-Management
Platform #1	Institutional Financial Incentive Supporting Provider Participation in a Pediatric to Adult Transition Program. *Stephanie Pratt MSW, LMSW; Michelle Bozarth; Timothy E. Corden MD* Background: The Physician Incentive Practice Plan at Mercy Children’s Hospital Kansas City (CMH) is a group model based on a guaranteed base salary plus incentives for various productivity elements. CMH recognizes the health value a smooth transition process brings children transitioning into young-adult care and that reimbursement for the process is limited. To increase provider participation across primary and subspecialty care clinics, a transition participation incentive was added to the CMH practice plan. CMH has a robust transition program infrastructure following the Got Transition model that includes dash boards showing completed transition readiness assessments and documented transition discussions for all eligible patient encounters. We examined how the program impacted transition activity over time. Methods: Transition to Adulthood was included as a metric in the practice plan through clinical incentives for each subspecialty and primary care in 2023. Division incentive payments were based on the percentage of completed transition readiness assessments paired with a documented transition discussion for eligible patients across three tiers: 10-24%; 25-49%; 50+%. Division participation and tier percentages were noted over time. Results: In FY 23, twelve divisions met transition criteria to participate in practice plan incentive with eligible patients, Tier percentages for all divisions Tier 1: 36%; Tier 2: 36%; Tier 3 28%. FY 24, fourteen divisions met transition criteria resulting in the Tier 1: 42%; Tier 2: 29%; Tier 3: 29%. Six divisions outcomes increased from FY 23 to FY 24. Conclusions: The incentive program model appears to be an effective approach to increasing participation in the transition process. Contact: Stephanie Pratt MSW; scpratt1@cmh.edu
Platform #2	A Quality Improvement Initiative to Simplify Transition to Adult Neurology Care *Madeline Chiujdea, BA, CPHQ, CLSSGB; Natalie Mann, BSE; Mary Heins, MSN, RN, CPN; Julia Laurino, BA; Susan Shanske, LICSW; Tuba Rashid-Khan, MD; Sarah Spence, MD, PhD; Regina Laine, MSN, PNP-BC, CNRN* Background: Transitioning patients from pediatric to adult healthcare is complex, particularly within Neurology. Many neurology patients remain in pediatric care far beyond childhood, creating access issues for pediatric patients. We describe a quality improvement initiative aimed at simplifying transition to improve the ratio of pediatric to adult patients in one Pediatric Neurology clinic within a large free standing children’s hospital. Methods: A multi-disciplinary Transition Task Force was developed in May 2022. Using quality improvement methodology, we iteratively designed interventions, including two pilots to increase transition planning and documentation of counseling. We developed two guidelines - one for transition to adult care and one for triage of new adult patients. We also provided centralized resources for both providers and patients. A dashboard was

	developed to monitor visit data over time and qualitative feedback is solicited on an ongoing basis to drive improvements. Results: Between October 2022 and March 2024, visits for patients aged ≥18 decreased from 15% to 13%, despite an overall increase in clinic volume. Application of the ICD-10 code Z-71.89: Encounter for pediatric-to-adult transition counseling increased. Transition planning increased significantly from 13% (N=30) pre-intervention to 61% (N=71) post-intervention (p>.00000), and 35% (N=43) of patients with documentation had transfer plans indicating that their next neurology visit would be with an adult provider. In April 2024, a department-wide rollout was initiated, and new SMART aims were developed. Conclusion: Creating infrastructure that simplifies transition is needed to engage pediatric neurology providers in transition efforts. Engaging nursing, administrative staff, and clinicians is necessary to create a culture of transition and using a quality improvement approach may be useful. Clearly written guidelines, consistent positive messaging about transition and clear goals from leadership are essential, as is ongoing feedback from frontline staff to address barriers with transition. Transitioning adults can improve access to specialty clinics for pediatric patients. Contact: Madeline Chiujdea, BA, CPHQ, CLSSGB; Madeline.chiujdea@childrens.harvard.edu
Platform #3	Building Bridges: Development and Implementation of a Transition to Adult Care Program for Youth with Multi-Morbidity at a Canadian Children's Hospital *Sara Santos, BKin, MHI; Eryn Vandepoele, BScN, MHSc, MN; Julia Orkin, MD, MSc, FRCPC; Eyal Cohen, MD, MSc, FRCPC; Megan Henze, MScOT; Jessica Teicher, MD); Kimberly Colapinto, BScN, MN; Robyn Lippett, MSW); Susan Miranda, BScN; Karla Wentzel, BScN, MN, NP; Joanna Soscia, BScN, MEd, MN; Tomisin John, BScN, MPH; Darryl Yates, RN, MHSc, CHE; Brooke Allemang, MSW, PhD; Dara Abells, MD; Donna Thomson; Alène Toulany, MD, MSc, FRCPC* Background: Transitioning from pediatric to adult healthcare services is often challenging for adolescents with chronic health conditions, particularly those with multi-morbidity. These adolescents often require extra planning, coordination, and support during this phase of their healthcare journey. Our presentation will provide an overview of the development and implementation of a hospital-wide transition program for youth with multi-morbidity within Canada's largest children's hospital. Methods: Building upon existing provincial quality standards for transition to adult healthcare services, the SickKids Transition to Adult Care (TAC) Program incorporates integrated care models aimed at empowering and supporting youth with multi-morbidity who are at high risk for poor transitional outcomes. TAC was launched in 2023 after extensive program planning, stakeholder engagement, piloting and targeted outreach strategies. A key factor in our success lies in our continued commitment to fostering partnerships across the healthcare system. By collaborating with experts in primary care, adult subspecialties and pediatrics, we have gained a deeper understanding of transition barriers and are working collaboratively to find sustainable solutions. Results: The program's inter-disciplinary team offers support for transition readiness, individualized transition planning, care coordination, youth empowerment, and connection to primary and adult care. Additionally, the program provides ongoing support for adolescents following transfer to adult care at age 18 for one to two years, to ensure

	secure attachment to adult services. Preliminary pilot findings will be presented, including changes to outcome measures, operational enhancements, and streamlining clinical pathways. Baseline study data will also be presented as part of the initial model evaluation. Conclusions: To our knowledge, we are one of the first in Canada to implement and evaluate a hospital-wide transition program that extends support beyond age 18. Our presentation will provide learnings that enhance the field’s understanding of how to address the transitional needs of a growing population of adolescents with multi-morbidity. Contact: Sara Santos, BKin, MHI; sara.santos@sickkids.ca
Platform #4	Primary Care Transition Assistance Program for Adults with Childhood Onset Medical Conditions: A Retrospective Evaluation of Program Effectiveness *Patrick Burke, MD, MHCDS; Raul Ayala, MD, MHCM; Tracy Gong, RN, BSN* Background: Multiple studies have documented low rates of first visit attendance for adult specialties across several conditions and circumstances, often observing wide outcome variation1-2. A recent study reported that “transition programs show the potential to reduce discontinuity of care, although more research is needed to draw firm conclusions.”3 Primary care transitions is not well studied, generally. Further, few studies report transfers between organizations, given the challenge of inter-institutional collaboration & data sharing. This study confronts all these research gaps, evaluating a mission-driven collaboration between Valley Children's Healthcare (VCH, Madera, CA) and Adventist Health (Hanford, CA). Ninety-two (92%) percent of the region is federally designated as a primary care shortage area. We posited that intentional collaboration and care coordination would result in high reliability transfers between pediatric and adult primary care. Methods: Single-center, retrospective review of a patient registry, from August 2019 through April 2024. Inclusion patients were 18 years old and older referred internally to the VCH Adult Transition Clinic. Using an “opt-out” approach, the intervention population benefited from a structured care coordination process and had selected Adventist Health for their Adult PCP. Results: 100 patients elected to transfer to Adventist Health for primary care. 85(%) attended their first appointment and 81(%) attended their second appointment in an intention-to-treat analysis. The remaining patients either delayed care beyond the study period, changed to another clinic, died, or were loss to follow-up. Conclusion: Through intentional collaboration and a structured care coordination process, we demonstrate that 81% of young adults with childhood onset medical conditions can transfer from pediatric to adult primary care in a primary care shortage area. Its design and outcomes can serve as a template and comparator rate respectively for other programs and inform future quality improvement research. Contact: Patrick Burke, MD, MHCDS; pburke@valleychildrens.org
	Poster Session 1
Poster #1	Adult Retention Rates within Pediatric Specialty Care Practices: Developing Models using Historical Data *Adam Greenberg MSN, CRNP; Evan Fieldston MD, MSHP; Dava Szalda MD, MSHP* Background: Transition to adult care is a complex but necessary process that ensures

	adult-aged patients receive age-appropriate clinical care. However, for many medically complex patients, it can be difficult to identify adult medical systems that can readily accept them into care. Often, these patients remain in pediatric care well into young adulthood, straining already pressed systems. Accordingly, we aimed to quantify retention rates in our specialty care practices in order to model future adult patient capacity and inform enterprise transition strategies. Methods: From our patient data warehouse, we pulled total numbers of specialty care visits for patients aged 15 to 27 from fiscal year 2018 to 2023; we additionally pulled total number of unique patients using the same parameters. Retention rates were calculated in Excel by dividing total number of specialty care visits for FY23 by total specialty care visits in FY18 but using age cohorts five years younger to represent the patient ageing through the system (i.e., if a patient was 20 in FY23, they would have been 15 in FY18). This formula was repeated for unique patients. Results: For patients 15 to 17, preliminary analysis suggests that retention rates for specialty care decreased as age increased: ~22% of 15-year-olds (YO), 14% of 16YO, and ~11% of 17YO in FY18 remained through FY23. For patients 18 to 22, retention rates increased with age: ~13% of 18YO, ~18% of 19YO, 22% of 20YO, ~32% of 21YO, and ~36% of 22YO in FY18 remained in pediatric specialty care through FY23. Overall volume of specialty care appointments declined as age increased. Unique patients exhibited similar patterns. Conclusion: Though these are initial calculations, modelling practices like these can help predict young adult patient volumes and patterns to help build or expand transition related resources and programming in children’s hospitals to meet patient demand. Contact: Adam Greenberg MSN, CRNP; greenberga1@chop.edu
Poster #2	Differences in Sub-specialty Care Utilization Before and After Transfer to Adult Health Care among Autistic Youth *Laura Hart MD, MPH: Joseph Sirrianni PhD; Steve Rust PhD; Chris Hanks, MD* Background: Autistic youth are more likely than non-autistic youth to have chronic health conditions. Differences in care practices between pediatric and adult care may result in differences in sub-specialty care utilization before and after transfer to adult health care. The extent of these differences is unknown. Methods: Using a retrospective data set of pediatric and adult electronic medical record data of over 250 autistic youth, we evaluated the number of patients who accessed sub-specialties in pediatric care, adult care, or both within 2 years of transfer to adult primary care. Results: Among physician visits, the most frequently seen specialists before transfer to adult primary care were psychiatry (33 patients), neurology (32 patients), developmental pediatrics (30 patients), gastroenterology (23 patients), and otolaryngology (ENT) (11 patients). Specialty visits occurred in both pediatric and adult health care before and after the first adult primary care visit. For example, among patients who saw psychiatry before transfer to adult primary care, 15 patients saw pediatric psychiatry, 19 saw adult psychiatry, and one saw both pediatric and adult psychiatry. After the first adult primary care visit, 5 patients saw pediatric psychiatry, whereas 46 saw adult psychiatry, suggesting a shift to adult psychiatry. ENT showed less of a shift to adult care because the 9 patients who saw

	pediatric ENT before adult primary care transfer stayed in pediatric ENT after adult primary care transfer. In some cases, more patients were seen after transfer to adult care - psychiatry (n=50 after vs. 33 before), neurology (n=39 after vs. 32 before), and ENT (n=13 after vs. 11 before). Other specialties had fewer patients after transfer: gastroenterology (n=18 after vs. 23 before), endocrinology (n=5 after vs. 8 before), nephrology (n=5 after vs. 6 before). Conclusions: Our results show that sub-specialty utilization changes before and after transfer to adult health care. Contact: Laura Hart MD, MPH; laura.hart@nationwidechildrens.org
Poster #3	Pilot testing of PREPARE for Autistic Adults: An Adult Autism Training for Resident Physicians Designed with Autistic Adults and Family Members *Brittany Hand, PhD; Daniel Gilmore, MS, RDN; J Madison Hyer, MS; Holden DeVassie, BS; Deondray Radford; Lisa Juckett, PhD; Christopher Hanks, MD; Susan Havercamp, PhD; Daniel Coury, MD* Background: Physicians rarely receive training in providing care for adults with disabilities, like autistic adults, in their medical education. Many physicians have low self-efficacy in meeting autistic adults' needs. Thus, in partnership with autistic adults and family members of autistic adults, we developed an innovative autistic adult-focused training program for resident physicians called Promoting Residents' Excellence in Patient-centered cARE (PREPARE) for Autistic Adults. In this pilot study, we examined the training's feasibility, acceptability, appropriateness, and effectiveness. Methods: We recruited residents (N=11) from Internal Medicine, Family Medicine, and Internal Medicine and Pediatrics (Med-Peds) at one institution to participate in the training. The training was delivered virtually over eight weeks and consisted of six pre-recorded lectures, six facilitator-led case studies, and two standardized patient encounters. Participants completed an autism knowledge assessment before and after the training. After the training, they also rated feasibility, acceptability, and appropriateness and completed qualitative interviews. Quantitative data were analyzed with descriptive statistics, and changes in autism knowledge were analyzed with Wilcoxon-signed rank tests. Qualitative interviews were analyzed using inductive thematic analysis. Results: Feasibility, acceptability, and appropriateness were rated highly for the training as a whole and for the individual training components. Autism knowledge improved by a median of 11.8 points (p=0.015). Qualitative analysis revealed four themes: 1) Flexibility facilitates feasibility, 2) High-value experiences increase acceptability, 3) Other practicalities affecting implementation, and 4) It's made me a better doctor. Five subthemes were identified among the themes. Conclusion(s): Our results suggest that PREPARE for Autistic adults is highly feasible, acceptable, appropriate and yields significant gains in autism knowledge. Next, we will make necessary refinements to the training and conduct a randomized waitlist-controlled study among residents measuring self-efficacy, attitudes and beliefs, and knowledge about providing care for autistic adults. Contact: Brittany Hand, PhD; brittany.hand@osumc.edu
Poster #4	A System-Wide Healthcare Transition Consult Service: Reflections After Our First Year *Chelsea Ghena, DNP, APRN, CPNP-PC; Carolyn Reynolds, MSN, APRN; Aileen Casas; Camille Reay; Stephanie Sund, MSN, RN, HWC*

Background: There are many models of care for delivering healthcare transition (HCT) support within a health system. Given the large geographic area of our system, a centralized team of transition guides was developed to provide support to clinics on a consult basis.

Methods: Three transition guides worked with three clinics (Spina Bifida, Rheumatology, and Diabetes) within our system. Step 1: Each clinic identified a transition champion to work with the transition guide. The Got Transition® Six Core ElementsTM were reviewed and a Got Transition® Self-Evaluation Measurement Tool was used to prioritize the work. The transition guide shadowed a clinic day and created a process map of clinic workflow. Step 2: The transition champion worked with the transition guide to identify gaps in current processes and determine where the transition guide would best fit into workflow. A process was created for identifying patients who are high risk during the HCT process and how to notify the transition guide of patients. Step 3: The transition guide worked with high-risk patients between clinic visits to develop HCT related skills, connect with community resources, and provide guidance as they navigated the system.

