14TH ANNUAL

Health Care Transition Research Consortium (HCTRC)

RESEARCH SYMPOSIUM

VIRTUAL CONFERENCE

October 26, 2022

8 a.m. – 4:15 p.m. CDT

Co-provided by:

Texas Children's Hospital®

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The Robbins Foundation

14th Annual Health Care Transition Research Consortium Research Symposium
October 26, 2022

Agenda

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

8:15 AM Keynote: Health Care Transition Services in the Middle East
Nabeel Al-Yateem, PhD, RN
Department of Nursing, College of Health Sciences
University of Sharjah,
Sharjah, United Arab Emirates

Faculty of Science, School of Nursing and Midwifery and Indigenous Health,
Charles Sturt University, Sydney, NSW, Australia

Research Institute of Medical and Health Sciences (RIMHS),
Sharjah, United Arab Emirates

8:45 AM Platform Session 1: Health Care Transition Outcomes and Readiness Measures (5 presentations)

Transition Readiness, Skills, and Patient Retention: Impact of a Formal Congenital Heart Disease Transition Program
John Shabosky, MD; Victoria Brentari, BSN, RN; Nicole Broussard, LCSW; Donna Lovick, MBA, BSN, RN, CCCTM; Vincent Gonzalez, MD; Shaine A. Morris, MD, MPH; Keila Lopez. MD, MPH

Development of an Autistic Young Adult self-reported Health Care Transition Readiness Assessment
Nancy Cheak-Zamora, PhD; Luigi Boccardi, MPH; Grant Bertucci

Gynecological Concerns for Women with Spina Bifida
Elizabeth E Harper, MD, Kristen A Staggers, MS, Tara J Harris, MD

A Clinic-Based Project to Improve Healthcare Transition Education for Underserved Youth with Sickle Cell Disease
Dhanashree Bahulekar, BA; Charmaine Bond, MSW, LCSW; Lora Joyner, MS, PT, PCS; Sarah Leonard, MD; Chelesa Riverbank, MSN, FNP-C; Aimee W. Smith, PhD

Validation of the UNC TRxANSITION Index among Adolescents and Young Adults with Sickle Cell Disease
Kristen Howell, PhD; Maria E. Ferris, MD, MPH, PhD; Kathryn Russell, PhD; Jane Brigden, BA, CCRP; Jamilla Griffith, MSW; John Saunders, BS, CCRP; Patricia Simpson, MS, CCRP; Jane Hankins, MD, MS; Jerlym S. Porter, PhD, MPH

10:00 AM Break

10:15 AM Platform Session 2: Intellectual Disabilities and Developmental Disabilities

Health Care Transition for Young People with ID/DD and with ID/DD and Co-Occurring Mental Health Conditions (CMHC): Stakeholders' Perspectives
Christine Bottrell Mirzaian, MD, MPH: Sharon M. Hudson, PhD; Alexis Deavenport-Saman, DrPH, MPH; Cecily L. Betz, PhD, RN, FAAN

Caregiver Support, Burden, and Long-Term Care Planning Among Caregivers of Individuals with Intellectual and Developmental Disabilities: A Cross-Sectional Study

Telmo Santos, MD, Caren Steinway, MPH, LMSW; Ariana Mastrogiannis, BA; Jack Chen, MBS; Jason Woodward, MD, MS; Ilka Riddle, PhD; Brittany Spicer, BS, CCRP; John Berens, MD; Thomas Davis, MD; Michelle Cornacchia, MD; Charmaine Wright, MD, MSHP; Mary Ciccarelli, MD; Lee Lindquist, MD, MBA; Sophia Jan, MD, MSHP

Development of a Web-Based Long-Term Care Planning Tool to Assist Individuals with Intellectual Disabilities and their Families Plan for the Future
Caren Steinway LMSW MPH, Ariana Mastrogiannis; Telmo Santos MD; Jack Chen MBS; Jason Woodward MD; Ilka Riddle PhD; John Berens MD; Thomas Davis MD; Michelle Cornacchia MD; Charmaine Wright MD MSHP; Lee Lindquist MD MBA; Sophia Jan MD MSHP

Identifying Long Term Care Planning Needs of Caregivers of Individuals with Intellectual and Developmental Disabilities
Ariana Mastrogiannis; Caren Steinway, MPH, LMSW; Telmo Santos, MD; Jack Chen, MBS; John Berens, MD; Thomas Davis, MD; Michelle Cornacchia, MD; Jason Woodward, MD, MS; Ilka Riddle, PhD; Brittany Spicer, BS, CCRP; Charmaine Wright, MD, MSHP; Lee Lindquist, MD, MBA; Sophia Jan, MD, MSHP

Mental Health and Treatment Access among Adolescents with Intellectual and Developmental Disabilities
Julie Doran, MS, CRC, Aimee Smith, PhD

11:30 AM Lunch Break/ Breakout Sessions

A Guide for Designing a Value-Based Payment Initiative for Pediatric-to-Adult Transitional Care
Margaret McManus, MHS; Annie Schmidt, MPH; Patience White, MD, MA

A Multidisciplinary Pilot Program to Improve Implementation of Transition Best Practices
Barbara Hepp, BSN, RN, CPN, CCCTM; Juan Ramos, FHN; Jennifer J. G. Scott, MSN, RN, CPEN; Shelly Heinrichs, LCSW; Jennifer A. Disabato, DNP, CPNP-PC, William C. Anderson III, MD

12:30 PM Poster Session 1
Participants will have access to view posters beginning early October with website links available upon registration. During Session 1, topical breakout sessions will be available to query panels of poster presenters about their work.

1:30 PM Platform Session 3: Continuous Quality Improvement/Self-Management/AEA and Family

Changes in Legal Responsibilities for Healthcare Decision-Making at Age 18: AYASHCN and Caregiver Knowledge, Satisfaction with Preparation Received, and Recommendations for Improvement
Blanca E. Sanchez-Fournier BA: Jordyn Babla, BS; Beth H Garland, PhD; Mary Majumder, JD, PhD; Constance M. Wiemann, PhD; Albert C Hergenroeder, MD

Health Care Transition in School-Based Health Centers: A Playbook
Samhita Ilango, MSPH; Margaret McManus, MHS; Laura Brey, MS; Diana Bruce, MPA; Patience White, MD, MA

Self-Harm Mortality in Adolescents and Young Adults in the United States: 1999-2020
Matthew GoodSmith, MD, Nabil Abou Baker MD, Mengqi Zhu MS, Rita Rossi-Foulkes MD

The ImPACT (Improving Pediatric to Adult Care Transition) Program: Building Capacity for Best Practices and Transition Consultation in a Pediatric Hospital on an Urban Academic Medical Campus
Jennifer Disabato, DNP, CPNP-PC, AC; William Anderson, MD

Multi-stakeholder Design and Development of a Self-Management Mobile Health Application for Young Adults with Sickle Cell Disease
Caren Steinway LMSW, MPH; Ariana Mastrogiannis; Telmo Santos, MD, MPH; Jack Chen, MBS; Jason Woodward, MD, MPH; Ilka Riddle, PhD; John Berens, MD; Thomas Davis, MD; Michelle Cornacchia, MD; Charmaine Wright, MD, MSHP; Sophia Jan MD MSHP

2:45 PM Break

3:00 PM Poster Session 2
Participants will have access to view posters beginning early October with website links available upon registration During Session 1, topical breakout sessions will be available to query panels of poster presenters about their work.

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Research Symposium Abstracts

8:45 AM Platform Session 1: Health Care Transition Outcomes and Readiness Measures

Rita Nathawad, MD

Presentation 1

Transition Readiness, Skills, and Patient Retention: Impact of a Formal Congenital Heart Disease Transition Program

John Shabosky, MD; Victoria Brentari, BSN, RN; Nicole Broussard, LCSW; Donna Lovick, MBA, BSN, RN, CCCTM; Vincent Gonzalez, MD; Shaine A. Morris, MD, MPH; Keila Lopez. MD, MPH

Background: Successful transition and transfer to adult care for congenital heart disease (CHD) patients requires disease knowledge and skills to navigate a complex medical system. The objective of our study was to assess changes in CHD patient knowledge, skills, and overall patient retention based on serial visits in a cardiology transition medicine program.

Methods: A REDCap database captured TCH cardiology transition participants from 2019-2021. Inclusion criteria were patients aged 14-21 with either CHD or electrophysiological diagnoses. Exclusion criteria included inability for transition assessments due to significant developmental delay and cardiac transplant patients who have their own transition program. Patient transition readiness was assessed via: 1. TCH Heart Knowledge Tool (K-Tool) – our questionnaire created by merging existing transition knowledge assessments in the literature, and 2. Transition-Q – a validated transition skill questionnaire for adolescents with chronic diseases. Outcome variables included change in K-Tool and Transition-Q scores with serial transition visits. Multivariable analyses were adjusted for age and transition clinic visit number. Multivariate mixed linear regression modeling accounted for repeated measures. Additionally, overall retention rates were assessed by comparing CHD patient retention rates pre-transition programming at the same TCH site (2012-2016), as well as during the same transition period (2017-2021) for TCH satellites without transition programming.

Results: A total of 519 patients had 716 serial transition encounters between 2019-2021. Transition visit number was an independent predictor of increasing both K-Tool and Transition-Q scores regardless of age (p<0.001). At the end of the pre-transition program era, 27.8% CHD patients remained in care; in the current transition program era, 29.1% remained in care for non-participants vs. 86.5% patients participating in the cardiology transition medicine program.

Conclusions: Our cardiology transition medicine program demonstrates increased patient knowledge and skills, and is associated with increased patient retention, which may be important for future successful transfer to adult care.

Presentation 2

Development of an Autistic Young Adult self-reported Health Care Transition Readiness Assessment

Nancy Cheak-Zamora, PhD; Luigi Boccardi, MPH; Grant Bertucci

Background: Health care transition (HCT) services help adolescents prepare for a smooth transition to adult care, ensure insurance retention, and promote adolescents' independent management of their health care and life needs. Lack of HCT services can result in negative outcomes such as unmet needs, over-medicated, and loss of decision-making authority. Autistic young adults (AYA) are a quarter as likely to receive HCT services compared with young adults with special health care needs. Furthermore, there are no self-reported HCT readiness measures that address the unique needs of the AYA population.