Results: As of March 31, 2024, our transition guides supported 204 youth and their families in three subspecialty clinics. Average age of youth was 18.7 years with a range of 13-24 years. Transition guides were able to confirm 18 successful transfers to adult services (average age at time of transfer was 19.2 years with an average time between last pediatric and first adult visit of 114 days)

Conclusion: The gap most commonly identified in clinic workflows where the transition guide stepped in was the process of transferring to adult services (identifying adult providers, scheduling appointments, and confirming successful transfers).

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Poster #5

Parents report High Likelihood of Recommending a Transitional Readiness Assessment (TRA)

Shannon Anderson, LOT; Jonathan Cohen, MOT, OTR/L, SIPT; Jennifer Helshoj, MOT

Background: Since 2014, a Pediatric Physical Medicine & Rehabilitation department has completed Transitional Readiness Assessment (TRA) on adolescents (ages 12-22) This novel assessment was created using information from Got Transition®. Got Transition® is the national resource center on health care transition. The TRA has undergone several PDA cycles to improve the patient experience and outcomes. The TRA supports patients across a pediatric health system. The assessment measures the patient’s ability to engage in health care service processes and readiness to assume responsibility for daily tasks. Resources are provided to help identify needed areas of skill development and support the parent in connecting to local community resources.

Methods: In 2023, 71 adolescents were referred for a TRA, of those, 62 were completed. Three Assessment tools were utilized to gather data. Follow-up surveys were sent, within a week, to all parents with 14 surveys returned.

Results: Data from the TRA was gathered with parents reporting an average rating for likelihood of recommendation 9.6 (10-point scale). The TRA supports patients from 11 different clinics inside the pediatric health system with referrals received from 31 providers. Fifteen percent of assessments were completed virtually. Problems were identified

	regarding data collection when utilizing the Transition Readiness Assessment Questionnaire (TRAQ). During the assessment, 25 Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT) tests were completed. Scaled Scores were used to measure progress. 9 PEDI-CATs were repeated with Responsibility gains noted in 78% and ADL gains in 55%. Conclusion: Results indicated areas of strength were parent likelihood of recommending and using the responsibility section as a measure of gain. Areas of focus for 2024 included increasing number of parent surveys, improving standardization of process, increasing number of repeated assessments, prepare for Capstone Student 2025. Contact: Sharon Anderson, OT; shannon.anderson@childrens.com
Poster #6	Comparing Pediatric Care Transition Risk Predictors: BLSS and the TRxANSITION Index *Reny Partain, LCSW, MPH; Radha Nagarajan, PhD; Wendy Gray, PhD; Erin Benekos, FNP-C; Kenneth Grant, MD; Steven Martel, MD; Michael Weiss, DO* Background: Bob's Level of Social Support (BLSS) is a measure of social complexity that has been used in clinical practice to identify families in need of care management support. It has also been informally used to assess risk factors that may negatively impact a patient's transition to adult care. Although used clinically, the tool itself lacks clinical validation. In this study, we examine the validity of the BLSS in predicting transition readiness. Methods: Using our hospital's transition registry, we searched for adolescent/young adult patients who had both a completed BLSS and TRxANSITION Index™ in their medical record. Data from 413 patients were extracted and examined. Linear regression and robust linear regression examined the relationship between the total scores of these measures. Results: The BLSS Total Risk Score was negatively associated with and the TRxANSITION Index™ Total Score (slope = -0.39, p < 10-3, R2 = 0.27), suggesting that transition readiness is lower in youth (Age:19±2.8yrs) with higher identified risk. Robust linear regression confirmed the decreasing trend (slope = -0.41, p < 10-3). While the relationship between the BLSS and TRxANSITION Index™ was significant, the general effect sizes were small and the scatter plot of the association between these variables had considerable noisiness. Conclusion: Social complexity, as measured by the BLSS, is negatively associated with transition readiness. While the BLSS offers valuable insight, the noticeable variability in this association suggests the need for careful consideration when using BLSS as a surrogate for TRxANSITION Index™ in predicting care transition risk. This provides opportunities for refining how we evaluate and utilize these measures to enhance predictive accuracy and support effective transitions in care. Contact: Reny Partain, LCSW, MPH; lauren.partain@choc.org
Poster #7	A Machine Learning Approach for Predicting Care Transition Risk *Reny Partain, LCSW, MPH; Radha Nagarajan, PhD; Wendy Gray, PhD; Erin Benekos, FNP-C; Kenneth Grant, MD; Steven Martel, MD;* Michael Weiss, DO Background: Bob's Level of Social Support (BLSS) has been historically used to predict pediatric care transition risk. The BLSS assumes an underlying linear structure in its scoring, with pre-defined thresholds categorizing patient risk level into Low Risk (BLSS

	Score: ≤ 7), Moderate Risk (Score: 8–10) and High-Risk (Score: 11–15). However, as the BLSS is unvalidated, it is unclear to what extent these groupings represent increased risk. Methods: BLSS data for 495 adolescent and young adult (AYA) patients with chronic health conditions were collected as part of routine care at a children’s hospital. A data-driven unsupervised machine learning approach (PAM: partitioning around medoids) was used to group patients into distinct profiles. A chi-square test (□ = 0.05) assessed the similarity between the BLSS approach (Low/Moderate/High) and our data-driven clustering approach. Results: The clustering approach grouped the AYA patients (N = 495) into three groups. Rather than depict risk linearly (Low/Moderate/High), as the BLSS is currently used, results suggest non-linear, qualitatively different profiles. Specifically, patients in the BLSS Moderate group (N = 140) had higher behavioral/mental health risk. The BLSS High group (N = 231) contained patients that were medically-complex/likely requiring lifelong dependent care. Dendrogram from clustering also revealed hierarchical grouping of the patients within each of the risk groups. Chi-squared test revealed significant overlap (p-value < .05) between the approaches. Conclusion: The proposed study uses a data driven multivariate approach for pediatric care transition risk prediction. The approach determines the risk groups based on patient similarity rather than pre-defined thresholds currently proposed by the BLSS. These subgroups also reflect nuances such as high behavioral/mental health needs seen in the “Moderate Risk” group that need more investigation. Such an understanding may encourage targeted intervention and disease management of care transition subjects. Contact: Reny Partain, LCSW, MPH; lauren.partain@choc.org
Poster #8	Partnering Together to Elevate Health Care Transition in Special Education Transition Planning *Samhita Ilango, MSPH; Peggy McManus, MHS; Tim Markle, MA; Wendy Berghorst, MS, RN, PHN; Linda Starnes* Background: Health care transition (HCT) is an important component to post-secondary education, employment, and independent living. However, little attention has been directed at helping students in special education learn about their own health needs and medicines, how best to manage their own health, how to use health care, and how to plan for transfer to adult health care. Methods: Got Transition convened 8 states (FL, GA, MN, NM, NC, OR, TX, WI) in a learning community to elevate the importance of HCT planning for students with disabilities. Activities include 1)reviewing state IEP transition planning laws and rules, 2) customizing state HCT profiles to make the case with states’ Department of Education, 3) reviewing available HCT resources and trainings in state special education programs to determine areas where HCT could be added, 4) examining potential opportunities to add health indicators as part of state special education transition measurement, 5) with state special education leaders, identifying opportunities to incorporate HCT in IEP transition planning in training, transition assessments, goal setting, and resource development, and 6) sharing best practices across states. Results: Wisconsin is leading the learning community, working with Got Transition. To date, Wisconsin’s promising approach has included 1) identification of education partners,

	2) convening a meeting and making the case to elevate HCT to education department leadership, and 3) listing and ranking HCT opportunities by feasibility. Conclusions: The outcomes of this Title V learning community will bring new attention and examples of ways to align HCT and special education transition planning to a population of youth with physical, developmental, and behavioral health conditions. Contact: Samhita Ilango, MSPH; silango@thenationalalliance.org
Poster #9	Supporting Outpatient Transition Preparation Through an Inpatient Med-Peds Hospital Medicine Consult Service *Jennifer Disabato, DNP, CPNP-PC, AC; W. Aaron Manning, MD; William C. Anderson III, MD* Background: A Med-Peds Consult Service (MPCS) was created at an academic children's hospital, utilizing Med-Peds-trained hospitalists to improve care for hospitalized young adult (YA) patients. In the initial year of the service 50% of consults (average YA age of 24y) were to assist in transition to adult care, identifying a gap in transition services for hospitalized YAs. Traditionally, an acute care hospitalization is not an ideal setting to address transition. MPCS partnered with the Improving Pediatric to Adult Care Transition (ImPACT) program, an ambulatory-based program operating within the children's hospital. Methods: MPCS and ImPACT collaborated with hospital leaders to develop an inpatient-based intervention, using transition education, transition planning, and goal setting, all in collaboration with specialty clinic providers. The EMR was used to identify hospitalized YA patients > 21 years. The chart was reviewed by MPCS, and if a transition consult was felt to be appropriate a standard message was sent to the admitting service. If deemed appropriate by this service, a consult was then performed by MPCS. Results: Project initiation occurred mid-2024. Anecdotally, YAs, families, and outpatient specialists have voiced strong appreciation for these transition consults, with multiple YAs transitioned successfully to adult care after consultation. We plan to analyze transition consult volumes and transition outcomes pre/post-intervention. We will utilize an iterative quality improvement approach to refine this novel approach and support YAs in transition. Conclusions: Hospitalization is considered a suboptimal time to discuss transition. However, it can create a "captive audience" of a particularly high-risk subgroup who would benefit from intensive transition discussions. Future directions include educating inpatient teams on the benefit of engagement with MPCS and encouraging specialty provider engagement with ImPACT to obtain additional outpatient transition support. Contact: Jennifer Disabato, DNP, CPNP-PC, AC; jennifer.disabato@cuanschutz.edu
Poster #10	Screen and Intervene: An Approach to Health Care Transition (HCT) Utilizing Inpatient Care Coordinators *Luke Coffman BS; Ashley McCool MHA; Tanika Middleton RN, BSN, CCM; Emily Nations Bufkin, MD* Background: When health care transition (HCT) needs arise while an adolescent or young adult with special health care needs (AYASHCN) is admitted to a pediatric hospital, care teams are often ill-equipped to address them. Inpatient care coordinators can play a vital role in successful HCT by identifying AYASHCN at risk for poor HCT-related outcomes. According to the 2020 National Care Coordination Standards for Children and Youth with Special Health Care Needs, HCT is a key domain for care coordination efforts [1]. At the

	project site, care coordinators administer a survey question on HCT as part of the intake general assessment. Reviewing 2022 general assessment data for all hospitalized patients age 16+, 2.1% of respondents reported that they had begun HCT, 46% indicated they had not, and for the remaining 52%, the question was left unanswered [2]. A lack of employee education regarding HCT is a driver of this inconsistent screening. Methods: As a part of a larger QI project, a dedicated training on core HCT principles was developed for care coordinators to better equip them in facilitating HCT conversations. The training uses a case-based format to establish a shared mental model. Results: The training sessions will soon be implemented (July 2024). Pre- and post-intervention surveys will be conducted to assess the training session’s effectiveness. Surveys utilize forced-choice Likert scales on the key objectives of the session and a 10-point Likert scale for care coordination self-assessment of overall confidence. Conclusions: Successful HCT is a team effort! Multidisciplinary HCT education is necessary to empower all team members to contribute to improving HCT outcomes, particularly for AYASHCN. This care coordinator training provides guideline-driven [3-5] HCT education to better equip inpatient care coordinators to perform HCT surveillance and link patients and their families to existing resources to aid in their HCT. Contact: Luke Coffman, BS; luke.coffman@utsouthwestern.edu
Poster #11	Co-Developing a Terms of Reference for Patient Engagement in Transition Research *Sarah Munce, MSc, PhD; Tomisin John, RN, MPH; Dorothy Luong, MSc; Sarah Mooney, Lisa Stromquist, Alene Toulany, MD, MSc.* Background: Patient engagement in research involves a partnership between researchers and patients and other knowledge user groups. It transforms patients from study subjects to collaborators and integrates their experiences and expertise, guiding research and shaping results. In the context of transition research, involving youth and caregivers in study design and implementation holds significant promise to enhance impact and relevance, benefiting all youth undergoing transition to adult care. Objective: To incorporate an integrated knowledge translation (iKT) approach to co-develop a Terms of Reference for Patient Engagement in Transition Research in Canada. Methods: An iKT panel comprised of 4 youth, 4 caregivers, 3 healthcare providers, and 5 health system leaders has convened multiple times to co-develop the Terms of Reference for Patient Engagement in Transition Research. Throughout these meetings, panel members provided valuable feedback on the content, ensuring that it encompassed elements crucial to their perspectives. Emphasizing the importance of adaptability, the panel advocated for the document to be a living document, subject to continuous updates to reflect evolving needs and insights. Results: The iKT panel successfully co-developed a terms of reference (ToR) as a structured framework for the engagement practice in the study’s ongoing activities. The ToR includes key elements of engagement practices, including the values and principles of the engagement approach, and clearly defined roles, responsibilities, and opportunities. An established decision-making process, with an outline of the expected output, recognition of the contributions and potential benefits for panel members, and promotion of inclusivity.

	Conclusion: The establishment of a ToR is a key step in fostering collaboration, accountability, and inclusivity among knowledge users engaged in research. The ToR will be iterated on as our research progresses. Other research teams conducting similar research can use our ToR to guide their efforts in engaging youth in research. Contact: Sarah Munce, MSc, PhD; sarah.munce@uhn.ca
Poster #12	Patient, caregiver and other knowledge user engagement in consensus-building healthcare initiatives *Sarah Munce, MSc, PhD; Elliott Wong; Dorothy Luong, MSc; Justin Rao; Jessie Cunningham; Katherine Bailey, BSc; Tomisin John, RN, MPH; Claire E.H. Barber, MD, PhD; Michelle Batthish, MD, MSc; Kyle Chambers; Kristin Cleverley, RN, PhD; Marilyn Crabtree, MD; Sanober Diaz, MHSc; Gina Dimitropoulos, MSW, PhD; Jan Willem Gorter, MD, PhD; Danijela Grahovac; Ruth Grimes, MD; Beverly Guttman, MSW, RSW; Michèle L. Hébert, PhD, OT; Megan Henze, OT; Amanda Higgins; Dmitry Khodyakov, PhD, MA; Elaine Li; Lisha Lo. MPH; Laura MacGregor, PhD, MA, MSc, BScOT; Sarah Mooney; Samadhi Mora Severino, MA, HBA; Geetha Mukerji, MD, MSc; Melanie Penner, MD, MSc; Jacklynn Pidduck, MSW; Rayzel Shulman, MD, PhD; Lisa Stromquist; Patricia Trbovich, PhD; Michelle Wan; Laura Williams; Darryl Yates, RN, MHSc; Alène Toulany, MD, MSc* Background: Patient engagement and integrated knowledge translation (iKT) processes improve health outcomes and care experiences through meaningful partnerships in consensus-building initiatives and research. Consensus-building is essential for engaging a diverse group of experienced knowledge users in co-developing and supporting a solution where none readily exists or is less optimal. Patients, caregivers and other knowledge users provide invaluable insights for building consensus in decision-making around healthcare, policy and research. However, despite emerging evidence, patient engagement remains sparse within consensus-building initiatives. Objective: To synthesize the extent of the literature on patient and other knowledge user engagement in consensus-building healthcare initiatives. Methods: The scoping review was conducted in accordance with the Joanna Briggs Institute scoping review methodology. EMBASE, CINAHL and PsycINFO databases were searched from inception to July 2023. The following inclusion criteria were applied: all consensus study designs that employ commonly used methods; within the healthcare context; and explicitly describe patient engagement outcomes, strategies, methods or approaches. Abstracted data will be summarized into (1) how knowledge users were engaged; (2) use of patient engagement models, values/principles, theories, and frameworks; and (3) overarching consensus-building approach. Results: The initial search yielded 7919 studies and 2803 duplicates were removed. After title and abstract screening, 5116 articles were excluded. Subsequently, 373 articles were excluded at full-text screening. A total of 140 studies were identified for data extraction. Conclusion: The results of this review will inform iKT processes for our larger project on engaging youth, caregivers and other knowledge users to prioritize previously identified quality indicators applicable across chronic health conditions through consensus-building. Beyond optimizing our research, the results will inform meaningful best practices for engaging knowledge users in consensus-building research and provide a rationale for including checklist items in guidelines such as the ACcurate COnsensus Reporting Document (ACCORD) for reporting patient involvement beyond being participants.