Methods: This study used a qualitative approach to develop a holistic self-reported measure of HCT readiness for AYA called the Health-Related Independence Self-Report (HRI-SR). A previously developed caregiver-reported HRI measure was revised based on two iterations of AYA data collection. AYA first took part in individual interviews (n=5) to assess the constructs and questions included in the caregiver-reported HRI. Cognitive interviews (n=15)

	are currently being conducted to assess the survey structure, question-wording, and online usability (completion date August 2022). **Results:** Qualitative interviews identified high needs for HCT services and a desire for a self-reported measure of HCT readiness. All six constructs within the caregiver-reported HRI measure were highly rated by all participants. The highest-ranked constructs were Knowledge of Physical and Mental Health Conditions and Safety. Major themes within the qualitative data included: lack of provider engagement, caregiver support to navigate HCT, and desire for more independence. **Conclusion:** The development of the HRI-SR measure was a comprehensive and iterative process. AYA was very supportive of this and additional self-reported measures. They identified themes that can help improve health care provider engagement and promote AYA independence.
Presentation 3	**Gynecological Concerns for Women with Spina Bifida** *Elizabeth E Harper, MD, Kristen A Staggers, MS, Tara J Harris, MD* **Background:** Women with spina bifida (SB) have under described and potentially under-met reproductive healthcare needs.. This study aimed to describe the demographic and clinical characteristics of adult women with SB transitioning to adult gynecology. Secondly, it aimed to determine the rates and associated factors of meeting recommended preventative reproductive screenings. **Methods:** A retrospective chart review was completed of women with SB who established care with an adult gynecology clinic associated with a medical home for adults with developmental disabilities between June 2018 and May 2020. Demographic and gynecological data were analyzed via logistic regression to determine factors associated with reproductive care. **Results:** Sixty women with SB with a median age of 24 (range 19-46) established care in the time period. While the most common reason for establishing gynecological care was for a well-woman visit (n=31, 51.7%), almost half had other gynecological concerns regarding menstruation, sexual function, and pelvic organ prolapse. Only 23.3% (n=14) had previous HIV screening, 43.3% (n=26) had begun the HPV vaccine, and 26.7% (n=16) of women aged 21 and above had received cervical cancer screening. Older age correlated positively with HIV screening (3.97, 95% CI: 1.23, 12.86) and negatively with initiation of the HPV vaccine series (adj OR 0.09, 95% CI: 0.02, 0.49). Cervical cancer screening rates correlated with reported sexual activity. On exam, the majority of women had normal findings (n=19, 43.2%), with some instances of pelvic organ prolapse, Mullerian anomalies, anorectal malformations, labial hypertrophy, and elongated cervix. **Conclusion:** This study is one of the first to describe general gynecological care needs for women with SB transitioning to adult gynecology. Women with SB may have significant gynecological concerns and unmet preventative reproductive care needs that should be addressed as they transition into adult care.
Presentation 4	A Clinic-Based Project to Improve Healthcare Transition Education for Underserved Youth with Sickle Cell Disease *Dhanashree Bahulekar, BA; Charmaine Bond, MSW, LCSW; Lora Joyner, MS, PT, PCS; Sarah Leonard, MD; Chelesa Riverbank, MSN, FNP-C; Aimee W. Smith, PhD* **Background:** The transition from pediatric to adult healthcare is difficult for youth with sickle cell disease (SCD), resulting in worsening disease status (e.g., pain crises), increased healthcare utilization (e.g., more emergency room visits), and poor quality of life. The current study describes the development of a pediatric SCD transition program incorporating patient transition education and a Transition Retreat to provide hands-on experiences to improve the transition to adult care. **Methods:** Transition education topics were determined through consultation with the interdisciplinary team providing care at a rural-serving Comprehensive Sickle Cell Clinic. Topics aligned with the Sickle Cell Transition Intervention Program (TIP) (Treadwell et al., 2011). Education was disseminated via handouts and a monthly Transition Clinic Lunch and Learn. The Transition Retreat included educational activities (e.g., pain management), hands-on experiences (e.g., budget simulation, college tours), and social events. Participants (n=17) in the retreat included 12 SCD patients (15-22 years old) and 5 chaperones. A questionnaire evaluating patient experiences, transition readiness, and future suggestions was administered post-retreat. **Results:** Education topics included SCD knowledge, social support, and self-efficacy concerning the transition process. Examples of education materials will be included. Lunch and Learn topics included budgeting, adult primary care, and advanced care directives. Patient feedback indicated 92% found the retreat beneficial. Overall, 75% of patients felt more prepared for transition following the retreat. Ongoing Transition Retreats were supported by 100% of participants. Suggestions for the future included more breaks and limited college tours. **Conclusion:** This project describes the process of developing and refining transition education materials/processes and a transition-specific educational weekend for youth with SCD. Other SCD clinics may choose to incorporate hands-on experiences related to transition education following our early positive findings. Due to positive feedback and clear benefits, the use of the handouts and Transition Clinic are ongoing, and another Transition Retreat is planned for next year.

Presentation 5	Validation of the UNC TRxANSITION Index among Adolescents and Young Adults with Sickle Cell Disease *Kristen Howell, PhD; Maria E. Ferris, MD, MPH, PhD; Kathryn Russell, PhD; Jane Brigden, BA, CCRP; Jamilla Griffith, MSW; John Saunders, BS, CCRP; Patricia Simpson, MS, CCRP; Jane Hankins, MD, MS; Jerlym S. Porter, PhD, MPH* **Background:** Most individuals with sickle cell disease (SCD) survive into adulthood and transition to adult care. The TRxANSITION Index is a measure of transition readiness. The objective of this study was to assess the validity of the TRxANSITION Index among adolescents and young adults (AYA) with SCD. **Methods**: AYA (16-21 years) with SCD completed the TRxANSITION Index at baseline (N=87) and six months (N=54). The TRxANSITION Index is comprised of 33 questions within ten subscales. Each subscale score is given a score (0, 0.5, 1.0) for a maximum score of ten. Specific to SCD self-management, we added a "Pain Management and Coping Strategies" subscale for a maximum score of 11. T-tests were used to assess the change in scores over the follow-up period. Internal validity was assessed by measuring the correlation between the subscales and total scores at baseline. Regression models were used to examine the association between the total scores at baseline and medical and transition outcome (i.e., transfer gap, acute events, routine clinic visits) and another measure of transition readiness (STARx). **Results**: Participant mean age at baseline was 18.13(±1.53) years (51%female; 57%severe genotype). The mean TRxANSITION Index total score was 7.42(±1.02) and with pain was 8.35(±1.06). There was a significant increase in the total scores and subscales "Self-Management Skills" and "New Health Care Providers" (p<0.05) from baseline to six months. All subscales except "Trade/School" were significantly correlated with the total scores with the added pain subscale weakly correlated. Increased total scores were significantly associated with hydroxyurea utilization, routine clinic visits, and the StarX questionnaire. **Conclusions:** The current study demonstrates the internal validation of UNC's TRxANSITION Index. It also demonstrates that scores improve over time and higher scores are associated with increased exposure to clinic and medical professionals through routine care; however, it was not associated with acute events.
BREAK	
10:15 AM Platform Session 2: Intellectual Disabilities and Developmental Disabilities	
Moderator: Nancy Cheak-Zamora, PhD	
	Health Care Transition for Young People with ID/DD and with ID/DD and Co-Occurring Mental Health Conditions (CMHC): Stakeholders' Perspectives *Christine Bottrell Mirzaian, MD, MPH: Sharon M. Hudson, PhD; Alexis Deavenport-Saman, DrPH, MPH; Cecily L. Betz, PhD, RN, FAAN* **Background:** A chasm exists between the pediatric and adult health and mental health service systems for young people with ID/DD and ID/DD-CMHC impeding their transfer to adult health and mental health services and transition to adulthood. Limited evidence exists to provide support for a model of care on transition for young people with ID/DD and ID/DD with CMHC. **Methods:** This cross-sectional survey study explored respondents' perceptions of the transition experience and needs of young people with ID/DD and ID/DD-CMHC. 273 respondents composed of disability advocates (n=128; 46%) community-based representatives (CBO) (n=92, 33%), and providers (n=58, 21%).completed the ID/DD and ID/DD-CMHC Transition Survey. Differences in responses were analyzed using chi-squared tests. **Results:** There was near unanimous agreement by all stakeholder types as to the HCT barriers, services and supports needed for HCT for both ID/DD groups. Significant differences were identified among stakeholder types on barriers, services and supports needed. A barrier associated with stigma/bias for the transition to adult health care for individuals with ID/DD was identified significantly more often by CBO respondents compared to providers and advocates (p =.02). Significant differences were found among stakeholders pertaining to services/supports needed for individuals with ID/DD and ID/DD-CMHC. CBO and provider respondents identified access to post-secondary training or education significantly more often than advocates (p=.041) for the ID/DD group. For ID/DD-CMHC group, CBO and provider respondents reported job training (p=.028), employment-related accommodations (p=.012) significantly more often compared to advocates. Stakeholders serving individuals with ID/DD-CMHC reported that individuals with ID/DD had significantly greater need for these services compared to stakeholders serving individuals with ID/DD; employment-related accommodations (88% vs. 70%; p=.0031), assistance navigating other systems or programs (90.7 vs. 75%; p=.005), housing options (p<.0001), transportation assistance/community mobility (88.4% vs. 75%; p=.022), financial assistance and/or food security (85.8% vs. 67.5%; p=.005) as compared to stakeholders serving only individuals with ID/DD. **Conclusions:** Substantial agreement was found among stakeholders as to the HCT barriers, services and supports needed, with some differences noted between groups serving individuals with IDD only vs. individuals with ID/DD-CMHC.

Caregiver Support, Burden, and Long-Term Care Planning Among Caregivers of Individuals with Intellectual and Developmental Disabilities: A Cross-Sectional Study

Telmo Santos, MD, Caren Steinway, MPH, LMSW; Ariana Mastrogiannis, BA; Jack Chen, MBS; Jason Woodward, MD, MS; Ilka Riddle, PhD; Brittany Spicer, BS, CCRP; John Berens, MD; Thomas Davis, MD; Michelle Cornacchia, MD; Charmaine Wright, MD, MSHP; Mary Ciccarelli, MD; Lee Lindquist, MD, MBA; Sophia Jan, MD, MSHP

Background: About 3% of the population has an intellectual/developmental disability (IDD) and many of these individuals outlive their caregivers. This prevalence highlights the importance of supporting caregivers in developing long-term care (LTC) plans for their loved one. Identification of a primary caregiver has been established as a key step in future planning, but further insight into the relationship between caregiver social support and both planning development and caregiver burden is critical.

Methods: Our study included a convenience sample of caregivers of individuals with IDD. Participants received a cross-sectional survey distributed via IDD advocacy groups and health care systems in NY, OH, TX, and PA. Questions explored caregiver demographics, socioeconomic factors, burden (Zarit Caregiver Burden Index (ZCBI)), caregiver social support (presence of an individual who could assist with care recipient needs), and engagement in LTC planning behaviors.

Results: Caregivers (n=405) were predominantly parents (91.6%), female (89.4%), and non-Hispanic (88.6%). Approximately 38.3% of participants (n=155) identified a source of social support. Caregivers with an identified source of social support engaged in more LTC behaviors compared to those unable to identify a source of social support (3.4 +/- 1.0 versus 3.1 +/- 0.9, p=.009). Although caregivers reported a high degree of burden, those with a source of social support had lower mean ZCBI scores (16.3 +/- 8.5 versus 23.6 +/- 9.4, p<.001).

Conclusion: Caregivers of individuals with IDD were found to have a high level of burden. Although caregivers with identified social support were associated with having both further progression in LTC planning, and a lower degree of burden, less than 40% of caregivers were able to identify a source of social support. Medical providers of individuals with IDD should engage social workers who can link caregivers with resources for mental health services, social support networks, and caregiver support groups.

Development of a Web-Based Long-Term Care Planning Tool to Assist Individuals with Intellectual Disabilities and their Families Plan for the Future

Caren Steinway LMSW MPH, Ariana Mastrogiannis; Telmo Santos MD; Jack Chen MBS; Jason Woodward MD; Ilka Riddle PhD; John Berens MD; Thomas Davis MD; Michelle Cornacchia MD; Charmaine Wright MD MSHP; Lee Lindquist MD MPH MBA; Sophia Jan MD MSHP

Background: Risks for negative health outcomes for persons with intellectual/developmental disabilities (IDD) increase as persons with IDD and parental caregivers age. Insufficient long- term care (LTC) planning, compounded by insufficient knowledge of social services and legal supports, may lead to crises and emotional trauma for all concerned, unexpected dilemmas for siblings or extended families, and at its worst, inappropriate or unwanted placement in nursing home settings, unsafe living conditions, or harm to individuals with IDD.

Methods: To address a gap in LTC care preparation for individuals with IDD and their families, we sought to adapt Plan Your Lifespan (PYL), a web-based planning tool for older adults. Focus groups and in-depth interviews were conducted with family caregivers and individuals with IDD across five states (PA, NY, DE, OH, TX). Semi-structed questions asked about the acceptability of an intervention like PYL for LTC planning, barriers and facilitators to planning, and for suggestions for web-tool adaptation. Information gathered was used to directly adapt PYL for this population.

Results: Forty-nine caregivers participated in focus groups and in-depth interviews. They agreed that the concept and structure of PYL was helpful and acceptable. Participants suggested the following additional domains: (1) addition of transition to adulthood as another life event; (2) improved accessibility for adults with IDD through links to videos; (3) organization of content around age of care recipient; and (4) inclusion of financial planning, Medicaid waivers, housing planning. With their feedback, the web-based planning tool was adapted and is undergoing pilot testing.

Conclusion(s): An adapted web-based planning tool for individuals with IDD and their caregivers was found to be acceptable. Input from focus groups and in-depth interviews informed the web tool adaptation. After being further refined during the pilot phase, studies will test the effectiveness of the intervention on caregiver health and wellbeing.

Identifying Long Term Care Planning Needs of Caregivers of Individuals with Intellectual and Developmental Disabilities

Ariana Mastrogiannis; Caren Steinway, MPH, LMSW; Telmo Santos, MD; Jack Chen, MBS; John Berens, MD; Thomas Davis, MD; Michelle Cornacchia, MD; Jason Woodward, MD, MS; Ilka Riddle, PhD; Brittany Spicer, BS, CCRP; Charmaine Wright, MD, MSHP; Lee Lindquist, MD, MBA; Sophia Jan, MD, MSHP

Background: As individuals with intellectual/developmental disabilities (IDD) and their caregivers age, long term care planning (LTC) is required to address their changing needs. Although families worry about the future, few make concrete LTC plans.
Methods: Caregivers over the age of 18 of individuals with IDD were recruited from health systems and advocacy organizations in New York, Ohio, Texas, and Pennsylvania. Caregivers completed a 183-question survey. To understand the caregiver experience, the short Zarit Burden Interview, which measures caregiver burden, and the Holmes-Rahe Stress Inventory Index, which measures the stress probability of caregivers, were used. Participants were compensated with a $10 gift card.
Results: Caregivers (n=405) had a mean age of 52.3 + 9.8 (22-84), were mostly female (89.4%), white (81.5%), and non-Hispanic (88.6%). Around 37.4% of participants had an annual household income >$100,000 and 64.2% of participants had a bachelor's degree or higher. Despite the higher income cohort, 25.9% of participants did not meet essential expenses in the year before the study. The mean Zarit score was 19.8 + 9.1(0-44), indicating a moderate degree of caregiver burden. The mean Holmes-Rahe score was 152.9 + 145.2(0-1084), indicating caregivers had a moderate susceptibility of stress-induced health breakdown. Caregivers found managing difficult behaviors to be the most challenging part of caregiving and found managing their own emotional distress to be the most challenging part personally. Despite controlling for ADLs, caregivers of individuals with a Medicaid Waiver reported managing medications, providing physical assistance, and finding paid help as challenges significantly more than caregivers of individuals who did not have a Medicaid Waiver (p<.05) .
Conclusion: Caregivers identified LTC planning needs. Even in this high-income, highly educated cohort, significant caregiving challenges were identified. These needs were present even with access to Medicaid Waiver services. Future research should investigate the specific burden of caregiving in underserved populations.

Mental Health and Treatment Access among Adolescents with Intellectual and Developmental Disabilities
Julie Doran, MS, CRC, Aimee Smith, PhD

Background: Transition for youth with intellectual and developmental disabilities (I/DD) often focuses on independent living and employment, but not mental health. Adolescents with I/DD experience barriers to mental health treatment, and these challenges may be more pronounced among certain demographic groups. This study aimed to 1) describe adolescents with I/DD who report anxiety and/or depression and receive treatment; and 2) examine disparities among demographic groups in accessing care.
Methods: Participants (N=150) from the 2019 National Survey of Children's Health were 13-17 years old and had a caregiver-reported diagnosis of I/DD. Demographic information and caregiver-reported diagnosis of anxiety and depression were collected. Caregivers reported if the adolescent had received mental healthcare in last year and endorsed the difficulty of receiving care. Data analysis is ongoing. Chi-square and logistic regression will be used to determine differences in access and difficulty in receiving mental health treatment among demographic groups.
Results: Approximately 46% (n=69) and 18% (n=28) reported a current diagnosis of anxiety and depression respectively, and some (n=25) reported both anxiety and depression. Of this group, 62% (n=45) received mental health treatment in the past year, while 38% (n=27) did not. Of those who did not receive care, 74% (n=20) of caregivers indicated it was not needed. Forty-six percent of caregivers reported difficulty in accessing mental health treatment. There were no significant differences in treatment access between males and females, $\chi 2(1, N=72) = 0.40$, p =.526, or between white and minoritized racial groups, $\chi 2(1, N=72) = 0.20$, p =.655.
Conclusions: Anxiety and depression are common among youth with I/DD, and many are not receiving needed treatment. Facilitating mental health education (e.g., promoting caregiver awareness of treatment need and treatment options), and mental health provider training on treatment modifications for this population will be important targets for improving transition among youth with I/DD.

BREAK

11:30 AM Lunch/Breakout Sessions

Moderator: Thomas Davis, MD

Breakout Session 1

A Guide for Designing a Value-Based Payment Initiative for Pediatric-to-Adult Transitional Care
Margaret McManus, MHS; Annie Schmidt, MPH; Patience White, MD, MA

Background: Pursuing value-based payment (VBP) options, which offer financial incentives for meeting certain performance measures, represents an important opportunity to encourage transitional care improvements in pediatric and adult primary, specialty, and behavioral health care settings. Although VBP arrangements are expanding rapidly among Medicaid, Medicare, and commercial payers, these payment innovations have yet to consider pediatric-to-adult transitional care.
Methods: The National Alliance, with funding from the Lucile Packard Foundation for Children's Health, provided technical assistance (TA) to payers and managed care organizations (MCOs) from May 2019 through January 2022, which included ongoing, intensive TA to eight Medicaid payers. From discussion with payers, it was clear that the absence of VBP HCT pilot examples and guidance is a limitation. Thus, The National Alliance developed a guide to provide a foundation for payers and MCOs to use when designing a transitional care VBP pilot.
Results: The guide contains a step-by-step approach for payers and MCOs interested in starting a VBP initiative around pediatric-to-adult transitional care. Steps include 1) Defining the HCT Intervention VBP Pilot, 2) Identifying

	Transition-Aged Populations for a VBP Initiative, 3) Selecting Accountable Pediatric and Adult Sites, 4) Choosing VBP and FFS Options, 5) Choosing Quality Metrics, and 6) Getting Started. Each step includes strategies to consider and real-life examples from Texas AmeriGroup, Intermountain Healthcare/Select Health, Florida Department of Health Children's Medical Services Health Plan, and DC HSCSN. **Conclusion:** This is the first HCT VBP guide for payers and MCOs who are paving the way for others by designing innovative methods to finance and measure quality of HCT interventions. As payers and their contracted plans and provider networks implement new VBP programs, this is an opportune time to make the case for including pediatric-to-adult transitional care.
Moderator: Lynn Davidson, MD	
Breakout Session 2	**A Multidisciplinary Pilot Program to Improve Implementation of Transition Best Practices** *Barbara Hepp, BSN, RN, CPN, CCCTM; Juan Ramos, FHN; Jennifer J. G. Scott, MSN, RN, CPEN; Shelly Heinrichs, LCSW; Jennifer A. Disabato, DNP, CPNP-PC, William C. Anderson III, MD* **Background:** The Improving Pediatric to Adult Care Transition (ImPACT) Navigation Hub (INH)'s goal is to decrease care fragmentation and increase safe and successful transitions by leveraging both a transition referral resource center and organizational transition education. The INH consists of a nurse care coordinator, social worker, family health navigator, and an adult primary care provider. A pilot program evaluated the feasibility of the INH to co-develop, with medical and surgical specialties, clinic-specific transition processes that balanced evidence-based transition practices and specialty-specific needs. **Methods:** A survey was distributed to medical and surgical sections at Children's Hospital Colorado requesting pilot clinic volunteers. Clinics were selected to ensure a diversity of conditions treated, clinic stakeholders, and baseline transition practices. The INH team worked with stakeholders in a series of coaching sessions following a comprehensive transition assessment to develop a unified workflow, integrate transition tools, and align clinics with hospital tenants for best transition practice. PDSA quality improvement cycles were utilized. This process allowed for INH to identify barriers and goals that guided subsequent teaching. **Results:** Two medical (neurology, rheumatology), two surgical (bariatric, neurosurgery), and two integrated (solid organ transplant, congenital heart disease) clinics participated. Across all 6 clinics, 138 transition eligible patients 18 years and older with medical complexity scheduled in the next 6 months were identified. During the pilot, each clinic wrote a patient transition policy, utilized an electronic medical record (EMR)-based transition readiness assessment tool, and developed disease-specific patient education. Pre and post clinic satisfaction surveys, INH referrals, and EMR tool utilization will be obtained. **Conclusion:** The INH pilot program demonstrated the feasibility and acceptability of a longitudinal coaching program to develop specialty-specific transition infrastructure that aligns with organizational and national best practices. Orchestrating coordinated transition care in the pediatric setting can improve health care for young adults with medical complexity.
12:30 PM Poster Session 1 **Group 1: Continuous Quality Improvement/Program Development/ Models of Care** **Group 2: Intellectual Disabilities and Developmental Disabilities** **Group 3: Adolescents and Emerging Adults/Mental Health**	
Group 1: Continuous Quality Improvement/Program Development/Models of Care	
Poster 1	**Building Uninterrupted Paths to Quality Adult Primary Care Medical Homes** *Courtney Porter, MPH, CPHQ; Ellen Iverson MPH; Jennifer Baird PhD, MPH, MSW, RN, CPN; Roberta Williams MD* **Background:** Adolescents and young adults (AYA) with chronic conditions transferring to adult health care systems face numerous challenges, including lack of logistical support for identifying appropriate adult providers, navigating insurance changes, and transferring care to new providers. The Center for Healthy Adolescent Transition (CHAT), an institution-wide transition support program for medically and socially complex AYA receiving care in a free-standing pediatric institution, developed strategies and processes to address these challenges and ensure uninterrupted transfer to appropriate adult medical homes. **Methods:** Two transfer pathways were identified based on AYA patients' diagnostic profile and complexity of needs - academic medical centers for patients with complex conditions needing extensive subspecialty support or community primary care medical homes for patients whose care can be managed with enhanced resources. CHAT partnered with the county's largest Medicaid Managed Care plan to identify appropriate adult medical home options