	Contact: Sarah Munce, MSc, PhD; sarah.munce@uhn.ca
Poster #13	Protocol for a Consensus-Building Multistakeholder Initiative to Establish Quality Indicators for Transition to Adult Care *Alene Toulany, MD, MSc; Katherine Bailey, BSc; Claire Barber, MD, PhD; Michelle Batthish, MD, MSc; Kristin Cleverley, RN, PhD; Gina Dimitropoulos, MSW, PhD; Jan Willem Gorter, MD, PhD; Danijela Grahovac, Ruth Grimes, MD; Beverly Guttman, MSW, RSW; Michèle L. Hébert , PhD, OT; Tomisin John, RN, MPH; Dmitry Khodyakov, PhD, MA; Lisha Lo, MPH; Dorothy Luong, MSc; Laura MacGregor, PhD, MA, MSc, BScOT; Sarah Mooney; Geetha Mukerji, MD, MSc; Jacklynn Pidduck, MSW; Rayzel Shulman, MD, PhD; Lisa Stromquist, Patricia Trbovich, PhD; Sarah Munce, MSc, PhD* Background: The transition from paediatric to adult care poses a significant health system-level challenge impeding the delivery of quality health services for youth with chronic health conditions. Transition to adult care is regarded as a top priority in need of readily applicable, adaptable, and relevant national metrics to evaluate and benchmark transition success across disease populations and clinical care settings. Existing literature fails to account for the lack of engagement from youth and caregivers in developing indicators, as well as its applicability across chronic conditions, primary care involvement, and health equity considerations. Objective: To establish a key set of consensus-derived quality indicators for transition to adult care that are applicable across chronic conditions, clinical care settings, and health jurisdictions in Canada. Methods: Using an integrated knowledge translation (iKT) approach, we are collaborating with a panel of youth, caregivers, interdisciplinary healthcare providers, and health system leaders to ensure study methodology, materials, and knowledge dissemination are appropriate and reflect the perspectives of youth and their families. We will conduct a 3-round Online Modified Delphi (OMD) (n=160) to (1) prioritize a key set of quality indicators for transition applicable across disease populations that are the most important and feasible and (2) compare and contrast the prioritized quality indicators of each knowledge user group. Results: 169 indicators have been identified from a previous systematic review and were categorized into 29 themes. The research team and iKT panel have further refined this number to 22 themes. Round one of the OMD is set to start in October 2024. Conclusion: Determining the most beneficial indicators from the perspectives of each knowledge user group, most importantly youth and caregivers, is a fundamental step to identifying areas for improvement in transition, evaluating processes, benchmarking across jurisdictions, and optimizing health outcomes for youth with chronic conditions into young adulthood. Contact: Alene Toulany, MD, MSc; alene.toulany@sickkids.ca
Poster #14	Integrating primary care and transition support into survivorship care *Emma Wilcox, BA; Roma Bhuta, DO, MPH; Amanda Bellamy, MSN, RN, FNP-C; Jennifer Welch, MD; Suzanne McLaughlin, MD, MSc* Background: Pediatric oncology survivorship focuses on the care of survivors of childhood cancer. The nearly 500,000 childhood cancer survivors in the United States need

surveillance for recurrence and late effects in addition to usual age-appropriate care. In 2019, we restructured our institution's survivorship care model by relocating to a primary care site distinct from our oncology clinic and incorporating medicine/pediatrics primary care into our clinic. The primary care provider (PCP) focuses on transition counseling, needs assessment, and support.

Methods: We used EPIC to summarize all survivorship clinic visits since restructuring in September, 2019 through May, 2024. Chart review assessed PCP and vaccination status; seasonal influenza was considered complete only if specified for a year when seen in survivorship. At each visit, patients aged 12-17 discuss transition needs and plans and patients 18+ focus on ensuring continuous primary care.

Results: The survivorship clinic completed 962 visits for 351 unique patients (mean 2.7 visits per patient, median 3). Patient age distribution: 12.6% <12 years, 24.3% 12-17 years, 24.2% 18-24 years, 19.6% 25-30 years and 9.2% >30 years. PCP specialties of patients aged 18-24 (n=155): pediatrics (28.3%), family medicine (30.3%), internal medicine (28.3%), and medicine-pediatrics (6.5%), while 6.5% had no PCP. Two-thirds had seasonal influenza, COVID and Human Papilloma Virus, with 48.4% having all 3. Only 11.6% lacked record of any.

Conclusions: Inclusion of a PCP within survivorship care is a novel practice structure. With a goal of transition preparedness and ensuring primary care continuity, early data suggest benefits in maintaining and, when appropriate, transitioning primary care. Compared to general population trends, there are higher than expected rates of periodic and age-appropriate vaccinations in our 18-24 year old cohort and lower rates of patients lacking primary care.

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Poster #15

Self-Perceived Importance and Confidence Scoring for Adolescents and Young Adults Transitioning to Adult Care

Lisa Lestishock DNP, RN, CPNP-PC; Carrie Cuomo DNP, RN, CPNP-PC/AC; Teresa Hickam MSW, LSCSW, CCM; Tisa Johnson-Hooper MD, FAAP; Michele Maddux PhD; Evan Muzzall PhD; Margaret McManus, MHS; Patience White, MD, MA FAAP

Background: Motivational interviewing (MI) techniques are used by health care teams to engage adolescents and young adults (AYAs) in health care self-management and pediatric to adult health care transition (HCT) planning efforts. The aim of this study was to assess the initial level of motivation of AYAs, prior to receipt of HCT anticipatory guidance, and to determine associations with demographic and health coverage factors.

Methods: This retrospective study included a convenience sample of 5112 AYAs, ages 12 to 26 years, from four health systems: Children's Mercy Kansas City, Cleveland Clinic, Henry Ford Health, and Ravenswood Family Health Center. All AYAs completed the Got Transition readiness assessment that includes MI questions of importance and confidence related to the move to an adult provider. Importance and confidence questions were the dependent variables. Independent variables included demographic and health coverage factors: age, sex, race, ethnicity, language, and insurance. The statistical approach included summary statistics, chi-square tests of independence and log-likelihood ratio tests, and generalized linear model contrasts to investigate patterns in adolescents' motivation towards transitioning to adult care.

	Results: Results demonstrate trends in scores when AYAs were establishing with a HCT program. Importance scores increased from 12-14 through 18-20 years, then decreased in the 21–26-year group. Confidence scores increased from the 12-14 through the 21–26-year group. Confidence scores were generally higher than importance scores and were accompanied by smaller standard deviations. Ethnicity and insurance type also demonstrated an association with MI scoring. Conclusion: This study provides baseline scores on two key MI questions that can facilitate clinician understanding of youth engagement in discussing the changes needed to move to adult care and guides clinicians to start considerably earlier than just before transfer that often occurs around age 21. Contact: Lisa Lestishock DNP, RN, CPNP-PC; llestishock@stanfordchildrens.org
Poster #16	Understanding the needs of youth living with spina bifida during transition to adult care: a quality improvement initiative *Laurence Veilleux, MSc, NP, RN; Kimberly Anganu; Nadine Korah MDCM, MSc, FRCPC; Sara Long-Gagné MD, MSc, FRCPC* Background: Spina bifida is a complex congenital disorder that can lead to lifelong sequalae, including motor and sensory impairments, bladder and bowel dysfunction, and orthopedic problems. Transition to adult care for this population is associated with declining health outcomes, struggles with self-management and poor social participation. This project aims to determine areas of need related to the transition practices of youth with spina bifida and identify priorities for future quality improvement initiatives. Methods: Using a Lean six sigma quality improvement methodology, a patient-reported Transition Readiness (TR) Questionnaire will be collected from 29 potential patients aged 14-18 years followed at a children's hospital multidisciplinary spina bifida clinic from October 2023 to December 2024. The questionnaire uses a 4-part response set (no help needed, some help needed, substantial help needed, non-applicable) to assess the status of transition-related competencies in 5 categories (Knowing my Health, Using Healthcare, Lifestyle/Social Supports, Becoming Independent and Self-Advocacy). The average score in each category is used to determine the areas that may benefit from additional support and education. Results: On preliminary analysis, the TR Questionnaire was completed by 9 individuals with a mean age of 14.4 years (SD 0.7); 5 males (56%) and 4 females (44%). Many participants reported needing no help when it came to Knowing My Health, Lifestyle/Social Supports and Self-Advocacy (77%, 86% and 60% of participants, respectively). Conversely, Using Healthcare and Becoming Independent were categories where a large proportion reported needing some or substantial help (67% and 54%, respectively). Conclusion: Our preliminary results suggest that youth living with spina bifida may benefit from additional support using the healthcare system and developing the competencies to become independent members of society. Implementation of interventions targeting those areas, such as patient navigators and life skills workshops, may be considered to provide personalized support and resources. Contact: Laurence Veilleux, MSc, NP, RN; laurence.veilleux@muhc.mcgill.ca
Poster #17	Adaptation of Patient XLH Toolkit into Interactive Mobile Website that Incorporates Six Core Elements of Health Care Transition (HCT)

	Amber Parson, BA; Carolyn M. Macica, MS, PhD Background: X-linked hypophosphatemia (XLH) is a rare and progressive genetic bone disorder that has distinctive clinical features in children and adults. Transitioning from pediatric to adult care is crucial for managing the progressive nature of XLH, yet the condition poses challenges due to its rarity and need for specialized expertise. Structured transition programs, such as the nationally funded Got Transition model and its Six Core Elements of Health Care Transition (HCT), are crucial for preparing patients for shifts in care. To meet the specific needs of transition care in XLH, this project will enhance the existing XLH Transitions Toolkit by transforming it into an interactive website that uses the Got Transition model as its foundation, for all stakeholders (patients, families, healthcare providers). Methods: Adaptation of the toolkit will include comprehensive research on the Six Core Elements of HCT and consultations with multiple XLH patients and providers. Post-development, the website will undergo beta-testing via one-on-one interviews with a select group of stakeholders, in accordance with the IRB. Results: The following website components were developed: 1) a video tutorial explaining engagement with the website throughout HCT for individuals with XLH, 2) a module for understanding key changes in XLH across the age span, 3) webpages for distinct age groups that include age-appropriate HCT planning checklists and self-care assessments, 4) a module for understanding changes in shared management of XLH with caregivers, and 5) transition resources that can be referenced by XLH providers and potential providers. Conclusion(s): After its adaptation, the XLH Transitions Toolkit will be more engaging and effective for young individuals with XLH and better aligned with nationally recommended HCT guidelines. This alignment is anticipated to reduce adverse outcomes associated with ineffective HCTs. Contact: Amber Parson, BA; amber.parson@quinnipiac.dhi
Poster #18	Inclusion of Individuals with Intellectual and Developmental Disabilities into Research: A Process for Informed Consent *Caren Steinway, MPH, LMSW; Jason Woodward, MD, MS; Charmaine Wright, MD, MSHP; Sophia Jan, MD, MSHP* Background: In September 2023, the National Institutes of Health designated people with disabilities as a population with health disparities. This designation puts inclusion of individuals with disabilities at the forefront of research activities. However, people with intellectual and developmental disabilities (IDD) specifically are frequently excluded from research due to concerns about abuse and exploitation. Methods: An expert panel of clinicians, social workers, researchers, and collaborators convened to identify a workflow to assess capacity for informed consent for individuals with IDD. The process was developed for the Future Planning and Well-Being for Individuals with Intellectual Disabilities and Family Caregivers study, a PCORI-funded comparative effectiveness trial. The panel met to review existing capacity determination methodologies, develop a concrete process workflow, and try the workflow out with collaborators. Results: The resulting process workflow is conducted in a tiered approach. First, study staff ask the individual with IDD two questions to assess their developmental age. Both are

	questions that the CDC deems age appropriate for individuals in middle childhood (6-8 years), the age at which assent is required in research. If the individual with IDD cannot answer those questions assent is not obtained. Individuals who can answer those questions and who are under the age of 18 are asked to assent. For individuals who can answer those questions and who are 18 years or older, the study is described using standardized scripts. Once the study has been explained, study staff use six established questions to assess understanding of study activities. If the individual can answer all six questions, informed consent is obtained. If they cannot, assent is obtained. Conclusions: Inclusion of individuals with IDD in research is imperative to eliminating health disparities. Doing so is possible with inclusive and thoughtful processes by which to assess understanding of human subjects research and study activities. Contact: Caren Steinway LMSW MPH; csteinway@northwell.edu
Poster #19	Preliminary Findings of a Peer Navigator Health Care Transition Planning Employment Pathway Program *Cecily L. Betz, PhD, RN, FAAN; Christine Mirzaian, MD, MPH, IBCLC; Rowan Smith, MPH* Background: The focus of the Peer Navigator program is to implement and test a peer navigator employment pathway program for young adults with intellectual and developmental disabilities (IDD) to facilitate the transfer of care to adult health care and assist with service referrals and supports for transition and adult services for employment, education, training, and community living for youth and young adults with IDD. Methods: To date, two Peer Navigators have been trained in case management and transition services and systems and provided services to 19 youth and young adults with IDD with transfer of care to adult-focused providers and transition referral services to transition and adult-focused community-based services that include postsecondary education, training, employment and community living. By October 9, we will have trained 2 to 3 more peer navigators and provided services to a larger number of youth and young adults with IDD Results: Currently, 1 Peer Navigator has obtained part time competitive integrated employment in social services and 1 Peer Navigator has obtained a second paid internship and returned to school to complete her certificate and build a portfolio for her future grad school application. Peer Navigators have assisted connecting patients to postsecondary education, regional centers, advocating for specific regional center services, conservatorship workshops, and adult healthcare providers, which we will report in terms of transfer of care and service referral to transition and adult community-based services. Conclusion: The program has resulted in competitive integrated employment and steps towards competitive integrated employment for both Peer Navigator interns. Patients and their families are being connected to resources they did not know about previously and are working toward transitioning their health and social services to adult care. Contact: Cecily L. Betz, PhD, RN, FAAN; cbetz@chla.usc.edu
Poster #20	Modifying the Transition Readiness Assessment to better meet the needs of families of Children with Medical Complexity. *Stephanie Pratt MSW, LMSW; Leslee Throckmorton Belzer PhD; Emily J Goodwin MD; Timothy E. Corden MD, MS* Background: The transition readiness assessment survey is an essential tool used to identify transition gaps and goals as a child and family journey from pediatric to adult care. We noted that current surveys directed at parents/caregivers of children with medical