	aligned with patients' level of complexity and develop systematic mechanisms for communication and transfer coordination. **Results:** We established processes of coordination and communication between pediatric provider teams, representatives from insurance plans, and adult care teams, assigning specific transfer-related responsibility to each group. The insurance plan vetted and identified 13 community-based primary care medical home networks comfortable providing care to medically complex young adults with resources to support care coordination and comprehensive patient care management. Primary care clinics within these networks are geographically accessible and dispersed across the county. Patient education materials were developed to aid patients in selecting medical homes most appropriate to their needs. **Conclusion(s):** Systematic planning, coordination and communication through the transfer process is critical to ensure care continuity and health maintenance as young adults enter adulthood. Evaluation of this process and related outcomes, including patient, family and provider input, will ensure ongoing refinement of transfer strategies.
Poster 2	**Developing Year-round Healthcare Transition-focused programming for Young Adults with Childhood Onset Chronic Conditions** *LaKaya Craig, LCMHCA, NCC; Alison Manning, MD; Mary Long; and Jodie Neukirch Elliott, LCSW* **Background:** Adolescents Transitioning to Leadership and Success (ATLAS) is a collection of programs for adolescents and young adults (AYA) with childhood onset chronic conditions (COCC) at Duke Health. ATLAS Leadership and summer Campference (part camp, part conference) are healthcare transition focused programs for adolescents. College-age mentors who also live with COCC help facilitate ATLAS Leadership, and are eligible to be mentors for adolescent Campference and be participants for young adult (YA) Campference. However, there is a gap in year-long programming for other YA with COCC at Duke Health. **Methods:** A focus group was held among current ATLAS Leadership mentors to discuss preferences for a YA year-long program. After utilizing this information, surveys were sent to all current ATLAS Leadership mentors, ATLAS Leadership alumni over the age of 18, and past YA Campference participants. **Results**: Focus group participants identified that a year-long program would be beneficial for YA with COCC. To best support the needs of potential participants, there was consensus that the program should be offered virtually for 18-28 year olds, either monthly or bimonthly, and using a peer support format. The survey of potential participants had similar results in terms of the format and frequency of the program. Those surveyed identified topics for meetings throughout the year and feedback on preferred days and times. **Conclusion:** YAs have different perspectives when in the mentor role compared to being a participant in healthcare transition focused programming. The results of this quality improvement program led to the creation of the ATLAS LEAP (Leadership, Experience, Advocacy, and Progress) program, which started in January 2022. YA with COCC have an interest in connecting with peers, giving and receiving support, and learning to navigate growing into an adult with a COCC.
Poster 3	**Environmental Scan of Health Care System Transition Practices in Wisconsin** *Lynn Hrabik, MPH; Julie Hajewski, MSN, A-NP, APNP; Anne B. Harris, PhD, MPH, RDN* **Background:** Wisconsin's Title V Block Grant funds the Youth Health Transition Initiative (YHTI, contracted with the Waisman Center UCEDD, UW-Madison) as the hub of expertise for training community and health care service providers in best practices for health care transition (HCT) for youth with special health care needs. During 2021-22, the YHTI initiated an environmental scan to determine what HCT practices were being implemented in major health care systems in WI. **Methods:** Initially key contacts from 10 major health care systems were identified for an interview. Interviews were conducted and recorded via Zoom utilizing questions that were developed and piloted by evaluators and clinicians on the YHTI team. Transcripts of the interviews were analyzed using NVivo 2020 software to identity themes and practices. This project was self-certified to be a quality improvement project using the UW-Madison's IRB online tool. **Results:** Data from the health care systems interviewed indicated that fewer than half had a policy or guideline in place for HCT or were using formal Transition Readiness Assessments. Currently, none have transition clinics. Though most of the interviewees indicated system-level support for transition care, most transition care was being implemented through individual providers or specialty clinics. Additional themes will be presented. **Conclusions:** Wisconsin health care systems are interested in promoting best practices for HCT, but very few of them are currently using a transition policy, providing system-wide guidance or funding to support HCT. It is hard to identify transition "champions" within a system, but when they do exist, these individuals or clinics are often providing model transition services and, more rarely, quality improvement activities. Conducting the environmental scan helped the YHTI to initiate and maintain contacts in most health care systems opening the door for future training and technical assistance.
Poster 4	**Development and Evolution of a Transition-to-Adult-Care Program for Pediatric Oncology Survivors** *Adam René Rosenbaum, MD; Laura Reinman, PhD, MA; Robert L. Casey, PhD; Genevieve Sylvain, RN; Jenna Sopfe, MD, MS*

	Background: As many as 95% of pediatric oncology survivors face at least one treatment-related chronic health condition by middle age. Transitioning from pediatric to adult medical care can present many challenges, including problems associated with accessing adult-appropriate health services and continued survivorship-specific care. We have developed and evaluated a multi-disciplinary program aimed at improving the transition to adult care for pediatric oncology survivors and their families. **Design/Method:** We developed our transition program following a literature review and needs assessment survey of pediatric oncology survivors and guardians. A multi-disciplinary team developed programing for the transition program. Ongoing program assessment and modification is occurring via Plan-Do-Study-Act cycles. Program assessment is occurring via patient and guardian surveys of effectiveness, acceptability, and appropriateness before, immediately after, and 6 months following program participation. **Results:** The Pediatric-to-Adult Care Transition Program consists of annual assessment and coaching for transition readiness, starting at age 16, and a single formal transition-focused multidisciplinary visit, which is offered quarterly. Thus far, the program has had two sessions, serving 9 survivors and 5 guardians. These sessions consist of a survivorship visit and specialized sessions for both survivors and guardians with nurses, psychologists, health navigators, and a genetic counselor. Although data collection is early, survivors' level of preparedness for the transition to adult healthcare rose from an average 5.5 to 7.1 (0-10 Likert scale), and guardians' from 5.8 to 6. Program usefulness was rated at 8.75 (patients) and 9 (guardians). **Conclusion:** This pediatric-to-adult care transition program for oncology survivors has been well-received by both survivors and guardians. As additional sessions occur, we will continue to modify and improve the program based on feedback from participants as well as reflection from the project team. Preliminarily, this program shows promise for improving the degree of preparedness for pediatric oncology survivors transitioning to adult healthcare.
Poster 5	**Transitioning into Adulthood through Primary Care** *Kira C. Watson, MD, MPH; Molly Doose MD; Katie Irby, MD* **Background:** Approximately 18 million U.S. adolescents will transition into the adult healthcare system in the next few years, many of whom have chronic medical conditions. However, there has been limited investigation into successful models of care for these patients to transfer to the adult system. We created a primary care-based model to facilitate appropriate transition of adolescents into the adult healthcare system and improve health outcomes of this vulnerable population. **Methods:** Our pediatric to adult transition clinic will be housed within a patient-centered medical home. The clinic will accept children transferring out of a pediatrics comprehensive care program, a clinic that follows children with complex chronic conditions, medical fragility, or technology- dependence. Referred patients will be tracked by a formal code and be transitioned into specific template slots. We will perform pre- transition questionnaires as well as questionnaires at first visit with adult provider. **Results:** The framework and concept was presented to the General Pediatrics Division at our institution. The clinic will start on July 1, 2022, with 60-120 patients eligible for transition from the comprehensive care program in the next year. Transitioning youth will have first appointments with Internal Medicine-Pediatric providers and a care management team. We will track, as outcome and process measures, the number of patients transitioned; duration of time between last pediatric visit and first adult visit; number of ED and urgent care visits during first year of transition; and percentage change of the score on the Transition Readiness Assessment from Got Transition between last pediatric visit and first adult clinic. **Conclusions:** Millions of adolescents and young adults are entering into the adult health care system yearly. A dedicated primary care-based pediatric to adult health care clinic model may improve this process by reducing time to first visit, eliminating loss to follow up, and improving healthcare access.
Poster 6	**TPT "2.0": Modifications to the Transition Planning Tool to Improve Care Team Requested Functionalities** *William C. Anderson III, MD; Jennifer A. Disabato, DNP, CPNP-PC, AC* **Background:** The Transition Planning Tool (TPT) is an Epic-based electronic medical record tool, initially developed at Texas Children's Hospital, designed to document education provided to adolescents and young adults (AYA) and caregivers during the transition from pediatric to adult care. It can facilitate communication across providers and clinics using a synopsis view. The TPT was launched at Children's Hospital Colorado (CHCO) in August 2018. Utilizing continuous improvement methods, the TPT has been modified to reflect users' preferences. **Methods:** A series of interviews and meetings were conducted with stakeholders utilizing the TPT. An interdisciplinary work group was assembled to propose a modified version of the TPT based on feedback. Epic analysts were engaged in the build to streamline functionality. **Results:** An updated TPT "2.0" was launched in October 2021. Added functionalities included incorporation of the Transitional Readiness Assessment Questionnaire (TRAQ) 6.0 and the Got Transition readiness assessment for caregivers of patients with intellectual and developmental disabilities (I/DD). The educational prompts from the TPT were matched to the topics covered in these questionnaires. These questionnaires were formatted to be sent electronically through the patient portal to be completed prior to the visit. From 11/2021 to 05/2022, the TRAQ was distributed to 1740 patients (4800 encounters) and the I/DD questionnaire was distributed to 17 patients (17 encounters) with completion rates of 43% and 65%, respectively. Status tab additions included documentation of