	complexity (CMC) who will need full care/guardianship, did not adequately assess caregiver readiness. The goal of our project is to modify the transition readiness survey given to CMC families such that the instrument better informs their transition experience and outcomes. Method: A multidisciplinary workgroup consisting of complex care physicians, a psychologist, complex care RNs, care coordinators, social workers, and the hospital's transition program (first author, also a parent of CMC), gathered to create transition themes that might best address the transition needs of CMC families. The group then developed survey questions that assess the family's status regarding transition readiness associated with each theme. The themes and questions where than reviewed with the CMC Parent Family Advisory Council prior to approval and use. Results: The workgroup identified eight themes and 16 associated survey questions. Themes: medical care, insurance, guardianship, education options, residential needs, finances, adult provider information, and transportation access. An example question extending from the medical care theme: As my youth's caregiver, I do or do not know what to do in case of a medical emergency. The new assessment tool went into use on April 1, 2024. Complex Care specific goals and caregiver educational materials were also created to address gaps identified through the new readiness assessment survey. Discussion: Initial uptake and subjective responses of the new survey have been highly favorable. We will continue to monitor caregiver engagement of the new instrument, selected goals, use of educational material; along with family, CMC provider and staff subjective impressions of the survey; and impact on a successful CMC transition process. Contact: Stephanie Pratt MSW, LMSW; scpratt1@cmh.edu
Poster #21	Comprehensive Assessment of Lived Experience and Burnout in Caregivers of Transitioning Young Adults with Childhood Medical Complexity in Alabama: A Mixed Methods Approach *Raksha Ramdas, BS; Heather Johnson, DrPH, MPH, Carlie Somerville, MD, Madeline Eckenrode, MD, Betsy Hopson, MSHA* Background: Adolescents with complex medical conditions, such as spina bifida, require ongoing multidisciplinary care into adulthood. Evidence suggests that patients with complex medical conditions are susceptible to poor health outcomes, particularly in transition to adulthood. The "Staging Transition for Every Patient" (STEP) Clinic at University of Alabama at Birmingham (UAB) is designed to prepare patients with complex conditions to transition from pediatric to adult care. A mixed methods study in this population provides a comprehensive understanding of factors contributing to caregiver burden and accounts for socio-cultural context and real-world lived experience to meet the needs of caregivers and optimize patient care and safety. Methods: After IRB approval, a 39-item survey was created to be administered to caregivers of 150 patients to assess barriers of those supporting patients with complex conditions at the STEP Clinic. Quantitative data will be analyzed before selecting caregivers for semi-structured interviews for qualitative data collection. Thematic analysis will be done to interpret data collected from interviews, followed by integration of quantitative and qualitative data.

Preliminary Results: Fifty-five percent of caregivers are above 55 years of age. Forty-eight percent of caregivers reported their status as full-time employees. The personal income of 55% of caregivers was below $49,000 in the past year. 30% of caregivers “sometimes” feel lonely or isolated from their peers and family. In the past month, 50% of caregivers “sometimes”, “quite frequently” or “nearly always” felt they could not control important things in their lives.

Conclusion: Preliminary results are proving the significance of burden during the transition period from pediatric to adult care for the caregivers of adolescents with medical complexity. Isolation and lack of resources are early findings that need further exploration. The qualitative component to these survey findings will allow greater opportunity to develop interventions to reduce caregiver burden in this vulnerable population.

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Poster #22

A Multidisciplinary Clinic for Adults with Medical Complexity: Understanding the Challenges of Hospital Courses for Patients Navigating Healthcare Transition

Margaret Rosenthal, BS; Madeline Eckenrode, MD; Betsy Hopson, MSHA; Carlie Stein Somerville, MD

Background: The “Staging Transition for Every Patient” (STEP) program at University of Alabama at Birmingham (UAB) is a specialized clinic designed to address difficulties patients with complex conditions face in transitioning from pediatric to adult healthcare. Surveys of patients with childhood medical complexity have shown they are fearful of hospital stays after transition. The STEP program works to mitigate those fears through establishing emergency care plans and deliberate hospital co-management. A critical step in understanding how to reduce hospital utilization where appropriate and best employ our consultative services was to characterize our patients’ hospital courses.

Methods: We performed retrospective chart review of all hospitalizations that STEP clinic patients had at UAB after they established care at the STEP clinic from September 2020 to June 2023. We reviewed electronic medical records of 56 STEP patients with a total of 112 hospitalizations.

Results: The majority of STEP patients requiring hospitalizations were young adults, with a mean age of 24. 69.6% of hospitalized STEP patients had technology dependence of some form. Ten patients had 3 or more hospitalizations during the study period. The hospital courses were a median length of four days (range 1 – 97 days) and often complicated, with 21.4% of hospitalizations involving 3 or more consulting services. Follow up STEP clinic appointments within 2 weeks of hospital discharge were attended after 19.6% of all STEP patient hospitalizations.

Conclusions: We understand that our patients who are hospitalized have a similar degree of technology dependence compared to the overall clinic population and a small number of patients used significant hospital resources. Patients were also unlikely to follow-up immediately following their hospitalization. In response to this data review, policy changes have included the development of an “emergency room passport,” the creation of a vulnerable patient task force, and an inpatient complex care consultation service.

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Poster #23	A Contextual Analysis of a Swiss Model of Transition from Pediatric to Adult Rheumatology as Part of the Heroes (Rheumatology Transition for Young People in Switzerland) Study *Séverine Soiron, MSN; Sandra Staudacher*, PhD; *Natalie Tarr, PhD; Marlis Matter, BSN; Andreas Wörner, MD; Thomas Daikeler, MD; Mary-Louise Daly, Msc; Lut Berben, PhD, RN* Background: In Switzerland, up to half of the 3000 children and adolescents diagnosed with rheumatic diseases need continuous medical care into adulthood. A structured, individualized transition plan is needed to ensure successful transition. However, there are major differences in transitional care (TC) practices between Swiss rheumatology centers. The overall aim of the HEROES study is to improve TC in Swiss rheumatology centers. In the first phase we need to understand contextual factors influencing the implementation of TC. Here, we will describe not only adolescents' and young adults' (AYA) and parents' experiences related to current TC practice, but also includes perspectives of healthcare professionals and clinical/administrative leadership representatives at one study site. Methods: Ethnographic case methods, such as observations and semi-structured interviews, are used. Data collection and analysis follows Braun and Clarke's six phased thematic analysis. Results: Transition is planned in close cooperation between the patient and the TC team. The transition nurse (TN) plays a central role and provides a stable anchor for the AYA throughout the transition process. TN tasks include organization and coordination of consultations; she also functions as advisor for the AYAs and is easily accessible for them. She is in constant contact with professionals in other disciplines. The TC team needs good insights into and knowledge of specialized rheumatology, biopsychosocial and developmental issues of adolescence, as well as good understanding of the functioning of social services and administration. In the therapeutic setting of the team's institution, building a relationship with patients is one important precondition for a successful transition into adult care. Financial barriers, knowledge gaps and human resources present major challenges to achieving a successful transition. Conclusion: Relationship between all people involved is a key component for successful TC. Further research will show if these results are consistent across Swiss rheumatology centers. Data collection in all Swiss TC centers will allow us to determine if these themes are consistent across centers. Contact: Lut Berben, PhD, RN; lut.berben@ukbb.ch
	Breakout Sessions
Breakout Session #1	Policy and Program Recommendations to Reduce Disruptions and Disparities Among Youth with Disabilities Aging Out of Public Programs *Margaret McManus, MHS; Samhita Ilango, MSPH; Annie Schmidt, MPH; Patience White, MD, MA* Goals: This session will focus on a series of recommendations developed to address the cliff experienced by low-income youth and young adults with disabilities and their families as they age out of childhood public program services through Medicaid, CHIP, SSI, and Title V. Evidence shows that many become uninsured, face worsening poverty levels, experience disruptions in care, and report extraordinary worries and pressures. Black young adults with disabilities, especially those with intellectual and/or development disabilities, report even greater difficulties when they age out of these programs. This set of policy and program recommendations was developed based on findings from analysis of

	the American Community Survey, 55 key informant interviews, a literature review, and a five-state case study as well as guidance from a National Advisory Committee. The recommendations are intended for consideration by Congress, federal and state agencies, family and disability advocates, and health care clinicians. For SSI, for example, the report calls for extending the age of childhood eligibility, simplifying documentation requirements, and public reporting age 18-redetermination cessation rates by state and race. For Medicaid/CHIP, recommendations include establishing a uniform definition of childhood eligibility, including managed care contract provisions on aging out processes, and providing earlier notification of eligibility and benefit changes when no longer a child. For Title V, recommendations include creating mechanisms to identify and track those aging out, providing benefits counseling to inform them of adult public program options, and partnering with the state Medicaid agency's EPSDT program on outreach and communication strategies. Intended audience: Youth, young adult, and family advocates, disability advocates, and health care professionals who work with youth and young adults with disabilities. Contact: Margaret McManus, MHS, mmcmanus@thenationalalliance.org
Breakout Session #2	Using Project ECHO to Build a Statewide Health Care Transition Learning Collaborative *Rhonda Cady, PhD, RN; Tori Bahr, MD; Patience White, MD, MA, MACP, FAAP; Peggy McManus, MHS; Wendy Berghorst, MS, RN, PHN; Megan Lutz, MPH; Katie Stangl; Alyssa Green, LPCC; Maria Medina, MPH; Debbi Harris MS, MA, GCAS* In Minnesota (MN), only 29% of youth with special health needs receive transition preparation from their health care providers, underscoring widespread health care transition (HCT) gaps. With funding from MN's Title V CYSHCN Program, Gillette Children's with The National Alliance to Advance Adolescent Health/Got Transition, initiated a statewide health care transition learning collaborative (HCT LC). We used the evidence-based Project ECHO framework to support virtual sharing of best practices and apply case-based learning through a culturally responsive and trauma-informed lens and invited a core faculty representing families with lived experience, clinicians, and experts in equity and trauma-informed care. Beginning in October 2023, eight monthly ECHO sessions were conducted on topics ranging from ensuring diversity, equity, inclusion, trauma-informed care, patient/family partnership throughout HCT, supported decision-making and guardianship options, evidence and best-practice for HCT processes, transfer and integration into adult practice, adult practice considerations for young adults with intellectual and/development conditions and partnership with special education and vocational rehabilitation during HCT. Attendance at each session ranged from 80 to 125 learners from MN and other states and countries and included young adults and family members, payors, providers, rehabilitation therapists, researchers, school nurses, social workers, and state agency personnel. Post-ECHO session evaluations indicated the majority will apply the knowledge gained to affect change in their practice. Many also described organizational barriers impeding practice change. The HCT LC will convene in June 2024 for an all-day, hybrid HCT Summit, with a focus on patient and family-centered health care transition and addressing organizational barriers to HCT process implementation. Using Project ECHO to build a statewide HCT learning community and offer state-of-the-art knowledge and application of best practices provides a low-cost, accessible platform that is

	easily translated to other states and settings. The intended audience for this session are persons interested in advancing HCT education. Contact: Rhonda Cady, PhD, RN; rhondagcady@gillettechildrens.com
Breakout Session #3	Educating the Next Generation: How can you champion education in healthcare transition and the care of individuals with IDD at your institution? *Jordan Kemere MD MS FACP; Priya Chandan, MD, MPH, PhD; Elisha Acosta MD* As more and more individuals transition from pediatric to adult healthcare services, the literature has shown that physicians feel ill-equipped to help during transition and to care for adults with chronic conditions of childhood. Increased education is needed at all levels to bridge this gap and provide more equitable care. This lunchtime workshop will focus on the education of healthcare learners in transition and IDD care. We will begin with a brief presentation of examples of curricular modalities already in use such as clinical and pre-clinical electives, interactive lectures, patient navigator roles, community-engaged work, CME lecture series, resident rotations, and even fellowship programs. Attendees will then be broken into small groups to brainstorm and plan out innovative curriculum for their home institution with each group led by an experienced educator in this space. Take-home messages will include: 1) Consider opportunities to insert education regarding healthcare transition and IDD care in already existing curriculum 2) Devise new ways to introduce education in transition and IDD care and plan how to introduce this in an academic setting 3) Connect with experts to explore lessons learned, formulate new ideas and refine current offerings. Intended audience: Anyone who teaches healthcare learners that wishes to boost teaching at their home institution in healthcare transition and the care of individuals with IDD. This would include faculty as well as learners such as fellows, residents, and medical students as learners are often driving new curricular innovations! Contact: Jordan Kemere MD MS FACP; kemere@bcm.edu
	Platform Session 2: Health Care Transition Outcomes and Readiness Measures
Platform Presentation #1	Challenges and Inequities Facing Youth and Young Adults with Disabilities Aging Out of Public Programs *Samhita Ilango, MSPH; Peggy McManus, MHS; Annie Schmidt, MPH; Patience White, MD, MA* Background: Little attention has been paid to the disruptions in public program access faced by youth with disabilities, particularly Black youth and those with intellectual and/or developmental disabilities (ID/DD), as they age into adulthood. This two-year research effort sought to understand child to adult program eligibility shifts in Medicaid, CHIP, SSI, and Title V; state variations in policies and practices; and challenges and inequities experienced by youth when they lose their child eligibility status. Methods: A mix of quantitative and qualitative methods was used, including analysis of the American Community Survey; 55 key informant interviews; a literature review; online surveys; a five-state case study; and guidance from an expert advisory committee.