	transition policy distribution, identification of the healthcare decision maker, and transition summary letter completion. **Conclusions:** The updated CHCO TPT 2.0 allows healthcare teams both to address gaps in transition readiness skills guided by the incorporation of validated readiness assessment questionnaires paired with educational prompts and to document completion of transition best practices. The modifications made to this Epic-based tool by our team can be incorporated into transition readiness planning at other institutions.
Poster 7	**Expanding Access to Pediatric to Adult Transition Planning Services Via a Supplementary Telehealth Program** *Gina Urbine RN AE-C; Elizabeth F Vann MS RN CPEN AE-C; William C. Anderson III, MD* **Background:** The Asthma Self Care, Education, and Transition (ASCEnT) program at Children's Hospital Colorado (CHCO) prepares adolescent and young adults (AYA) with asthma for adult care. Secondary to nurse care coordinator (NCC) staffing, the ASCEnT Program initially only served patients on the CHCO campus, thereby limiting access to patients seen at network of care (NOC) clinics. The COVID-19 pandemic emphasized the need for novel strategies to engage with patients outside of an in-person visit. The ASCEnT program piloted supplementary NCC-led transition planning telehealth encounters tied to in-person visits at CHCO NOC locations. **Methods:** An electronic medical record (EMR)-based reporting tool was developed to proactively identify established patients aged 14 years and older with a primary diagnosis of asthma being seen by either Pulmonology or Allergy at 7 CHCO NOC sites across Colorado (CO). Providers were contacted in advance for permission to join the visit remotely. Patients completed the Transition Readiness Assessment Questionnaire electronically during the visit. NCCs provided education via iPad and completed the Epic Transition Planning Tool (TPT) based on TRAQ results. **Results:** From 09/2021 to 05/2022, the ASCEnT program had 130 patient encounters, of which 22.3% (n=29) occurred via telehealth to NOC clinics. NCCs conducted an additional 15 remote follow-up encounters with NOC patients. The majority (66.5%) of patients were aged at least 17 years. AYAs from 9 CO counties and Wyoming were served. The TRAQ and TPT were completed 30 and 37 times, respectively, during NOC telehealth and follow-up encounters. **Conclusions:** The addition of telehealth-based interactions to in-person clinic visits expanded pediatric to adult transition planning to AYA with asthma across the state of Colorado. Utilization of EMR-based TRAQ and TPT facilitated directed education during these remote encounters. A supplementary telehealth program can increase access to transition preparation services in areas with otherwise limited staffing.
Group 2: Intellectual Disabilities and Developmental Disabilities	
Poster 1	**Medical Management of Constipation in Autism Spectrum Disorder** *Alexis Matarangas MD; Raghuveer Puttagunta, MD; Thomas Davis, MD* **Background:** Gastrointestinal symptoms, with constipation being the most common, have been shown to be highly associated with Autism Spectrum Disorder (ASD) and its core symptoms. However, the approach by which constipation is managed in this population over time as they undergo the adult transition has remained unexamined. **Methods:** This is a retrospective cohort study that examined patients ages 2-65 years with a diagnosis of ASD and the medication management of constipation in this population as it related to age over a five year period (1/1/2015-12/31/2019). Specifically, the number and types of anti-constipation medications prescribed were noted. During this same period, overall healthcare utilization in the form of hospitalizations, emergency department (ED) visits, and office visits was examined. **Results:** Of 4,082 patients included in the study, 25.9% had anti-constipation medications prescribed during the study period (n=1059). Among this patient population, there was an increase in hospitalizations and ED visits in the 6-9 year and 19-24 year age ranges ($p< 0.05$). When examining the prescription patterns of these medications, there was a noted increase in anti-constipation prescriptions for every decade above 21 years of age compared to the previous decade (p<0.01). When agents were divided among the subclasses, there was an increased diversity of agents prescribed to those above 18 years of age ($p< 0.01$). Primary care providers (pediatrics, family medicine, internal medicine) were the main specialty prescribing anti-constipation medications at all patient ages except for those less than 15 years of age, for which pediatric gastroenterology was the dominating prescribing specialty (43.4%). **Conclusion:** This study demonstrates a change in both healthcare utilization and constipation management in patients with ASD as they undergo the transition into adulthood. This is evident not only in the number and diversity of agents prescribed during this transition, but in the discipline of prescribing provers.
Poster 2	**Health Care Transition Barriers Experienced by Youth and Young Adults with Intellectual and/or Developmental Disabilities and their Families: a Literature Review 2015-2022** *Annie Schmidt, MPH; Samhita Ilango, MSPH; Margaret McManus, MHS; Patience White, MD, MA* **Background:** The majority of youth and young adults (Y/YA) in the US with intellectual and/or developmental disabilities (ID/DD) do not receive recommended health care transition (HCT) support from their health care

	providers. This effort aimed to identify specific HCT barriers faced by this population and their families and clinicians. **Methods:** With funding from the Administration for Community Living, Got Transition partnered with Family Voices, SPAN, UMKC, and Waisman Center to establish a National HCT Resource Center for Y/YA with ID/DD. As part of this effort, the authors conducted a literature search to identify relevant articles that reported HCT barriers for Y/YA with ID/DD, their families, clinicians, and underserved populations. The authors used the following search terms in PubMed: underserved, gaps, barriers, challenges, minority, minoritized equity, LGBTQ, disparity. Articles had to be peer-reviewed, in English, and published between 2015-2022. After reviewing abstracts, relevant articles were read, and reported barriers were abstracted. A final list of barriers was compiled and organized, using the AAP/AAFP/ACP Clinical Report as a framework. **Results:** The search yielded 36 relevant articles. Sixteen barriers were reported by Y/YA with ID/DD and their families, and 11 were reported for clinicians caring for this population. Common barriers for Y/YA and their families included inadequate HCT preparation and lack of tools/education, poor and inconsistent communication about HCT, difficulty finding adult providers and support services/resources, and lack of care coordination and communication between providers. Common barriers for clinicians included lack of HCT guidelines and system supports, lack of training on specific conditions, and lack of knowledge of HCT and their role in the process. **Conclusion:** This review highlighted the HCT barriers facing Y/YA with ID/DD, their families, and clinicians. The barriers identified should be taken into consideration when developing HCT resources and interventions for this population.
Poster 3	**Tailoring a Health Clinic-based Parent-to-Parent Peer Support Intervention for Black and Latinx Families** *Michelle S. Franklin, PhD, APRN; McLean Pollock, PhD; LaKaya Craig, MA; Madeline Fowler, MS; Gary Maslow, MD, MPH* **Background:** People with intellectual and/or developmental disabilities (I/DDs) experience significant health disparities when compared to those without I/DDs. These health disparities are amplified among Black and Latinx adolescents and young adults (AYAs) who are most at risk for poorer health and other outcomes. The Duke Family Partner Program and the Family Partner Coach (FPC) intervention emphasize patient-centeredness, prevention, and patient and family engagement but lacks cultural adaptation. The purpose of this study was to evaluate the acceptability of the Duke Family Partner Program and obtain guidance for the cultural adaption of the FPC intervention for Black and Latinx families. **Methods:** We utilized a qualitative descriptive design using a semi-structured interview guide to interview Family Partner Coaches and Black and Latinx caregivers of AYAs 16-26 years of age with I/DD. The Family Partner Coaches (N=3) and a purposive sample of 10 caregivers (5 Black; 5 White) have been included to date. The final expected sample is 24 caregivers (8 Black; 8 Latinx; 8 White). **Results:** The Family Partner Coaches analysis revealed three overarching themes: Support during Transition to Adulthood is Critical; Shared Experience is the Key Ingredient, and the Importance of Cultural Adaptation of Intervention and Diversity Training for Family Partners. Caregivers' results elucidated their a) perceived benefits of family partner support and the resources they received, b) met and unmet cultural needs, and c) ideas to improve the FPC intervention. **Conclusions:** The FPC intervention is supporting caregivers of AYAs with I/DDs to successfully navigate complex systems (medical, educational, community) and caregivers report improved outcomes as they transition to adulthood because of this support. However, our findings illuminate strategies to employ to tailor the FPC intervention to help improve the outcomes of AYAs with I/DD from Black and Latinx populations and reduce systemic barriers to access and engagement.
Poster 4	**Transitioning Youth with Medical Complexity & Intellectual and Developmental Disabilities: A Multidisciplinary Approach to Unique Needs,** *Erin Benekos MSN, NP-C, CPHON; Courtney Malave LCSW; Wendy Gray, PhD, ABPP, BCB; Reny Partain LCSW, MPH' Angelique Carrasco Parasto Dorriz, MPH; Michael Weiss, DO* **Background:** Youth with intellectual/developmental disabilities (IDD) are at higher risk for poor transition outcomes. Risk is further heightened when IDD co-occurs in youth with medical complexity (YMC). We examine the barriers unique to YMCs with IDD through analysis of transition readiness and initial risk assessment. **Method:** A 13-month retrospective chart review assessed needs of YMCs with and without IDD referred to a disease-agnostic specialty transition clinic for high-risk youth. YMC transition needs and risks were identified using the UNC TRxANSITION Index and Bob's Level of Social Support. In the presence of severe cognitive impairment, caregiver transition readiness skills were assessed. Barriers to transition were identified based on patient and caregiver report. **Results:** Of the 142 YMCs (M age = 19.05 years, SD = 1.72) assessed, 72% had IDD. A greater number of YMCs with IDD scored in the moderate-to-high risk range on social support than YMCs without IDD (100% vs. 60%). 31% of YMCs with IDD completed the transition readiness assessment on their own. Overall transition readiness scores differed between groups, F(2, 136) = 85.42, p < .001. YMCs with IDD scored the lowest (43%), followed by YMCs without IDD (73%), then caregivers of YMCs with IDD (82%, all p's < .05). Barriers unique to YMCs with IDD

	included limited communication, lack of decision-making support, time constraints with specialists, and behavioral issues. **Conclusion:** An IDD diagnosis alone should not preclude a YMC from transition readiness assessment as nearly one-third of our patients could answer questions on the UNC TRxANSITION Index. While there are many barriers to transition experienced by all YMCs, those with IDD experience unique barriers. The multidisciplinary clinic composition allowing for a wraparound approach to transition readiness and dedicating additional time towards transition planning with YMCs with IDD may help enhance their outcomes.
Poster 5	**Emergency Preparedness Toolkit for Young Adults with Intellectual and Developmental Disabilities and their Primary Care Team** *Patience White, MD, MA; Annie Schmidt, MPH; Margaret McManus, MHS* **Introduction:** Young adults (Yas) with intellectual and developmental disabilities (ID/DD) and their parents and/or support persons have unique needs during disasters and emergencies. The COVID-19 pandemic brought to light that there are many emergency issues that require additional planning. Equally important, many Yas with ID/DD and their parents and/or support persons look to their primary care team to assist them in this planning and during such stressful times. **Methods:** We conducted an environmental scan searching for resources relevant to emergency preparedness for Yas with ID/DD and interviews with Yas with ID/DD and their parents to learn about key areas of concern they have around disasters and emergencies. We formed an advisory panel with advocates for Yas with ID/DD and representatives from the major primary professional organizations and convened the group three times to elicit feedback throughout the process of developing an emergency preparedness toolkit. **Results:** Informed by findings from the environmental scan, interviews with Yas with ID/DD and their parents, and advisory panel feedback, we developed a new emergency preparedness toolkit with two tip sheets. One is for primary care teams to use in assisting Yas with ID/DD and their parents to develop a disaster emergency care plan, which consists of a set of steps to consider when creating the plan. The second is for Yas with ID/DD and their parents, and it addresses key areas of concern identified in the interviews. It has questions for them to consider as they are creating their disaster emergency care plan, which can be done together with their primary care team. **Conclusion:** This new toolkit can be used by primary care teams and Yas with ID/DD and their parents and/or support persons to develop personalized disaster emergency care plans that address the unique needs of the YA.
Group 3: Adolescents and Emerging Adults/Mental Health	
Moderator: Megumi Okumura, MD, MAS	
Poster 1	**Effective Recruitment Strategies to Engage Diverse Transition-aged Youth in Clinical Trials** *Tanisha Belton, MPH; Caren Steinway, MSW, MPH; David Rubin, MD, MSCE; Kim Smith-Whitley, MD; Sophia Jan, MD, MSH* **Background**: Randomized clinical trials (RCT) are imperative in building the evidence base of effective transition interventions. Previous research has illuminated the challenges of recruiting and retaining adolescents and young adults (AYA) in research studies due to environmental, community, and personal factors. The COMETS Study is a RCT comparing the effectiveness of two self-management support interventions (community health workers and mobile health) versus enhanced usual care to improve health-related quality of life for transitioning AYA with sickle cell disease (SCD). The aim of this abstract is to describe recruitment and retention strategies used in the COMETS study. **Methods:** Guided by the Social Ecological Model, recruitment and retention strategies were identified that prioritized the complex relationships between AYA with SCD and their environments. AYA (17 and older) were approached for study participation across five SCD centers in NY, PA, OH, and CT. Study team members approached patients to complete surveys at 6-, 12-, and 18- months after study enrollment. **Results:** Of the 432 eligible AYA approached for enrollment, 355 (82%) enrolled (mean age =19.05 years (SD=1.93) (range=17-28)). Enrolled subjects evenly identified as male and female (49% male). Most identified as African American (95%) and 9% identified as Hispanic/Latino. Recruitment strategies include in-person enrollment during appointments or admissions and mailed/emailed communications with a recruitment letter, study flyer, and a recruitment video. Telephone recruitment and electronic consent were added during the COVID-19 pandemic. Retention rates are: 79% at 6 months, 79% at 12 months and 75% at 18 months. Retention strategies include completion in-person, telephone, or an email/text, automatic reminders, and incentives for effort. **Conclusion(s):** Implementing recruitment and retention strategies that take in consideration participant environmental, community, and personal factors are imperative for success. Study teams should be prepared for ongoing refinement of strategies based on participant and collaborator feedback.
Poster 2	**Mental Health Transition Readiness in Youth With Co-Occurring Chronic Health Conditions and Public Insurance** *Wendy N. Gray, PhD, ABPP, BCB; Carlos Y. Konishi, PhD; Adrianne N. Alpern, PhD; Erin Benekos, NP; Courtney Malave, LCSW; Michael Weiss, DO*

	Background: Having a chronic health condition, a mental health diagnosis, or public insurance increases the risk for poor transition outcomes in adolescents and young adults (AYAs). Transition research often focuses on the chronic health condition, with less attention given to the transition of the mental health disorder. The current study examines transition knowledge and readiness in AYAs with all three risk factors: a mental health diagnosis, a chronic health condition, and public insurance. **Methods:** Our Medicaid-funded clinic specializing in treating mental health concerns in youth with co-occurring medical diagnoses is conducting a clinic-wide assessment of AYA (ages 12+) mental health transition knowledge and readiness skills. In additional to assessing mental health using the UNC TRXANSITION Index, AYAs/parents will also report on their knowledge and experience of clinic policies and practices surrounding transition, and their plans for transitioning to adult mental health care services. **Results:** Approximately 150 AYAs will participate in the study, with ongoing data collection efforts anticipated to be concluded by July 2022. In addition to presenting key findings regarding transition readiness, key demographics (e.g., age, gender, # of mental and health diagnoses) will be extracted from the medical record and examined as correlates of patient transition knowledge and readiness skills. Among a sub-sample of patients with available transition readiness data related for their medical condition, we will also examine how mental health transition readiness compares to chronic illness transition readiness. **Conclusion(s):** Youth with co-occurring mental and physical health concerns and public insurance are at higher risk for poor transition outcomes. Understanding the needs and challenges experienced by youth with multiple risk factors can inform future intervention efforts adopting a more holistic approach addressing AYA transition needs.
Poster 3	**Development of a Community Health Worker Training Program for Improving Transition to Adulthood for Young Adults with Sickle Cell Disease** *Tanisha Belton, MPH; Katherine Wu, MPH; Caren Steinway, LMSW, MPH; Symme Trachtenberg, MSW; Tahirah Austin, MPH; Kyle Smith; Samantha Luma; Trudy Tchume-Johnson, MSW; Sophia Jan, MD; Kim Smith-Whitley, MD; David Rubin, MD* **Background:** Transition to adulthood is a vulnerable time for adolescents and young adults (AYA; 16-25 years old) with sickle cell disease (SCD). Community health worker (CHW) programs have been developed for many patient populations to address outcomes such as patient activation, quality of life, and health care utilization for patients with chronic illnesses. However, few programs specifically target transition-age patients with SCD. The aim of this abstract is to describe the adapted CHW training and implementation model being tested in the COMETS Trial. **Methods:** The aims of this training program were to (1) adapt the existing Penn Center for Community Health Worker's IMPaCT CHW model materials for CHWs use with transition-aged patients with SCD and (2) create additional materials and trainings to enhance CHW knowledge of SCD and transition to adulthood. A multidisciplinary workgroup defined specific goal-setting categories and developed a targeted CHW training curriculum. Additionally, the workgroup wrote a job manual including guidelines with example talking points and defined an ongoing supervision CHW. **Results:** The existing CHW model was adapted for CHWs working with AYA with SCD by incorporating tools specifically tailored to this new population, such as a comprehensive set of patient-facing education materials, and a series of "goal-setting support" documents. To date, 15 CHWs had been trained in this adapted model. Of those, 7 (47%) had previous research experience, 8 (53%) had clinical experience, and 11 (73%) reported SCD experience. **Conclusions:** Development of a CHW training program for improving transition for AYA with SCD is feasible. Further adaptations to transition to a fully virtual intervention was successful and acceptable to CHWs. This model may serve as an effective intervention for improving health-related quality of AYA with SCD.
Poster 4	**Perceptions of Transitional Care Needs of Adolescents and Young Adults with Special Healthcare Needs** *Benedicta, MPH, RN; Sharon D. Horner, PhD, RN, FAAN* **Background:** Many major pediatric hospital systems do not have established healthcare transition (HCT) programs to support the transition from a pediatric care to an adult care model. Needs assessments can provide critical data to guide the creation of an optimal system of transitional care. The purpose of this study was to conduct a needs assessment with two specialty care clinics in the beginning stages of developing transitional care programs. **Methods:** A qualitative descriptive study design was used to examine the perceptions of the transition experience for adolescents and young adults (AYA) with special healthcare needs (SHCN) and for their parents or caregivers. A convenience sample of AYA, ages 16-25 and one of their parents were recruited from specialty care clinics that served patients with inflammatory bowel disease and congenital heart conditions. A semi structured interview guide was approved by the clinic staff, the hospital steering committee, and the University IRB. Interviews with AYA and with parents were conducted separately, transcribed, and then coded. **Results:** Interviews were completed with 8 AYA and 8 parents. The themes were Transfer of Care, Mastery and Support. With Transfer of Care, participants were worried about being able to consult with both their pediatric and their new adult provider. For Mastery participants were concerned not only about mastering self-management of their condition but also about the technical capabilities of the new provider. For Support participants wanted to be prepared and familiar with the transition process and comfortable in the new adult world.

	Conclusions: Recommendations given to providers were to start talking about the transition process early, encourage AYA to start filling out clinic visit paperwork independently or with help from parent.
Poster 5	**Barriers and Facilitators to Self-management, Self-advocacy, and Community Inclusion for Adolescents and Young Adults with Spina Bifida** *Rhonda Horick, MSW; Jason Woodward, MD, MS; Diane Burns, B.A.; Lisa Vaughn, PhD; Simon Abimosleh, BS; and Brittany Spicer,BS, CCRP* **Background:** Eighty-five percent of children born with spina bifida (SB) now survive to adulthood. However, adolescents and young adults (AYA) with SB experience significant challenges in developing independence with self-management/self-advocacy skills and in achieving desired community participation and supportive relationships. Our objective was to understand the barriers/facilitators that impact self-management, self-advocacy, and community inclusion and supportive relationships of AYA with SB as they transition to adulthood. **Methods:** An academic-community research partnership with members from a multidisciplinary SB clinic and a community-based SB organization conducted a mixed methods study with focus groups/informant interviews via Zoom with adolescents with SB (age 14-19), adults with SB, and parents/caregivers of transition-age youth with SB. Participant surveys provided contextual and demographic data. Paraphrased statements from our previous study describing the three domains of self-management, self-advocacy, and inclusive communities/relationships were shared with participants to facilitate discussion. Focus groups/ interviews were recorded and transcribed. An iterative coding process by research team members identified preliminary themes. **Results:** Eight focus groups and four interviews were completed with 29 participants. Barriers to self-management, self-advocacy, and community inclusion frequently reported were difficulty asking for help, challenges with organization skills, anxiety, and lack of reliable transportation. Facilitators commonly described included having a mentor with or without SB, family or friends who encouraged and modeled independence, scaffolding when learning new skills, community organizations that understand SB, and adaptive sports. Common solutions identified included mentors, opportunities to practice tasks/learn on own, opportunities for peer interactions (e.g., camps), life coach/navigator, assistance with planning (e.g., breakdown tasks, apps, support person), and supportive work environment. **Conclusion:** Opportunities for mentorship and peer interactions and supports for life planning and executive function challenges may improve self-management, self-advocacy, and community inclusion in individuals with SB as they transition to adulthood. Findings will inform pilot transition interventions for AYA with SB.
1:30 PM Platform Session 3: Continuous Quality Improvement/Self-Management/AEA and Family	
Moderator: Parag Shah, MD	
Presentation 1	**Changes in Legal Responsibilities for Healthcare Decision-Making at Age 18: AYASHCN and Caregiver Knowledge, Satisfaction with Preparation Received, and Recommendations for Improvement** *Blanca E. Sanchez-Fournier BA; Jordyn Babla, BS; Beth H Garland, PhD; Mary Majumder, JD, PhD; Constance M. Wiemann, PhD; Albert C Hergenroeder, MD* **Background:** Most Adolescents/Young Adults with Special Health Care Needs (AYASHCN) will assume legal responsibility for making decisions about their medical treatment at age 18. Simultaneously, Caregivers will lose AYASHCN medical record access. This study examined AYASHCN and Caregiver knowledge of, satisfaction with, and suggestions for improvement in preparing for these changes. **Methods:** Eighty-three dyads (18-year-old AYASHCN and Caregivers) completed a one-time assessment to evaluate their knowledge about changes in responsibility for decision making with a focus on consent, satisfaction with the preparation received, and recommendations for improved preparation. Descriptive statistics and mean comparisons were used. Responses to open-ended questions were coded by an interdisciplinary team. **Results:** AYASHCN and Caregivers did not significantly differ (70% vs. 66%, p>.05) in knowledge of changes that occurred at age 18. Areas where knowledge was lowest included whether after AYASHCN turn 18: AYASHCN must go alone to their doctor appointments; Caregivers will continue to have access to AYASHCN medical records; AYASHCN can request to delay a treatment decision to confer with Caregivers; and healthcare providers will continue to automatically provide updates to Caregivers. Less than half of AYASHCN and Caregivers reported being very satisfied with the preparation they received. AYASHCN would have wanted to practice skills, know more information, and be more actively engaged in their healthcare before turning 18. Caregivers desired more information/communication from the healthcare team, opportunities for AYASHCN to practice skills, and recognition that not every 18-year-old is ready to assume self-management. A subset of AYASHCN and Caregivers felt well prepared. **Conclusion:** AYASHCN and Caregivers are not being adequately prepared for the changes in medical consent and responsibility for decision-making that occur at age 18. Interventions to promote a clear understanding of these changes while providing opportunities for AYASHCN to practice self-management skills before age 18 are needed.
Presentation 2	**Health Care Transition in School-Based Health Centers: A Playbook** *Samhita Ilango, MSPH, Margaret McManus, MHS, Laura Brey, MS, Diana Bruce, MPA, Patience White, MD, MA*