	Results: Young adults with disabilities face more restrictive eligibility Medicaid and SSI criteria than youth, resulting in half as many 19-25 year olds being publicly insured compared to 12-18 year olds and a corresponding increase in uninsured young adults. An estimated 50% of SSI recipients lose their eligibility following age 18 redetermination. There are no adult counterpart programs for CHIP and Title V CYSHCN. Numerous challenges and inequities were identified: 1) state variability in availability of Medicaid; 2) inadequate notification about aging out and complex information about applying for adult programs; 4) limited availability of navigators to help; 5) lack of access to medical and behavioral services, especially in rural areas; and 6) racism, prejudice, and unconscious bias against people of color, especially those with ID/DD. Conclusions: The transition from child to adult Medicaid coverage and SSI benefits is not well understood, anticipated, or facilitated, resulting in many young adults with disabilities losing access to critical adult program benefits, adversely affecting their health and well-being. A new national report on aging out, resulting from this research, offers policy and program strategies to improve the transition to adulthood. Contact: Samhita Ilango, MSPH; silango@thenationalalliance.org
Platform Presentation #2	Utilizing Electronic Health Record Data to Improve Patient Follow-up in the Transition Medicine Clinic *Erin E Brown FNP, Robin Spidell, John Berens MD* Background: Lapses in recommended follow-up care is a well-known problem that can have significant impacts on patients' health, particularly for vulnerable populations. In the Transition Medicine Clinic (TMC), a primary care clinic for adults with intellectual/developmental disabilities, patients do not return for a follow-up visit in the recommended interval approximately 30% of the time. The aim of this intervention was to improve patient follow-up by creating a streamlined process within the electronic health record (EHR) to identify and contact patients lapsed in follow-up care with minimal effort. Methods: An EHR-based report was developed to identify active TMC patients overdue for follow-up, defined as 30 days past recommended follow-up without an upcoming appointment scheduled. Every two weeks, the report was used to generate a list of patients overdue for follow-up, and through the patient portal, a reminder message was sent inviting them to schedule a visit. Percentages of patients overdue for follow-up and overdue by more than one year past recommended follow-up were recorded pre-intervention and weekly thereafter. Results: Overall percentages of patients overdue for follow-up declined steadily after intervention from a baseline of 30.1% (519 patients) to 20.6% (381 patients) at week 18. During this period, the TMC population grew from 1722 patients to 1846 patients. Patients more than one year overdue for follow-up also decreased from 6.6% (114 patients) of the clinic population to 4.7% (90 patients). Conclusion: Mass reminders sent through the EHR patient portal reduced total patients overdue for follow-up and patients overdue more than one year for follow-up. The study intervention relies mainly on EHR supports and requires minimal effort from the clinical team, making it an efficient and sustainable process to ensure timely, consistent care for this vulnerable population. Contact: Erin E Brown FNP; Erin.Brown2@bcm.edu

Platform Presentation #3	The Association Between Parental Nativity and the Use of Healthcare Transition Services for Youth with Intellectual and Developmental Disabilities *Catherine A. Harwood, MSSW PhD Student; Pei-Chiang Lee, MSW PhD Student; Sandra B. Vanegas, PhD,* Background: Research shows that being non-native to the United States (US) results in health disparities for children with and without disabilities (McGee and Claudio, 2018). Further, Becerra et al. (2014) found that having a foreign-born parent limits access to healthcare for children with autism. Extensive knowledge gaps about healthcare transition (HCT) for youth from diverse nativity backgrounds with intellectual and developmental disabilities (IDD) contribute to increasing health disparities. This study focuses on the association between parental nativity and access to HCT. Methods: To address research objectives around HCT, we explored the National Survey of Children's Health (NSCH) 2020-2022. The NSCH is a nationally representative survey of parents with children in the US. HCT questions included whether the youth spoke privately with the doctor, discussed transitioning to adult care, and were supported by their doctors to acquire skills and knowledge related to health care. IDD conditions included autism, developmental delay, intellectual disability, or Down syndrome. Parental nativity was measured by a dichotomous variable indicating if at least one parent was born outside the US. Results: The total sample included 3,106 youth with IDD. Ordinal regression was used to test the association. Results showed that having a parent born outside the US was associated with significantly lower odds of receiving HCT services (OR=0.54, CI=0.33-0.88), while controlling for other sociodemographic variables. Additional analyses will identify specific HCT activities that youth with IDD from diverse parental nativities are more likely to receive. Conclusion: Overall, these analyses show that parental nativity plays a significant role in receiving HCT services among youth with IDD. For example, children born to non-native parents may experience greater challenges in continuity of care. This suggests that greater efforts are needed to support youth with IDD whose parents are non-native to the US in making a successful healthcare transition. Contact: Catherine Harwood MSSW, PhD Student; caharwood@utexas.edu
Platform Presentation #4	The Impact of a Patient Navigator on Readiness Assessment Scores in Youth Transitioning to Adult Health Care in Alberta *Megan Patton, MSc; Cassandra Chisholm, MBA; Zoya Punjwani, MPH; Andrew S. Mackie, MD; Scott Patten; Daniella San-Martin Feeney, MSc; Samantha J. Anthony, PhD, MSW; Gina Dimitropoulos, PhD, MSW; Susan Samuel, MD* Background: At 16-19 years of age, youth with chronic medical conditions transition from their pediatric specialist to an adult specialist. Youth often feel unprepared for this transfer of care making transition preparations crucial. Transition readiness assessments may have a role in guiding transition preparation. The Transition Readiness Assessment Questionnaire (TRAQ) is the most validated readiness measurement. However, longitudinal examination of TRAQ scores is required to investigate the tool's suitability to assist in a successful transition. Methods: We conducted a sub-study of the Transition Navigator Trial, a pragmatic randomized controlled trial testing the effectiveness of a patient navigator intervention for youth with chronic health conditions transitioning to adult healthcare. A total of 129 participants were included in this analysis. Comparisons between the control and

	intervention group were performed with a Mann-Whitney U test. A mixed-model analysis with random intercepts was used to explore the relationship between access to a patient navigator, time, and TRAQ scores. Results: At baseline, there was no significant difference in mean TRAQ scores between the intervention and control group (β=0.05, p = 0.58, 95% CI -0.12, 0.22). Irrespective of treatment allocation, mean TRAQ scores did increase over time between both baseline to 12 months (β=0.54, p<0.001, 95% CI 0.44, 0.63), and baseline to 24 months (β =0.68, p<0.001, 95% CI 0.59, 0.78). In our sample alarmingly we note that only 56% of AYA were scoring > 4.0 ('ready' for transition as defined by the TRAQ) 24-months post enrollment into the study, which is between one to two years after their transition to adult care. Youth partners played a crucial role in providing insights into the study results, particularly in understanding the lack of significant findings. Conclusion: This study sought to examine the change in TRAQ scores in a longitudinal study between those assigned to a patient navigator intervention versus care as usual. We found that access to a patient navigator intervention did not significantly impact the rate of change in TRAQ scores. Our study underscores the criticality of partnering with youth in quantitative studies to ensure outcomes and analyses are relevant and impactful in addressing the needs of this population. Contact: Megan Patton, MSc; megan.patton@ucalgary.ca
	Poster Session 2
Poster #1	Assessing Healthcare Transition Readiness at a Multidisciplinary Neurodevelopmental Clinic in a Large County Hospital *Ruchita Iyer; Rishi Shah FACHE, Lauren Tardo, MD* Background: The multidisciplinary clinic model has been shown to improve health outcomes and decrease mortality in a cost-effective method for patients with complex health conditions. The Development & Cognitive Clinic (DCC) at Parkland Hospital is a multidisciplinary clinic for patients with neurodevelopmental conditions. To date, the clinic has received 21 referrals (20%) for patients transitioning from pediatric to adult care. To better understand transition readiness in this population, we conducted a mixed qualitative/quantitative survey. Methods: Patients and their families (participants) completing in-person were invited to participate in this study. Survey measures included patient satisfaction, perception of healthcare transition readiness (adapted from on gottransition.org), and an open-ended question asking how the clinic can improve. Qualitative data was analyzed using thematic analysis. Results: Data collection began in May and will continue through June 2024. Of the 22 responses collected to date, 9 patients recently transitioned from pediatric to adult care. 3 (33.3%) were female and 6 (66.7%) were male. 77.8-100% of patients reported receiving education on the healthcare transition process, differences between pediatric and adult care models, accessing medical information, and contacting their adult physicians. Preliminary thematic analysis identified parents requested additional care coordination support to help navigate multiple appointments, and social work support to better understand adult insurance options. One patient felt his transition education did not adequately prepare him the additional responsibilities that fall on an adult patient.

	Conclusions: In this preliminary mixed quantitative-qualitative analysis, we find a majority of patients do receive healthcare transition services. However, further investigation with thematic analysis shows participants still report gaps in transition readiness. Altogether, these preliminary findings demonstrate that DCC may further collaborate with the referring teams to better bridge care coordination, social work, and patient education. Future steps include completion of data collection and analysis to identify additional areas for improvement. Contact: Ruchita Iyer, ruchita.iyer@utsouthwestern.edu
Poster #2	Mental Health Transition Practices in College Students with and without Previous Suicide Attempts: An Exploratory Analysis *Nani Kim, BSN, RN, PhD student, Cara C. Young, PhD, APRN, FNP-C, FAANP, FAAN, Susan Calloway, PhD, FNP-BC, PMHNP-BC, FAANP* Background: The mental health of college students has worsened over the past decade, with the pandemic further exacerbating psychiatric symptoms. The suicide rate among transitional-aged youth increased dramatically, and mental disorders predispose them to suicidality. Successful transition practices are essential to supporting well-being; however, little is known about the difference in transition experiences between the group with and without a history of suicide attempt (SA). Methods: A cross-sectional survey was completed by college students with mental health disorders. The survey consisted of investigator-developed questions regarding transition practices, including (a) the perceived importance when selecting a university, and (b) the perceived importance of mental health-promoting activities (MHPA), as well as measures assessing the number of diagnosed mental health disorders, financial anxiety, life satisfaction, self-efficacy, and loneliness. With exploratory factor analyses to identify latent structures of the transition practices questions, a multivariate analysis of variance was performed to distinguish group membership based on the study variables. Results: A total sample of 94 college students (M [SD] = 20.6 [1.9]), of which 16 (17%) students with a previous SA and 78 (83%) who had no SA, completed the survey. The majority were female and White. Compared to the non-SA group, the SA group not only reported more importance on mental health services on campus and confidentiality but also had more negative views on MHPA. A significant multivariate effect of SA on the study variables was evident, and univariate comparison tests revealed the number of mental health disorders and loneliness were higher in the SA group. Conclusion: Study findings suggest that students entering college with a history of SA would benefit from additional support during the transition into college. Potential solutions may be peer mentor/support groups to alleviate loneliness and strategies to enhance the quality of mental health services available on campus and confidentiality. Contact: Nani Kim, BSN, RN, PhD student; nanikim@utexas.edu
Poster #3	Workshops to Support Transition-Age Patients Co-designed and Developed with Adolescent and Young Adult Advisory Council *Rachel Cuevas, BS, BA; Martha Mendoza Orozco, MPH; Emozino Ayetuoma, MPH; Brianna Capers, AA; Jesus Covarrubias; Soha Ghavami; Danissa Maroquin, MS; Monica Mejia; Adan Santiago; Asma Sodager, BS; Dalen Thomas, BA; Daron Wong; Courtney Porter, MPH, CPHQ*

	Background: To have a successful transition, adolescent and young adult (AYA) patients with chronic health conditions need to develop skills to manage their condition(s) and transfer to comprehensive health care services in adulthood. Although healthcare team members and caregivers play an essential role in introducing the skills and education needed for pediatric patients to begin exploring healthcare independence, patients can also benefit from learning from other AYAs. The engagement of individuals with lived experience in the co-design of interventions, including virtual workshops on transition skills, has been demonstrated to bring unique knowledge and experience and has been well received by AYA participants. Methods: A three-part workshop series was co-designed and developed with Children's Hospital Los Angeles (CHLA) AYA Advisory Council members to provide transition education, resources, and tools to patients aged 15-21. Fifteen council members used their lived experience to begin narrowing the list of transition topics identified through stakeholder assessment data. Ten council members formed a workgroup focused on co-designing and developing the three workshop topics identified by the larger council: healthcare transition and independence, insurance, and self-care and support. Results: Workgroup members attend bi-weekly, virtual meetings focused on reviewing content and providing suggestions and feedback based on their lived experience, expertise, and AYA perspectives. Feedback is incorporated into slides and engagement activities and presented to workgroup members for final edits. Members are also developing AYA-friendly supplemental resources for workshop attendees and will help facilitate the virtual workshops. Workgroup members will be compensated for time spent co-designing and facilitating the workshops. Conclusion: AYA patients aged 15-21 will be invited to attend the virtual AYA workshops this summer. Post-workshop surveys will be administered to evaluate workshop objectives. Workgroup will reconvene to debrief the workshop series, review evaluation data, and discuss future implementation. Workshop series will be offered once a year. Contact: Rachel Cuevas, BS, BA; rcuevas@chla.usc.edu
Poster #4	Massachusetts Statewide NDD Transition Summit 2023: Deepening Engagement with Stakeholders *Susan Shanske, MSW, BRIDGES; Lindsay MacAuley, MPH; Tuba Rashid Khan MD, MPH, Ed.M; Sarah Spence, MD, PhD* Background: The Massachusetts Initiative to Improve Healthcare Transition for Individuals with Neurodevelopmental Disabilities (NDD) began in 2018 and developed into a multiyear quality improvement collaborative. An initial statewide summit was held in 2020 to engage stakeholders. Building partnerships is an ongoing, primary aim of the initiative and an updated summit was held virtually in 2023. Methods: An interdisciplinary planning committee convened to create an agenda for the second statewide summit which included pediatricians, parents, adult providers, subspecialists and policy makers as presenters. The objectives for the summit were to: 1. Identify barriers and facilitators of equitable access to quality healthcare for transition-age youth with NDD; 2. Develop shared understanding of perspectives of diverse stakeholders, with particular attention to patient and family experience of the transition process; 3. Develop at least one action step to improve the transition process in their setting. Surveys were collected from participants to evaluate the program.

	Results: 170 people registered for the summit. Evaluation surveys were received from 65 participants, 100% of whom said that the summit met the learning objectives. The overall rating of the summit from the respondents was positive (98.5% rated very good or excellent) and respondents were satisfied with participation (completely satisfied=53.9%, mostly satisfied=41.5, somewhat satisfied=4.6%). Important for a summit built on inspiring action, 89.2% of respondents stated that they would make clinical, teaching, or administrative changes as a result of the summit, 98.5% expressed interest in further courses on the topic and 83.1% agreed that the summit helped to address, overcome or remove barriers to change in professional practice (16.9% neutral, 0% disagree). Conclusions: The summit, with the opportunities to engage with other collaborators from multiple perspectives, was valuable to participants. New stakeholders were engaged, and partnerships created. Contact: Susan Shanske, LICSW; susan.shanske@childrens.harvard.edu
Poster #5	Who Decides? Improving Documentation of Decision Makers for Adults in the Pediatric Setting *Salihah Hanson, LICSW; Susan Shanske, LICSW; Lindsey McMahon, MPH; Kristina Taylor, BSN, RN; Ahmet Uluer, DO, MPH* Background: Awareness of legal changes at age 18 is a national transition measure. An assigned health care proxy (HCP) is required for adults when incapacitated. For those requiring additional assistance, such as people with IDD, a guardian might be required. A Joint Commission survey of our institution in 2018 found that not all hospitalized adults had a documented HCP. Our transition team was repeatedly consulted regarding decision making authority for adult patients in the pediatric setting, including HCP or guardianship psychoeducation. The current system has significant room for error with multiple places to document decision maker status and inconsistency in obtaining and documenting the authority clearly. Methods: Social workers in the BRIDGES program developed a quality improvement project to improve documentation of HCP/guardianship. From June 2023 to May 2024, all patients 18+ admitted to the hospital were recorded in a database, along with their age and the admitting service. Records were reviewed to determine presence of HCP/guardianship. If neither were documented, social work intervened. Results: During the 10 months, an HCP or guardianship documentation was found in the chart 69.8% of the time. If neither were documented, social work intervened with 46.9% of the patients. The majority of the interventions involved outreach to colleagues to provide education (49%). In the 19% of patients where BRIDGES SW directly worked with the patient to obtain a HCP, the rate of HCP documentation increased from 51.5% to 54.2%. Conclusions: Documentation of decision maker status at our institution requires improvement. PDSA cycles helped determine potential interventions, uncovering administrative challenges, limitations in the electronic record and lack of knowledge by staff. Further education may improve social worker and other clinician understanding of both the need for and process of obtaining and documenting the important decision maker authority. Contact: Susan Shanske, LICSW; susan.shanske@childrens.harvard.edu

Poster #6	Multidisciplinary Pilot Program to Transfer Young Adults with Enteral Tube Needs to Adult Care *Ahmet Uluer, MD; Kristina Taylor, BSN, RN; Susan Shanske, MSW; Jennifer Lawlor, RN, BSN, CPN; Lori-Parker Hartigan, ND, RN, CPN; Tara McCarthy MS, RDN/LDN; Elizabeth Hait, MD MPH* Background: Enteral tube care in children is primarily managed by a multidisciplinary team consisting of a pediatric gastroenterologist, dietitian and nurse. Transfer of these patients has been challenging because this type of care does not typically fall under the purview of adult gastroenterologists. We describe a pilot program to streamline transfer of care for young adults with enteral tubes. Methods: Ten patients aged 21+ [range: 21 to 36 years] followed in the Pediatric Gastroenterology program at Boston Children's Hospital were identified as requiring enteral tube transfer support. Each patient's family underwent an intake interview with a BRIDGES Adult Transition Program nurse transfer co-ordinator (NTC). The BRIDGES NTC identified an adult PCP for the patient and set up appointments. The BRIDGES NTC collaborated with the Pediatric Gastroenterology team (gastroenterologist, nurse, dietitian) to create a written summary listing medications, type of enteral tube, frequency of tube changes, feeding orders, supply needs, and the medical plan. The summary was reviewed with the family and the adult PCP. The BRIDGES NTC also shared the medical summary with the adult Metabolic team at Brigham and Women's Hospital, a local tertiary care hospital, who will be responsible for mechanical tube exchanges and stoma care. Results: Between January and May 2024, two out of the 10 patients successfully transferred care. Seven patients have appointments scheduled with their adult team and are mid transition. One patient is awaiting a final endoscopic evaluation with the pediatric team before initiating transfer process. Conclusion: Our multidisciplinary pilot program to transfer young adults with enteral tube needs to adult care yielded improved patient care, decreased family anxiety, and successful transfer of care. A dedicated BRIDGES NTC was essential for co-ordinating the efforts of the multidisciplinary team. Contact: Elizabeth Hait, MD MPH; elizabeth.hait@childrens.harvard.edu
Poster #7	Assisting Teens and Young Adults Transition to Adulthood Through Short Educational Videos *Salihah Hanson, LISCW; Susan Shanske LISCW; Catherine Melnick; Nancy Easter LISCW; Alex Sullivan; Kristina Taylo RN; Colleen Huysman LISC; Ahmet Uluer, DO MPH* Background: Young adults with chronic and complex medical needs are living longer and farther into adulthood, which underscores the importance of a thoughtful and multi-modal transition process to speak to a broad range of learners. Through short second videos, we hope to provide education and enhance comfort level necessary for patients, caregivers and providers to feel comfortable covering transition related topics with youth and young adults under their care. We engaged with the Teen Advisory Committee (TAC) whose members provided feedback that helped with context, content and role-playing to engage a broad audience. Methods: With the expertise of OPENPediatrics (OP), an online medical education platform, the BRIGES Adult Transition (BAT) Program and TAC developed and continue to

	develop content applicable to youth and young adults transitioning to adulthood. A series of meetings with the TAC resulted in a list of themes, including self-management, decision making, time management, information sharing, emergency plan creation, self-advocacy, etc. The next step was script and storyboard development of 6 short videos, grouped around similar topics. The team created storyboards that included location, script, image description, animation, cast, settings, shot list and props needed. The OP video team educated the TAC and BAT on video production throughout the process. Barriers to completion included pandemic guidelines preventing video development and the project was resurrected after mask mandates were lifted and resources were reallocated. Results: Together with the TAC, BAT Program and OP, full storyboards were created for the topics: overview of transition, self-advocacy, how to find and meet new providers, topics on insurance, difference between pediatric and adult care, patient portal and information sharing. Conclusion: Two videos have been completed and the next 4 are in production to complete our first round of videos by this summer with an anticipated additional 6 educational videos planned. Contact: Salihah Hanson, LISCW; salihah.hanson@childrens.harvard.edu
Poster #8	Management of the mental health needs of autistic adults: A description of a psychiatric and primary care collaborative approach *Kristin Cooper, MD, Christopher Hanks, MD, and Ashley Byrd, MD* Background: Current data suggest that co-occurring mental health disorders are more prevalent in patients with autism spectrum disorder compared to the general population, which may reduce quality of life for these patients. While numerous models demonstrating a collaborative approach between primary care and psychiatry exist – few such models exist for the treatment of adults with autism. The Center for Autism Services and Transition (CAST) at The Ohio State University Wexner Medical Center provides primary care services for adults with autism. To improve access to psychiatric care, we partnered with a psychiatrist with expertise in treating patients with intellectual and developmental disabilities. Methods: We describe a collaborative approach for autistic adults between primary care physicians and a psychiatrist who began seeing CAST patients in the fall of 2021. In early 2022, CAST dedicated 0.1 FTE for this role, which increased to 0.2 FTE as of December 2023. We report on numbers of patients seen by the CAST psychiatrist to date. Results: Data collection is currently ongoing. Since joining the program, our psychiatrist has seen increasing numbers of CAST patients each year. In 2022, 2023, and 2024, CAST primary care providers saw 556, 566, and 378 (to date) unique patients. The psychiatrist saw 93 (17%), 120 (21%), and 132 (35%) unique CAST patients, respectively, amounting to 17%, 21%, and 35% of those patients seen in total through the CAST program. Conclusions: Management of mental health needs for adults with autism is a critical aspect of their care. As management of such conditions can be more complex within this population owing to communication barriers, varying manifestations, and challenging behaviors, providing high-quality mental healthcare is of upmost value. We report high rates of patients seeing psychiatry in our collaborative approach which may be of interest to other programs hoping to adopt a similar model.

	Contact: Kristin Cooper, MD; kristin.cooper@osumc.edu
Poster #9	Qualitative Study Examining the Experiences of CHWs in the Management of Care Transitions for Emerging Adults with Sickle Cell Disease (COMETS) Trial *Brahadesh Sivakumar; Sadie Butcher; Caren Steinway, LMSW MPH; Tanisha Belton, DrPH; Symme Trachtenberg, MSW; Desiree Williford PhD; Kim Smith-Whitley, MD; Sophia Jan, MD MSHP* Background: Community Health Workers (CHWs) have positive impacts on health and life outcomes. However, the CHW experience serving in this role, the impact the role has had on their professional trajectory, and perceptions of the profession are not well understood. Methods: From May-July 2023, semi-structured interviews were conducted with CHWs and CHW supervisors across the 5 recruitment sites affiliated with the COMETS study, a clinical trial comparing the effectiveness a CHW, mHealth application, or usual care on health-related quality of life of individuals with SCD transitioning from pediatric to adult care. Participants were asked about the importance of professional training and supervision for CHWs, the added value of CHWs to the care team, and growth due to being in the role. Interviews were transcribed and coded to identify major themes. Results: Interviews were conducted with 5 CHWs and 6 CHW supervisors. CHWs ranged from 24-72 years old (median age: 32). CHWs had previous personal or professional experience with SCD (3 of 5 disclosed a SCD diagnosis). Interviews with CHWs lasted approximately 1 hour 45 minutes (range: 61 -115 min). Interviews with supervisors lasted approximately an hour (range: 35-69 min). Participants felt that training provided was imperative in navigating conversations and building rapport with patients. All participants reported that CHWs had greater flexibility in communication and duration of patient support than other care team members. CHWs felt valued by other members of the care team but did not feel valued by the broader health care system. CHWs expressed that their role contributed to their professional and personal growth. Conclusion: CHWs and CHW supervisors reported that CHWs play unique and important roles within the care team. Future studies should further quantify the value of CHWs in the healthcare setting, especially for young adults with chronic illnesses transitioning to adult care. Contact: Caren Steinway LMSW MPH; csteinway@northwell.edu
Poster #10	Community Health Worker and Mobile Health for Emerging Adults Transitioning Sickle Cell Disease Care (COMETS Trial): Patient-Reported Outcomes at 6 Months *Sophia Jan, MD, MSHP; Caren Steinway, MPH, LMSW; Tanisha Belton, MPH, DrPH; Justine Shults, PhD; Laura Bennett; Heather Griffis, MS, PhD; Banu Aygun, MD; Abena Appiah-Kubi, MD, MPH; Nataly Apollonsky, MD; Donna Boruchov, MD; Omar Niss, MD; Lisa Schwarz, PhD; Lori Crosby, PsyD; Lamia Barakat, PhD; Biree Andemariam, MD); David Rubin; Kim Smith-Whitley* Background: Transitioning from pediatric to adult care presents challenges for young adults with sickle cell disease (SCD), including higher hospitalization rates and mortality risks. This study compares the effectiveness of community health worker (CHW) support, a mobile app (iManage), and usual care in improving quality of life, self-management, and hospitalization rates for these individuals.

	Methods: 405 participants aged 17 and older, from five children's hospitals in four US cities, were randomized to receive a six-month CHW program, iManage, or usual care. CHW and iManage participants set goals, developed self-care skills, tracked symptoms, and received transition support. CHW participants also received weekly support, while iManage participants had virtual peer support. The usual care group received standard care with a checklist for consistency. Primary outcomes included PedsQL for SCD, with secondary outcomes such as SCD knowledge, transition readiness, and social support. Results: At 6 months, both interventions (CHW or iManage) showed modest improvements in quality of life compared to usual care (PedsQL 3.5, P=0.003), with CHW intervention driving most of this improvement (PedsQL 5.2, P=0.0008). The largest change was observed in the communication II subscale. No significant differences were found in SCD knowledge, transition readiness, or social support. Conclusion(s): CHW and mobile health programs offer promise in enhancing the quality of life for young adults with SCD transitioning to adult care. These findings may guide clinic directors in adopting such programs. Contact: Caren Steinway, MPH, LMSW; csteinway@northwell.edu
Poster #11	Pre-Clinical Medical Students Piloting Transition *Elisha Acosta MD, Vaishnavi Sankar BS, and Jordan Kemere, MD, MS* Background: There is a current lack of training addressing the care of people with disabilities within national medical school curricula. The lack of training standards leads to a paucity of physicians trained to address the specific care needs and identify the barriers to optimal care for people with disability including during tenuous times such as health care transition from pediatric to adult care. It comes as little surprise that in a survey of fourth-year medical students, they reported that their education regarding people with disabilities had been inadequate, which resulted in feeling uncertain about obtaining a history, performing a physical exam, and helping patients with disabilities navigate their health care. Methods: Using an Understanding by Design educational framework, we developed learning objectives for our preclinical elective titled Navigating Barriers for Patients with Disabilities. We then considered how we would evaluate the impact of the course on the knowledge, skills, and attitudes of our students and developed a survey to be administered before and after the course. Lastly, we developed the educational content that would facilitate this learning including: 1 hour small group sessions, some of which were cofacilitated with individuals with lived experience; clinical sessions observing a visit in the pediatric health care setting and the adult health care setting; and reflection sessions. Results: The pre-clinical elective was offered in Fall 2023 as a pilot. 3 students registered for the elective and completed the course. We administered pre and post-surveys which included basic knowledge questions, space for feedback, and course satisfaction. Student comments provided useful feedback to future modifications of the course. Conclusion: Supplementing small group active learning sessions with clinical experiences is well received by pre-clinical students. This course will be offered again yearly with improvements based on the previous iterations and evaluation of knowledge as enrollment grows.

	Contact: Elisha Acosta MD, emacosta@bcm.edu
Poster #12	Healthcare Insights from a Neurodiverse Community Advisory Board *Ashley Smith; Kylie Cullinan, MD; Emily Nations Bufkin, MD* Background: Individuals with Neurodiversity (ND) experience health inequities and report lower healthcare quality and increased barriers to care compared to adults without ND. Identifying ND healthcare needs is necessary to equip physicians with the skills to provide equitable care. This community needs assessment investigates what patients with ND and their caregivers want physicians and medical trainees to understand about their healthcare experiences and how those experiences inform their transition and integration into adult care. Methods: Self-advocates and caregivers of people with ND volunteered to serve on a community advisory board (n=9). These volunteers completed a pre-interview survey that included Likert scales (with a visual response scale option) and open-ended questions regarding their experiences with healthcare. The survey was followed by semi-structured virtual interviews that were recorded and transcribed. Survey and interviews were conducted from April to May 2024. Thematic analysis was performed. Results: Thematic analysis identified six themes: (1) Sensory Sensitivities and Environmental Challenges; (2) Individualized Approaches and Accommodations; (3) Respect for the Patient and Patient Autonomy; (4) Partnership and Collaboration with Caregivers; (5) Lack of Physician Knowledge and Effects of Physician Assumptions; and (6) Organized Multidisciplinary Care. Conclusion: This community needs assessment underscores the importance of patient-centered and sensory-informed healthcare practices the prioritize understanding, accommodation, and empowerment for individuals with ND and their caregivers. It also highlights the need for structured training curriculums on the care of people with ND. The input from this community advisory board will inform the development of a Neurodiversity curriculum for clinical medical students, aiming to improve trainees' attitudes, knowledge, skills, and comfort in caring for patients with ND. Their input will also inform the future development of an adult medical home for people with ND and sensory pathways for current clinical spaces in a large academic health center. Contact: Ashley Smith; Ashley.Smith2@UTSouthwestern.edu
Poster #13	Predictors of the Transition from Pediatric to Adult Epilepsy Care *Jasmine Sondhi MD; Esraa Ali MBBS; Krishna Trivedi, MD; Stephanie DeCarvalho, DO; Traci M. Kazmerski, MD, MS: Laura Kirkpatrick, MD* Background: To identify predictors of discussion about transition from pediatric to adult care, transfer to adult care, and retention in adult care among people with epilepsy. Methods: We reviewed medical records for individuals with epilepsy age ≥15 years seen outpatient by pediatric neurology in 2019. We evaluated whether they had documentation of transition discussion, if they transferred to adult care, and/or if they were retained in adult care (defined as ≥1 appointment/year and ≥1 year from transfer to study end) from 2019-2022. Excluding individuals who died or were discharged, we performed logistic regression for transition discussion, transfer, and retention, adjusting for sex, age,