	Introduction: Adolescence can be a dynamic period with multiple changes co-occurring, especially as students transition out of high school and enter adulthood. To support young people with their transition to adult health care and to address the nationally low receipt of health care transition (HCT) services by young people, Got Transition and the School Based Health Alliance co-produced a playbook to equip school health staff with resources and information on how to incorporate HCT supports into school-based health centers (SBHCs). **Methods:** Based on previous pilot projects that customized Got Transition's Six Core Elements of HCT for SBHCs, this effort aimed to create a tool that SBHCs can use to guide their implementation of the Six Core Elements. We first convened an advisory group of young adults and SBHC clinician and administrators, some of whom were previously involved in piloting HCT supports in SBHCs, to elicit what information SBHCs need to incorporate HCT into their centers. Got Transition and the SBHA created and revised the playbook content based on the feedback received from the advisory group over the course of three virtual meetings. **Results:** The final playbook begins with defining HCT and an explanation about the importance and evidence for HCT guidance for adolescents. The subsequent section of the playbook guides a user through starting a HCT process, which includes guidance on forming a team and gaining school support, developing improvement and implementation plans, tracking and measuring improvements, and communicating and disseminating the outcomes. The playbook also details HCT intervention tools, examples from the field, and additional HCT resources. **Conclusions:** This new playbook addresses the need to assist students with their preparation for the transition from pediatric care to adult health care by offering guidance and tools to help launch the implementation of a HCT program in SBHCs.
Presentation 3	**Self-Harm Mortality in Adolescents and Young Adults in the United States: 1999-2020** *Matthew GoodSmith, MD, Nabil Abou Baker MD, Mengqi Zhu MS, Rita Rossi-Foulkes MD* Background: Self-harm is one of the leading causes of death in adolescents and young adults (AYA), and there has been media coverage surrounding worsening mental health in AYA during the COVID-19 pandemic. A Center for Disease Control (CDC) survey of high school students found 19.9% had considered suicide, and 9.0% had attempted suicide during the pandemic. According to the CDC, the rate of deaths resulting from self-harm in the general population peaked in 2018, with small declines in 2019 and 2020. However, this trend may obscure mortality rates in AYA from 1999 to 2020. **Methods:** National mortality data related to self-harm were obtained from the CDC mortality database. Population estimates are based on US Census Bureau data. Crude rates are the ratio of death counts to population per 100,000 people. Ninety-five percent confidence intervals and standard errors were summarized. Data were evaluated by year and by demographic factors like age, sex, race, and ethnicity. Data analysis was performed in R studio. **Results:** Between 1999 and 2020, crude rates of self-harm mortality increased after age 12, with rates plateauing after age 21. In all age groups studied, self-harm mortality increased significantly (p<0.05) between 1999 and 2020. In contrast to data in the general population, self-harm mortality did not decrease in AYA after 2018. Indeed, mortality rates trended towards increasing in the 20-24 and 25-29 age groups during this time period. This trend was particularly apparent among males. **Conclusions:** Mortality rates due to self-harm have been increasing for decades in AYA and did not decrease after 2018 despite decreases in the overall population. These trends have persisted despite the 2002 Consensus Statement on improving transition of care. This work shows the urgent need for additional mental health resources in this population as they grapple with worsening mental health.
Presentation 4	**The ImPACT (Improving Pediatric to Adult Care Transition) Program: Building Capacity for Best Practices and Transition Consultation in a Pediatric Hospital on an Urban Academic Medical Campus** *Jennifer Disabato, DNP CPNP-PC; William Anderson, MD* **Background:** A range of system-wide strategies exist to streamline resource utilization and enhance the adolescent and young adult (AYA) patient and family experience. Lack of communication and coordination between care teams and utilization of evidence-based practices can lead to suboptimal transition outcomes. Children's Hospital Colorado developed an interdisciplinary, systematic approach to address these barriers. **Methods:** Executive sponsorship supported co-directors to develop a hospital-wide program with input from hospital leaders and affiliated health systems. An in-depth needs assessment of 29 clinics' transition processes in the pediatric center were conducted through in-person interviews and online surveys. Co-directors convened 4 separate interdisciplinary groups to develop a mission and values statement, consolidate resources in a shared repository, revise electronic health record tools, and design a centralized transition care consultation and coaching hub. **Results:** The needs assessment distilled three foci for system-wide program development: access, education, and communication. Philanthropic funding was awarded to address care fragmentation through the development of a novel ImPACT Navigation Hub (INH). The INH team includes a nurse care coordinator, social worker, family navigator, and adult primary care provider. The INH provides coaching on best practices, use of hospital transition tools, and care coordination for AYA with more complex needs. Metrics are tracked from a Tableau dashboard,

	including patient demographics, referrals to the INH, use of the Epic Transition Planning Tool, and number of patients successfully transitioned to adult care pre-post establishment of the INH team. **Conclusion:** Building a successful system-wide transition program requires engaged hospital leadership, stakeholder input, and ongoing outreach to assure alignment with overall institution program objectives. Ongoing work includes greater engagement of on-campus adult care clinics and establishing strategies for fiscal sustainability and growth. The ImPACT Program and INH may serve as a model for similar transition programs in other healthcare settings.
Presentation 5	**Multi-stakeholder Design and Development of a Self-Management Mobile Health Application for Young Adults with Sickle Cell Disease** *Caren Steinway LMSW, MPH; Ariana Mastrogiannis; Telmo Santos, MD, MPH; Jack Chen, MBS; Jason Woodward, MD, MPH; Ilka Riddle, PhD; John Berens, MD; Thomas Davis, MD; Michelle Cornacchia, MD; Charmaine Wright, MD, MSHP; Sophia Jan MD MSHP* **Background:** Mobile health applications aimed at changing health behaviors are effective at improving behaviors and clinical health outcomes. Patients who utilize mobile health applications for this purpose report being more satisfied with use than with conventional care alone. Although these outcomes are appealing, little literature explores the challenges of app development or health system-application development firm partnerships. This project aimed to design and develop a self-management mobile health application for young adults with Sickle Cell Disease (SCD) transitioning to adult care. **Methods:** A multi-stakeholder group, including an application developer, clinicians, researchers, and young adults with SCD 5 health systems convened. Theoretical constructs, including extrinsic motivation, contingent reward, and fixed ratio reinforcement, were identified to structure intervention components. Eight topics were explored through interviews with stakeholders, including: 1) social behaviors and entertainment; 2) treatment; 3) pain impact; 4) pain management; 5) SCD knowledge; 6) lifestyle & goals; 7) communication & support; 8) envisioning the future. Design sprint cycles were used for iterative refinement of application components. **Results:** Interviews indicated preferences for social media apps, a repository for emergency information, and daily disease management. Application components include health behavior challenges, tracking of medications and symptoms, an educational library, discussion boards, and medical summary. Despite being grounded in theory, designing in conjunction with multi-level stakeholders, and working with experts in application development, challenges arose. Backend database infrastructure and architecture needed to be adapted to secure protected health information. Further, technology firms typically work quickly and health systems work at a slower pace. Tensions arose when trying to identify project milestones and timelines. Finally, frequency of changes in technology brought up questions of sustainability. **Conclusions:** Despite effectiveness of mobile health applications at improving health outcomes, significant challenges exist when designing and developing applications that interface with application development firms and health systems.
2:45 PM Break	
3:00 PM Poster Session 2 **Group 1: Continuous Quality Improvement/Program Development/Models of Care** **Group 2: Health Care Transition Outcomes and Readiness Measures**	
Group 1: Continuous Quality Improvement/Program Development/Models of Care	
Moderator: Thomas Davis, MD	
Poster 1	**Development of a Health Care Transition Program for Youth with a History of Renal Transplantation** *Bethany Coyne, PhD, CPNP-PC, RN; Karen Warburton, MD* **Background:** This presentation will describe the development and implementation of a Health Care Transition (HCT) program for youth with a history of renal transplantation at an academic medical center. During this presentation, challenges and recommendations for program development will be presented. **Method:** This HCT program was developed using the Got Transition'® implementation guide and uses transplant specific tools from the American Society of Transplantation (AST). The transition team is comprised of a transition coordinator and representatives from the pediatric and adult team (nephrologists, RN coordinators, and transplant social workers). Quarterly meetings with the transition team are used to discuss transition plans for individual patients. Transition materials include AST transition readiness checklists, plans of care, and transfer summaries. Transition visits are quarterly for individuals in late adolescence (≥17 years of age), semiannually for individuals in middle adolescence (14–16-year-olds), and annually for individuals in early adolescence (11-13-year-olds). Visits include discussion about transition, completion of transition readiness check lists, and targeted education based on readiness checklist responses. During the transition visits, individuals meet with the RN coordinator, social worker, and transplant nephrologist. Additional team members (nutrition, social worker, teen health) are consulted as needed. Joint visits occur at the time of transfer; the adult transition team meets with the youth and their family in

	the pediatric clinic in coordination with the pediatric transition visit. The first adult visit is scheduled within a month after the joint visit. **Results:** To date, 33 renal transplant recipients have been enrolled in the transition program, 21 individuals in late adolescence, 8 in middle adolescence. At this time, three individuals have successfully transferred to the adult program. Challenges to program establishment include time, staffing, knowledge related to transition, billing and reimbursement, and consistent tracking and monitoring. **Conclusion:** Recommendations include having a dedicated transition coordinator, administrative support, and key stake holder buy-in.
Poster 2	**The Adult Special Care Clinic: Integrated Transition to Adult Primary Care for Medically Complex Patients** *Eleanor Floyd, MD; Jennifer Fenton, RN, BSN, ACM-RN* **Background:** Children's Hospital Colorado (CHCO) and UCHealth (UCH) are distinct but geographically proximal institutions sharing a teaching university and serving pediatric (CHCO) and adult (UCH) populations. CHCO has a large (3000+ patient), longstanding complex primary care clinic, but there is no UCH counterpart. Consequently, complex patients were being served by pediatricians long into adulthood. **Methods:** A proposal for a primary care clinic serving complex adults at CHCO was developed by providers working with this population. Funding was obtained through institution-specific Medicaid grants. The clinic was located at CHCO due to space and budget constraints, with plan to locate primary care at CHCO but specialty and inpatient care at UCH. The leading provider at the clinic was hired with a dual CHCO-UCH appointment. **Results:** The Adult Special Care Clinic (ASCC) has been seeing patients with 0.5-1.0 provider FTE, a dedicated RN care coordinator, and a family navigator since late 2019. After an initial bolus of 100 over-25yo patients, we accept patients down to the age of 18 and see 2-3 new patients per week. Our patient load is 300 per provider FTE. Benefits of the CHCO location include easier transition of primary care and accessibility of existing pediatric resources. Drawbacks include lack of clarity from families and specialty providers regarding transition to adult specialty care, and difficulty with integration into the adult system. There are marked benefits to the split leading provider position, which have substantially eased transition into the adult system for patients. **Conclusions:** The medically complex adult population requires a dedicated primary care clinic with access to both pediatric- and adult-focused resources. This is difficult to accomplish in a split system, and it is beneficial to have a dually-trained and dually-appointed provider leading the clinic.
Poster 3	**Safety Events Amongst Young Adults Admitted to Pediatric Intensive Care Units: Where Are We and How Can We Improve?** *Dava Szalda, MD MSHP; Adam Greenberg, CRNP* **Background:** Nationally, pediatric intensive care units (PICUs) admit many young adults, particularly those with complex chronic conditions who have not yet transitioned to adult care. The purpose of this review was to determine whether safety events affecting adult-aged patients in ICU settings were specifically attributable to adult age, and among those that were, to identify trends in the types of safety events. **Methods:** A retrospective data review was performed at a tertiary pediatric academic hospital. 554 safety events, including near misses, were reviewed for patients greater than 18 years admitted 03/02/2021-02/28/2022 to the pediatric cardiac intensive care unit (CICU) or PICU. **Results:** Almost all (96%, n=529) safety events were not attributable to patient age greater than 18. Two percent (n=13) were likely, and 2% (n=12) were possibly, attributable to patient age greater than 18. Amongst safety events likely due to adult age, median age was 19 years (range 18-24 years) and median weight was 47.5kg (range 24-94 kg). The majority (85%, n=11) were related medication dosing, while 15% (n=2) were related to available medical equipment. Dosing issues accounted for 10 of 11 medication errors; overdosing (90%, n=9) was more common than under-dosing (10%, n=1). Acetaminophen the most common improperly dosed medication (40%, n=4). Ordering pediatric weight-based instead of adult standard dosing, or vice versa, led to 90% (n=9) of incorrect dose orders. **Conclusions:** In our review, very few safety events were due to adult age. As the few events attributable to adult age involved pediatric weight based vs. adult standard medication dosing, collaboration between clinicians and pharmacists and/or clear formulary guidelines for medication dosing represents an opportunity to improve care for adult-aged patients hospitalized in pediatric institutions.
Poster 4	**Implementation of a Structured Health Care Transition Program Utilizing the EMR, Nursing, and Support Staff** *Mary Wingert, BSN, RN, CPN; Kristen Carlin, MPH* **Background:** Approximately 500,000 adolescents and young adults transition from pediatric to adult health care annually and studies have shown improved health outcomes with a structured health care transition (HCT) process, like the Six Core Elements that were endorsed by the AAP, ACP, and AAFP in their 2018 clinical report. Despite clear recommendations for best practice and evidence of improved health outcomes, many health care providers face barriers in incorporating HCT activities as part of their standard practice in caring for adolescents and young adults.