	race/ethnicity, distance from institution, zip code median household income, rurality, drug-resistant epilepsy (DRE), intellectual disability (ID), and technology-dependence. Results: We tracked 274 individuals (50% female, median age 18, 84% white, 1.5% Hispanic, 24% DRE, 25% ID). Excluding 14 who died and 28 who were discharged, 57/226 (25%) had a documented transition discussion and 115 (51%) transitioned (median age 20 years). Of 95 eligible individuals, 77 (81%) were retained in adult care. Predictors (p<0.05) of transition discussion included older age (aOR 1.44, 95% CI 1.22, 1.70) and absence of ID (aOR 4.17 [1.51, 11.11]). Predictors of transfer included older age (aOR 1.19 [1.02, 1.39]), documented transition discussion (aOR 3.25 [1.48, 7.13]), and DRE (aOR 2.41 [1.10, 5.28]). We identified no significant predictors of retention. Conclusions: Discussion of transition promotes transfer to adult care among people with epilepsy. Development of patient-facing interventions, provider training, and tools in the electronic medical record may improve the transition of this population, especially in those with co-existing ID. Contact: Jasmine Sondhi MD; jasmine.sondhi@chp.edu
Poster #14	The Role of Social Work Leadership in Healthcare Transition Programs *Angela Berger, MSW; Terri Hickam, MSW, CCM; Reny Partain, MSW, MPH; Susan Shanske, MSW; Symme Trachtenberg, MSW* Background: Social workers are trained to help individuals navigate life transitions including transitions in healthcare. Healthcare transition comes with a myriad of psychosocial stressors and complex systemic challenges. Social workers practice at the micro, mezzo, and macro levels to address these transition needs. With this foundation, social workers are uniquely prepared to address needs at every level, including leadership of systemic approaches to transition challenges. Methods: Our aim was to look at the inclusion of social workers as transition leaders. Members of the Healthcare Transition Research Consortium completed an 11-item survey on the scope and staffing model of HCT efforts at their institution. Three questions were specific to the role of social workers on dedicated transition programs. Questions were developed by a team of social work leaders in HCT who work across the US. Results: Thirty-four healthcare professionals from 29 unique healthcare institutions across North America responded. Twenty-three institutions have a formal transition program with funded positions; 39% of programs were hospital-wide, 35% were disease-specific, and 26% had both. Most programs had 1.01-3.0 FTEs dedicated to HCT (35%) and 26% had more than 5.0 FTEs. The most common disciplines across programs were social work (N=22), physician (N=17), and nursing (N=11). Of the programs with social work, 91% have a master's degree and 9% have at least a bachelor's in social work. Conclusion(s): Social workers are integral members of HCT programs. As more healthcare institutions invest in transition programs, it is important to understand the role social workers play in not only providing direct patient care, but ideally trained to champion program development and serve in transition leadership positions. Given the clinical, systems navigation, and organizational leadership skills of social workers, it is critical to recognize the strong contributions social workers make to HCT programs on every level. Contact: Reny Partain, MSW, MPH; lauren.partain@choc.org

Poster #15

Mixed-Methods Evaluation of the Clients of the Adolescent and Young Adult Health Care Transition Clinic

Hannah Chew BS, Kemberlee Bonnet MA, David Schlundt PhD, Nina Hill MD, Leslie Pierce MPH, Aima Ahonkhai MD, MPH, Neerav Desai MD

Background: Young people living with HIV (YPLHIV) have numerous obstacles during transition to adult care. To address these challenges, the Adolescent and Young Adult Health Care Transition Clinic (AYAHCT) was created at Vanderbilt University Medical Center in 2017. This mixed-methods study evaluates the initial cohort of clients and solicits qualitative reflections from YPLHIV on barriers, facilitators to transition.

Methods: Qualitative interviews capturing patients' experiences at AYAHCT and their transition between care settings were thematically analyzed. Quantitative analyses characterized patients' demographics, time spent in AYAHCT, retention and viral suppression.

Results: 21 clients were included in the study, with a mean age of 19.6 years at their first visit. The average duration in the clinic was 2.21 years. Engagement in the first year was 100%, with a retention rate of 95.5%. Viral suppression rates improved from 66.7% at the first visit to 81.0% at the last visit. 11 clients successfully transitioned out of the AYAHCT program. Qualitative analyses indicate that transition was facilitated by trust in providers, staff support in building autonomy, communication, comfortable clinical environment, and youth-friendly services. Challenges include leaving a trusted provider, reduced parental guidance, developing autonomy, and loss of confidentiality in adult clinic environment.

Conclusions: YPLHIV report positive attitudes towards AYAHCT team and clinic. This study outlines interventions to successfully transition adolescents to adult HIV care. Future direction includes 1) optimize services to build YPLHIV's independence navigating their healthcare 2) support YPLHIV experiencing stigma 3) assuage concerns about switching providers 4) collaborate with adult clinic to protect confidentiality in common clinical spaces 5) identify interventions that focus on adherence during transition.

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Poster #16

A Novel Healthcare Transition Structure for Adult Patients with Medical Complexity

Kathleen Irby, MD FAAP; Kira Watson, MD MPH FAAP

Background: With advances in medical and surgical management, a growing number of children with medical complexity are reaching adulthood. Within our health system, there are many complex adults still in the pediatric system. A significant barrier to successful transition out of pediatric care is the availability of adapted adult care systems. We aimed to develop a comprehensive adult medical home, the Adult Developmental Medicine and Transition (ADMAT) clinic, to provide high quality primary care with age-appropriate care teams and processes.

Methods: Using active patient volumes from two pediatric subspecialty clinics, we identified 260 patients aged 18 years and older who qualified for specialized primary care. With the addition of a new med+peds provider trained in Developmental Medicine and Palliative Medicine, we were able to start the ADMAT clinic. We began accepting informal referrals to the ADMAT clinic in July 2023. We slowly built a patient panel while building referral networks and establishing a clinical support structure.

	Results: The ADMAT clinic currently consists of 45 primary care patients and averages 3-5 new patients per month without active recruitment. Ninety-one percent have 2 or more subspecialists. Thirty-eight percent have cerebral palsy GMFSC 4-5. Eighteen percent have tracheostomy and ventilator dependencies. Twenty-two percent are over 30 years old, and fifty-one percent are female. While most referrals came through specialty clinics, we did receive six through community connections. Conclusion(s): The early growth of the ADMAT clinic demonstrates a high volume of need for comprehensive adult primary care for patients with medical complexity. The most significant barrier to continued growth is lack of clinical support staff to manage care coordination needs. In the upcoming year, we plan to build a sustainable medical home for this population. The characteristics and utilization patterns of established patients will be monitored to scale the clinic structure and its growth. Contact: Kathleen Irby, MD FAAP; kathleen.irby@hsc.utah.edu
Poster #17	8 Years of Successful Transition: A Description of an Adult Clinic’s Transition Program *Cybele Ghossein, MD; Laura Nishi, DScPAS, PA-C; Lauren Suchy Marzinelli, LCSW, MPH* Background: Without proper support, pediatric patients transitioning to adult care are at risk for poor outcomes, including interruption in care. To address this high-risk population, we instituted a pediatric to adult nephrology transition clinic at our institution. Here we describe our eight-year follow up. Method: Once a month, our adult Northwestern Medicine (NM) transition team (comprised of an adult Nephrologist, Physician Associate, and social worker) holds a nephrology clinic at Lurie Children’s Hospital (LCH) for young adults (YA) who are ready to transfer their care from pediatric to adult nephrology. Prior to LCH clinic, we obtain medical and demographic information and meet with the pediatric team to review the patients. During the transition clinic appointment, we screen for high-risk behaviors, provide transition education and confirm insurance and communication preferences. Patients leave with an appointment at NM within a short interval. Our adult team reviews our transition cohort weekly and contacts patients, as necessary, for appointment reminders and check-ins. Successful transition (ST) was defined as returning for follow up at NM. Patients who No Show (NOS) for their follow up appointments receive an escalated communication protocol (ECP). Methods: This is a qualitative descriptive study with the purpose of identifying future research routes in determining successful transition interventions. Results: From 2014-2022, we saw 154 patients in our transition clinic with 141 ST, some required ECP. Conclusion: Here we describe our 8-year nephrology transition clinic in which evolving protocols resulted in ST of 141 patients. Ongoing studies will be needed to assess success in other specialties and institutions. Contact: Cybele Ghossein, MD; cybele.ghossein@nm.org
Poster #18	Family-Centered PCP-led Transition of Medically Complex Youth with Intellectual Delay to Adult Care: All Grown Up! *Charu J Sehgal, DO; Heather C Moore, MD; Elizondo, MSN, RN* Background: Medically complex youth with IDD have obstacles transferring to adult

	medical care. This causes unintentional health deterioration, increased community costs. resource overutilization, and patient/family dissatisfaction with the process. Family collaboration with Complex Care Pediatric teams prevents pitfalls of transition, and result in successful placement of medically fragile youth with appropriate adult medical providers. SMART/AIM statement: In 12 months, using the Complex Care-developed transition algorithm, the percentage of 20- and 21-year-old Complex Care patients transferred to adult care will increase to 25%. Methods: In 2022, the Complex Care Transition process map and Transition visits templates for PCP were developed and implemented to move 39 patients ≥20 years to adult medicine. The pathway contained all team member roles and routes depending on insurance. Transition visits template questions were designed to elicit patient transition needs to be completed yearly after 17. When PCP confirms readiness (ages 20-21), Transition registry is updated so care coordination knows to make outreach calls to families for scheduling with adult PCP. After an adult visit is completed, discharge from clinic flagged. Results: PDSA #1: From March 2022 to December 2022, noted number of completed transfers from EPIC CCC Transition registry ≥ 20 years old to generate an overall percentage for this cohort of patients: • % Transitioned = (#transfers completed/39)x 100% = 6/39 x 100%= 15.4%. Monthly rate of transition was 0-5%. PDSA #2 from January 2023-December 2023 was continued without changes for more data points, as PDSA #1 all teams were learning the process. Total percentage increased, with 11 patients out of 46 transitioned for a percent of 24%. Monthly rates varied from 0-6%. Conclusions: Transition process map/transition visits increased the percentage of complex ID youth transferring on time into adult care between PDSA cycles, going from 15.4% to 24%. Monthly transfer rates did not change, reflecting challenges that families face in transition: obtaining guardianship and social security, transportation to clinic, reluctance to move onto adult providers who do not have historic reference. For new clinic staff, the process map needs to be learned again which can lower the percentage transitioned for that month. Interventions discussed helped patient families and PCPs focus on the tasks they needed to complete for transition, improving confidence. This includes using the process map to see where an intervention can be placed to improve rates. Parent/caregiver qualitative interviews in this space would give some insight of where to intervene. Contact: Charu J Sehgal, DO; cjsehgal@bcm.edu
Poster #19	Educating Aspiring Healthcare Providers to Enhance Healthcare Delivery for Patients with Disabilities *Jonathan Tolentino, MD, MS-HPE; Anjali Saxena, MD; Rochelle Baer, MSW, LCSW; Jairo Arana; Jenna Tatavitto; Brady Wallace; Esther Cine; Ashley Falcon, PhD, MPH* Background: Health disparities experienced by individuals with disabilities can be attributed, in part, to the receipt of inadequate healthcare. A dearth of adequate training for healthcare providers (HCP) contributes to a documented, self-reported lack of knowledge about and confidence in providing appropriate care to this vulnerable population. Efforts to

	prepare HCPs should begin before entry into the workforce. This pilot study aims to assess the impact of an educational intervention among aspiring HCPs. Methods: A one-arm, uncontrolled interventional study was conducted. Current medical trainees completed an interactive online training. Pre- and post-surveys assessed changes in knowledge, attitudes, and confidence in providing care to patients with disabilities. After completing the online training, trainees currently in a disability-focused clinical rotation also led a patient visit, which was observed by a facilitator using a performance checklist to evaluate behaviors emphasized within the online training and participated in a follow-up debriefing session. Patients seen by a trainee also completed a brief satisfaction survey at the end of their visit. Results: Results are forthcoming and will include the impact of the online training as determined by trainees' online training survey change scores, performance during observed patient visits, and patient satisfaction levels. Conclusion: Disability awareness and sensitivity training can improve HCPs' attitudes and confidence, though assessment should aim to link behavioral antecedents to actual care delivery, including patient input. The proven effectiveness of these educational methods can affirm curricular integration initiatives, enhance healthcare experiences and health outcomes of patients with disabilities, and reduce healthcare costs overall. Contact: Ashley Falcon, PhD, MPH; afalcon1@miami.edu
Poster #20	Interdisciplinary Education in Transition for Internal Medicine-Pediatrics Residents *Erin Tully, MD: Brittany Glassberg, MD; Dava Szalda, MD MSHP* Background: Healthcare providers report lack of training in transition and caring for youth with special healthcare needs as a barrier to successful transition. Combined Internal Medicine-Pediatric (Med-Peds) residents may receive varied training around transition. This project aimed to facilitate resident transition education with an interdisciplinary approach as an initial step in building a formal transitions curriculum for our program. Methods: Med-Peds residents received a 1-hour didactic session followed by a discussion with an interdisciplinary transition team member (physician, nurse practitioner, nurse care manager and/or social worker) during ambulatory time during the 2023-2024 academic year. The didactic included definitions of healthcare transition, the six core elements of transition, variations in implementing transitions practices, and a framework for facilitating transition. Residents had the opportunity to discuss barriers to transition with members of the interdisciplinary transition team. Residents were surveyed before and after the session to assess knowledge and comfort level with the transition process. Results: All eligible residents participated in the curriculum. Knowledge of the definition of transition was unchanged and the ability to identify the six core elements of transition improved across pre-and post-survey data. Resident self-assessed comfort level with helping patients transition to adult care was assessed on a Likert scale from 1-5, with 1 being very uncomfortable to 5, very comfortable. The average comfort level improved from a mean of 2.1 pre-session to 3.1 in the post-session survey. Resident comments were largely positive, and feedback from the interdisciplinary transition team members was highly positive and indicated interest in future sessions.

	Conclusion: The introduction of a didactic and interdisciplinary discussion session into the Med-Peds residency ambulatory curriculum was met with high participation and satisfaction and can be a successful approach to incorporating an interdisciplinary transition curriculum into the Med-Peds residency experience. Contact: Erin Tully, MD: tullye1@chop.edu
Poster #21	Transitioning Adolescents/Young Adults to Adult Primary Care: A Resident-led Quality Improvement Initiative *Erin Tully, MD: Kevin Ackerman, MD; Madeline Chandra, MD; Swati Goel, MD; Dava Szalda, MD MSHP* Background: Young adult patients often face challenges accessing care after transitioning out of pediatric primary care. Pediatric primary care providers often cite difficulty identifying adult primary care providers for their young adult patients. Prior quality improvement research through our program identified that Internal Medicine-Pediatric (Med-Peds) residents and faculty feel more prepared to care for young adults and fill this role. This project aimed to enhance access to adult primary care providers for young adults. Methods: One internal medicine primary care clinic, staffed in part by Med-Peds trainees, was chosen for this study. Target patients included new patients between 18-30 years of age. Baseline data from July 2021 – June 2022 was collected to evaluate the number, demographics, and burden of chronic medical conditions of target patients seen by Med-Peds residents. In the initial Plan-Do-Study-Act cycle, a new appointment transition template was created, and two appointment slots were held per week per Med-Peds resident for target patients. Results: At baseline, Med-Peds residents saw an average of 0.58 new patients 18-30 years each quarter. During Cycle 1, Med-Peds residents saw 2.6 target patients per quarter. This represented an over 300% increase in new patients 18-30 years seen by Med-Peds residents. Results for cycle 2 are currently being collected and will be presented at time of conference. Conclusion: Our data suggests that (1) trainee QI activities can add robust access for young adult patients in adult primary care and (2) adding reserved new patient visit slots for young adult patients is an effective method to increase the number of young adult new patients seen by trainees. Subsequent cycles will address additional barriers to accessing these appointments, further focus on patients with medical complexity, intellectual disabilities, or social barriers to transition of care. Contact: Erin Tully, MD: tullye1@chop.edu
Poster #22	Systematic Review of Support System Interventions for Solid Organ Transplant Patients Transitioning from Pediatric to Adult Healthcare *Anji Zhu BSN, MPH; Karim. G. Mina MD, MPH, Shea. O. Herlihy MPH, Samad. Siddiqui MPH, Zexuan Yu MPH, Renata. W. Yen PhD, MPH*. Background: Pediatric Solid Organ Transplant (SOT) patients experience higher rates of non-compliance with care plans, graft rejection, graft loss, and mortality after their Health Care Transition (HCT). They require consistent, specialized care to ensure their well-being and reduce the likelihood of graft loss and other complications. There is some evidence that transitional support interventions for pediatric transplant recipients can improve care compliance, perceived health status, quality of life, and self-care skills. However, no formal

reviews have been conducted in this field. Our team is conducting a systematic review to determine whether formal support system interventions improve patient adherence to care plans in SOT patients (ages 12-26) transitioning to the adult care system compared to standard care. Additionally, we are comparing existing interventions with the latest frameworks for evaluating transitional care interventions, applying the new HCT quality measurement framework developed by Margaret McManus and colleagues in 2022.

Methods: We searched MEDLINE via PubMed, Cochrane Database of Systematic Reviews, and Scopus. The primary outcome was adherence to care, measured with immunosuppression metrics. Secondary outcomes included graft rejection episodes, graft loss, and mortality.

Results: We identified 3267 studies and, after screening, included 20 studies that met our criteria. We will perform a meta-analysis of the combined results where applicable and compare all interventions with McManus‘s framework using qualitative methods to describe the strengths and weaknesses of existing interventions.

Conclusions: The results of this study may reinforce support system interventions as a means of improving patient adherence and mitigating poor health outcomes during HCT for pediatric transplant patients. This may also assist healthcare institutions in deciding which support methods to implement and how to improve existing interventions.

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Poster #23

Higher Transition Readiness Scores Associated with Higher Emergency Department Visits in Adolescents and Emerging Adults

Zoya Punjwani, PhD, MPH; Cassandra Chisholm, MD(c), MMgmt, BSc; Megan Patton, MSc; Laurel Ryan, MFA; Daniella San Martin-Feeney, MSc; Andrew Mackie, MD, SM; Gina Dimitropoulos, PhD, MSW; Susan Samuel, MD MSc

Background: The transition from pediatric to adult health care for adolescents and emerging adults (AEA) with chronic health conditions is associated with increased emergency department (ED) visits. The Transition Readiness Assessment Questionnaire (TRAQ) is a validated measure of transition readiness that aims to assess how prepared AEA are to undergo this transition. The objective of this study was to examine the association between AEA’s TRAQ scores and ED visit rates during their transition to adult care.

Methods: This was a patient-oriented retrospective observational study assessing the association between TRAQ scores and ED visits in AEA enrolled in the Transition Navigator Trial (TNT). Data was obtained from TNT, a pragmatic randomized controlled trial evaluating the effectiveness of a patient navigator intervention. The National Ambulatory Care Reporting System (NACRS) provided all-cause ED visit data for participants. Descriptive statistics summarized the TRAQ scores and ED visit use by age, sex, ethnicity, immigration status, socioeconomic status as determined by the Pampalon Index, urban/rural residence, presence of co-occurring mental health condition, and primary chronic health condition. Zero-inflated negative binomial regression examined the association between TRAQ scores and ED visits. A sensitivity analysis was conducted to assess if the COVID-19 pandemic impacted the findings.

Results: A total of 208 AEA were included in this study. Higher TRAQ scores were associated with higher ED visit rates (adjusted IRR=1.49, 95% CI: 1.11-1.99, p=0.007). ED

	visit rates were higher for females, AEA who were racialized, those who were in the most deprived quintile of the Pampalon index, AEA in rural areas, and AEA with co-occurring mental health conditions. Conclusion: We observed that higher TRAQ scores were associated with higher ED visit rates. This prompts questions about whether TRAQ accurately measures readiness or whether more prepared AEA seek emergency care. Contact: Zoya Punjwani, PhD, MPH; zoya.punjwani@ucalgary.ca
Poster #24	A Multi-Site Study of Transition Improvement in Primary Care for Youth and Young Adults with Epilepsy (CYE) *Peter Corcoran, PhD; Patience White, MD, MA; Peggy McManus, MHS* Background: The transition period between 12 and 26 is an especially critical time for youth and young adults (Y/YA) with epilepsy. Y/YA with epilepsy have a higher epilepsy prevalence rate than their younger and older peers, transition is also associated with higher risk for mortality and morbidity as well as increased non-adherence to their medical regimen. Receipt of transition preparation among youth with special health care needs (YSHCN), including epilepsy, is low and transition intervention literature for CYE is sparce. Methods: Participating in this study were seven pediatric primary care sites working with children and youth with epilepsy (CYE) grantees participating in the Maternal and Child Health Bureau's Transforming Health Care for CYE Program from 2018 to 2022. A mixed methods approach was used to evaluate pediatric to adult health care transition (HCT) improvements. Got Transition's Current Assessment of HCT Activities was administered annually to measure implementation of the Six Core Elements of HCT along with youth and family leadership. Participants from the seven sites engaged in bi-monthly virtual learning collaborative sessions, including bi-monthly Plan-Do-Study-Act cycles, team huddles, chart reviews, and QI coaching calls to facilitate practice change. The QI sessions included presentations from the AAP and HCT content experts. Results: Over the four-year study period, findings from Got Transition's Current Assessment of HCT Activities (CA) showed improvements in the overall and individual core element scores going from 11.31 to 16.25 (out of a maximum score of 32). The increases are statistically significant (F=5.220, p=0.002, df=3) and represent a 43.7% increase. Conclusions: This is the first study looking at incorporating a HCT structured process for CYE. This study demonstrated HCT planning component improved and that primary care practices can embark on a multiyear HCT improvement process for their patients with funded time and external QI and subject matter support. Contact: Margaret McManus, MHS, mmcmanus@thenationalalliance.org
	Platform Session 3: Educational Perspectives, Innovations and Policy Implications
Platform Presentation #1	Do you have what it takes to transition? Association of coping strategies and social support on transition readiness among young adults with sickle cell disease *Apoorva Iyengar, MD; Tisheya C. Ward, BA; Tanisha D. Belton, DrPh, MPH; Banu Aygun, MD; Abena Appiah-Kubi, MD, MPH; Nataly Apollonsky, MD; Donna Boruchov, MD; Biree Andemariam, MD; Omar Niss, MD; Lori E. Crosby, PsyD; Lisa Schwartz, PhD; Lamia P.*

	Barakat, PhD; Jack Chen, MBS; Kim Smith-Whitley, MD; Sophia Jan, MD, MSHP; Caren Steinway, LMSW MPH Background: Suboptimal preparation of adolescents and young adults (AYA) with Sickle Cell Disease (SCD) from as they transfer from pediatric to adult-care can negatively impact disease outcome, medication adherence, and successful transition to adulthood. Positive coping strategies have been associated with improved transition readiness. This study evaluates whether coping strategies and social supports in AYA with SCD are associated with transition readiness in a large national sample, and which coping strategies had greatest impact. Methods: A retrospective observational study on data collected between 1/2019-12/2022 from AYA with SCD (ages 17-25) planning to transition to adult hematology within 12 months. Data collected from 5 institutions across NY, PA, CT and OH. Outcome was transition readiness, as measured by the Transition Readiness Assessment Questionnaire (TRAQ). Predictors were coping, as measured by Brief COPE, and social support, as measured by MOS Social Support Survey Emotional/Information Subscale. Multivariate analysis was used to assess the relationship between coping and transition readiness, after adjusting for age, gender, disease severity (acute stroke history, hydroxyurea prescription, hospitalization history), and worry (PedsQL Sickle Cell Module Worry 1). Results: The 373 participants were equally distributed by gender, largely non-Hispanic black by race/ethnicity, and 56% with severe sickle cell disease. Bivariate analysis showed that overall coping (B=.138, P=0.34) and social support (B=.127, p<0.001) were significantly associated with transition readiness. Problem-focused coping (B=.177, p<.001) was most strongly associated with transition readiness. After adjusting for age (<=21 vs. >21), gender, disease severity (moderate vs. severe), both coping (b=.130, p=0.008) and social support (b=0.089, p<.007) were still significantly associated with transition readiness. Conclusion: Targeted behavioral interventions that improve problem-focused coping may be used to improve transition readiness among AYA with chronic disease. Contact: Apoorva Iyengar, MD; aiyengar@northwell.edu
Platform Presentation #2	Association of disease specific-worry on pain-related quality of life in young adults with sickle cell disease *Apoorva Iyengar, MD; Tisheya C. Ward, BA; Tanisha D. Belton, DrPh, MPH; Banu Aygun, MD; Abena Appiah-Kubi, MD, MPH; Nataly Apollonsky, MD; Donna Boruchov, MD; Biree Andemariam, MD; Omar Niss, MD; Lori E. Crosby, PsyD; Lisa Schwartz, PhD; Lamia P. Barakat, PhD; Jack Chen, MBS; Kim Smith-Whitley, MD; Sophia Jan, MD, MSHP; Caren Steinway, LMSW MPH* Background: Sickle Cell Disease (SCD) is an inherited hemoglobinopathy with multisystem complications including painful vaso-occlusive crisis. People with SCD usually have worse quality of life (QOL) than the general population. Previous studies in adults with SCD show that the impact of worry influences QOL related to pain. This study evaluates the association between worry and pain related QOL in adolescents and young adults (AYA) with SCD. We also examined whether emotional social support and problem-based coping strategies moderate this association. Methods: This is a retrospective observational study on data collected between 1/2019-

	12/2022 from AYA with SCD (ages 17 – 25) at 5 pediatric SCD centers in NY, PA, CT, and OH planning to transition to adult hematology within 12 months. Predictor was worry, as measured by the PedsQL Sickle Cell Module Worry 1 subscale. Outcome was pain, as measured by the PedsQL Sickle Cell Module Pain Impact subscale. Multivariate regression assessed the effect of worry on pain, and moderating effects of social support – measured by MOS Social Support Survey Emotional/Informational Support subscale – and coping – measured by Brief-COPE, after adjustment for demographic and clinical characteristics, and transition readiness, measured by the Transition Readiness Assessment Questionnaire. Results: The 373 participants were equally distributed by gender, largely non-Hispanic black by race/ethnicity, with 56% considered having severe sickle cell disease. Worry was positively associated with pain in bivariate analysis (B .795, p <.001). In multivariate analysis, coping (P<0.001) but not social support (P=0.132) moderated the relationship between worry and pain. After controlling for age, gender, disease severity, and transition readiness, worry was still significantly associated with pain (p<.001). Conclusion: In this national cohort of AYA with SCD, worry and coping are closely connected to pain-related QOL. Future studies should focus on the development of interventions for pain management in this population. Contact: Apoorva Iyengar, MD; aiyengar@northwell.edu
Platform Presentation #3	Enhancing Education in Primary Care for Youth and Adults with IDD through Project ECHO® *Ellen Fremion, MD; K. Jordan Kemere, MD; Nital Appelbaum, PhD.* Background: The scarcity of adult healthcare providers who are knowledgeable about the care of individuals with intellectual/developmental disabilities (IDD) has long been acknowledged as a barrier to healthcare transition. To address this knowledge gap, a Project ECHO® series was developed for a multidisciplinary audience of physicians, advanced practitioners, nurses and social workers with the goal of improving knowledge and comfort in caring for the IDD population regarding: clinical accommodations, behavior change evaluation, constipation, aspiration, seizures, and aging. Methods: A multidisciplinary team of clinical experts in youth and adult IDD care was convened to develop the topics, didactic PowerPoints, and cases following the Project ECHO® format. Participants were recruited from a managed care organization Medicaid, the affiliated adult and pediatric hospital and medical school, the University Center for Excellence network, and professional organizations and attended monthly virtual sessions. Each of the six sessions had evaluation questions focused on knowledge and comfort related to the session objectives. Respondents used a 1-10 Likert scale (1= No Confidence/10=Very High Confidence; 1= No Knowledge/10=Very High Knowledge). Each paired item was analyzed independently through paired samples t-test and Hedge’s g effect size calculations. Results: In total, 120 registered for the course with 39 physicians, 11 advanced practitioners, 27 nurses, 28 social workers, 2 psychologists, and 13 other IDD care providers. All twelve knowledge and comfort items resulted in improved ratings after participation in the sessions. The largest effect sizes, representing meaningful improvement, came from the Aging with IDD session.

	Conclusion: This pilot ECHO curriculum improved participants' knowledge and comfort in IDD care topics indicating that the Project ECHO® platform may be a feasible modality to address gaps in provider knowledge and comfort in caring for patients with IDD transitioning to adult care. Contact: Ellen Fremion, MD; ellen.fremion@bcm.edu
Platform #4	The Feasibility, Acceptability, and Efficacy of an Intervention (IPACT) to Improve Provider Behavior in Promoting Autonomy and Competence in Transition-Aged Youth *Jordyn Babla, BS; Constance M Wiemann, PhD; Blanca Sanchez-Fournier, BA; Beth H. Garland, PhD; Cortney Zimmerman, PhD; Marietta M. de Guzman, MD; Seema Walsh, MD; Kimberly Houck, MD; Mary Majumder, JD, PhD; Albert C. Hergenroeder, MD* Background: Time alone with their pediatric provider is a core element in helping adolescents and young adults with special health care needs (AYASHCN) develop self-management skills. Only 44% of AYASHCN report meeting with providers alone due to providers' lack of time and training. This report details the provider training component of a multi-level intervention designed to promote autonomy and competence in AYASHCN. Methods: 22 providers participated in a two-session, virtual, multimodal intervention that included: 1) video of a physician inviting a caregiver out of the room; 2) encouragement to support AYASHCN self-management and seeing an adult provider; and 3) demonstration of how to generate an electronic portable medical summary (PMS). Outcome measures included percent of visits with AYASHCN interviewed alone and during which the provider generated a PMS; provider importance of autonomy supportive and transition planning behaviors and their frequency. Pre/post-intervention scores were compared using paired t-tests or McNemar change tests. Results: 100% of intervention sessions were implemented as planned. 89% of providers were very satisfied with the training and thought the intervention should be required for all providers in their service. 67% said they were very likely to continue inviting caregivers out of the room. By caregiver report, the percent of visits with AYASHCN interviewed alone increased from 21% at baseline to 79% after providers participated in the intervention (p<0.001). In contrast, the percent of visits wherein historical control AYASHCN (18yo) were interviewed alone was 36% (p<0.001). Providers generated a PMS in 77% of AYASHCN first visits after turning 18. Provider importance of engaging in transition planning activities and self-reported transition planning behaviors increased from pre- to post-training. Conclusion: IPACT was feasible, acceptable, and effective in encouraging providers to interview AYASHCN alone and generate a PMS. Provider importance of transition planning and their self-reported behaviors in promoting AYASHCN's self-management increased. Contact: Jordyn Babla, BS; jrbabla@texaschildrens.org