	Method: Using a prospective quality improvement approach, a structured process is being implemented for adolescents and young adults transitioning to adult care, utilizing the Six Core Elements of Health Care Transition which are aligned with guidance from several healthcare organizations (e.g., American Academy of Pediatrics). Patients 14 and older who are seen by Craniofacial, Dialysis, or Neurosurgery in the outpatient setting (anticipated N = greater than 1000) will receive standardized interventions utilizing the electronic medical record. As the interventions are linked to tools in the electronic medical record, the implementation rates of the interventions will be tracked by EPIC analytics. Provider's lack of time has been identified as a barrier in many previous studies, so a pre and post survey will be conducted with the health care providers involved to assess barriers and satisfaction with the interventions. **Results:** Results will include the proportion of eligible patients who received the age specific health care transition activities, and provider responses to the program. **Conclusion:** Findings will enhance knowledge about the implementation of effective HCT programs, the role of nurses in coordinating these programs, and provider satisfaction with the HCT program interventions.
Poster 5	**An Institution-Wide Assessment of Pediatric to Adult Health Care Transition Practices** *Anisha Maheshwari, MD; Anna Coronata, MD; Ahmed Sami Abdul-al; Laura Kirkpatrick, MD; Andrew McCormick, MD; Traci Kazmerski, MD; Loreta Matheo, MD* **Background:** Healthcare transition (HCT) is the process of moving a patient from pediatric, parent-supervised care to an independent, adult-centered model. While limited, available data suggest that the lack of effective HCT may contribute to fragmentation of young adult healthcare and increased risk for adverse health outcomes. This study assesses current HCT activities and explores the educational and system-based needs for effective HCT processes in a single institution. **Methods:** We interviewed division leaders at one free-standing children's hospital regarding HCT practices. We evaluated groups using an interview guide and rubric scoring from the "GotTransition Current Assessment of HCT Activities" (scoring range from 8 [low HCT] to 32). We audio-recorded and transcribed interviews. Two coders calculated each group's score on the assessment and qualitatively analyzed transcripts using a thematic analysis approach with deductive and inductive strategies. **Results:** We interviewed 28 participants, each representing one division/care program. The institutional mean on the HCT assessment was 15.5 +/- 4.5 (median 17.5, range 8-28). Key interview themes include: 1) Significant heterogeneity in the HCT process exists within the majority of divisions/care programs; 2) There is no coordinated institutional HCT approach despite some groups having their own HCT practices; 3) Participants find HCT difficult if they perceive the lack of an equivalent adult specialist for a patient's specific medical condition; 4) Participants desire ancillary staff to support HCT; and 5) The majority of participants report a lack of coordinated handoffs from pediatric to adult providers. **Conclusion:** Despite known benefits of a structured approach, most leaders report heterogeneity in current HCT practices and a lack of institutional resources and adult provider partners to support optimal HCT. This baseline assessment of HCT can inform institution-wide interventions to standardize transition practices and positively impact health outcomes.
Poster 6	**Tapping into Technology: Using Virtual Methods to Improve a Cardiology Transition Clinic** *Courtney Porter, MPH, CPHQ; Roberta Williams MD* **Background:** The need for a structured process for healthcare transition is well-documented. In our previous experience with an in-person cardiology transition clinic for adolescents and young adults, there was a high no-show rate and inefficient coordination of patient and provider schedules. **Methods:** In July 2021, we converted the Transition Clinic to a telehealth format with a single nurse leader, scheduler, and in-house cardiologist with experience in both life-long course of disease and specific developmental and mental health issues of the population. Target age range was 17-21 years. The process for referral from the primary cardiologist was streamlined to introduce patients to transition clinic and more broadly capture appropriate patients. Visits focused on assessment of readiness for self-care and health literacy, education about navigating adult health systems, natural history of their specific condition, and plans for timing and destination of adult care for cardiology and relevant subspecialties. Reproductive and mental health issues were assessed for and referred to Adolescent Medicine. All educational materials were adapted from a paper-based binder and provided virtually in a more concise manner. **Results:** We have seen 38 unique patients compared to 28 with in-person visits for a similar timeframe and no-show rate dropped from 26% to 12%. Additionally, we uncovered unexpected problems or detrimental plans in 15% patients such as discontinuity of care, high-risk pregnancy, organ dysfunction or plans for life-threatening arrhythmia care. Some patients revealed information, not previously disclosed to their long-standing cardiology team. **Conclusions:** In our preliminary experience, patients appear to disclose more openly when meeting virtually with unfamiliar providers than at standard clinic visits. No-show still occurred but was less frequent and less disruptive to provider schedules. The virtual approach relieved pressure on busy clinic space and designated team insured consistent coordination and communication. Additional evaluation is planned to explore the long-term impact.

Poster 7	**Massachusetts Initiative to Improve Transition to Adult Healthcare for Individuals with Neurodevelopmental Disabilities (NDD): Innovation Collaborative Processes** *Lindsay MacAuley, MPH; Meredith D. Braza, AuD; Sarah J. Spence, MD, PhD; Lindsay Hunt, MEd; Susan Shanske, MSW* **Background:** The Massachusetts Initiative to Improve Healthcare Transition for Individuals with Neurodevelopmental Disabilities (NDD) began in 2018. The last nine months utilized an innovation collaborative model to test change ideas generated by diverse stakeholders across the state. **Methods:** The purpose of the innovation collaborative was to build team-based partnerships serving individuals with NDD. Initiative co-chairs worked with a quality improvement coach and were supported by fellows from the Leadership in Education for Neurodevelopmental Disabilities program. Eight teams (five primary, three specialty) were recruited, composed of pediatric practices, adult practices, and patient/family partners. Each team articulated an aim statement, created process maps, and identified change ideas to test. Teams continuously implemented plan-do-study-act (PDSA) cycles, capturing outcome measures related to their aims. Team leaders met monthly with initiative leadership, sharing successes and challenges, and developing partnerships with fellow participants. Learning sessions were held at the beginning (September 2021), middle (February 2022), and end (June 2022) of the collaborative, designed to educate teams on relevant topics and facilitate sharing of improvement strategies. **Results:** Teams successfully identified change ideas, completing 38 PDSA cycles. With eligible patients/families, teams engaged in six new touchpoints (e.g., providing transition resources, creating transition summaries). Two teams generated surveys to measure clinician and family/patient awareness of transition processes. Other teams developed internal transition tools, including EMR tracking of durable medical equipment, therapeutic transition groups, and transition-related EMR smartphrases. Common challenges included organization of tasks, weak adult provider engagement, billing/coding, and low transition visit attendance. **Conclusions:** Learning collaborative teams successfully generated aim statements for healthcare transition improvement, identified patients with NDD eligible for transition, and completed PDSA cycles. Monthly team lead meetings and reporting held teams accountable for progress. Collaborative teams of pediatric providers, adult providers, and family partners ensured valuable perspective in developing successful processes.
Group 2: Health Care Transition Outcomes and Readiness Measures	
Moderator: Lynn Davidson	
Poster 1	**The importance of the Geneticist in Healthcare Transition of Adults with 22q11.2 Deletion Syndrome** *Jessica Gold, MD, PhD;T Blaine Crowley; Donna M McDonald-McGinn, MS, CGC; Elaine H Zackai, MD* **Background:** Due to medical advancements, people with 22q11.2 deletion syndrome (22q11.2DS) have improved health outcomes and increased survival into adulthood. There is a new imperative to provide adult-oriented medical care. While recent guidelines have been published on caring for adults with 22q11.2DS, there is no evidence on best practices for healthcare transition (HCT). We created a targeted needs assessment of adults with 22q11.2DS in the Children's Hospital of Philadelphia (CHOP) cohort to evaluate current patterns of care and introduction of HCT. **Methods:** We performed a retrospective chart review for adults with 22q11.2DS (>21-years-old) seen at CHOP since 2012. We established two cohorts: patients who presented to genetics and those seen only in other CHOP clinics. Primary outcomes included secondary diagnoses, employment status, and education level. Secondary outcomes included lapses in insurance or access to care, hospitalization rate, and emergency room utilization. HCT introduction and planning was also analyzed. **Results:** During our study period, the genetics department saw 69 patients with 22q11.2DS between the ages of 22 and 58 years-old (mean 27 years). Our second cohort contained 70 patients ranging from 21 to 57 years old (mean 28 years). HCT was discussed more frequently with patients followed by genetics (54% v 31%, p<0.001). HCT was limited to advising referral to adult providers. There was no clear, consistent documentation of patients' disease knowledge nor assessment of patient medical autonomy. Portable healthcare summaries for 22q11.2DS were not regularly used. **Conclusion:** Adults with 22q11.2DS are a growing cohort of patients in our large genetics clinic and quaternary pediatric hospital. Currently, HCT planning for this population at CHOP is scant and mainly addresses transfer to adult providers. It is significantly more likely to be introduced to patients with regular contact with genetics. Subspecialists are well poised to lead HCT, especially for individuals with rare diseases.
Poster 2	**Self-Perceived Importance and Confidence of Adolescents and Young Adults Transitioning to Adult Care** *Lisa Lestishock DNP, RN, CPNP-PC; Carrie Cuomo DNP, CPNP-PC/AC; Terri Hickam, MSW, LCSW, LSCSW, CCM; Tisa Johnson-Hooper MD, FAAP; Michele Maddux PhD; Patience H. White, MD, MA, FAAP, MACP* **Background:** Motivational interviewing 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. As part of a national HCT improvement learning community, four participating institutions seek to describe AYAs' levels of self-perceived importance and confidence in their readiness to transition to an adult-oriented model of care/adult clinician, at the initiation of health care transition activities. Importance and confidence are validated

	domains related to patient engagement. Using the convenience sample of AYAs who were already established with health care transition quality improvement (QI) programs, participating institutions seek to compile and analyze retrospective data over a period of several years from initiation of quality improvement activities (varies by institution) through March 2020 (onset of COVID-19 pandemic). The primary aim is to describe typical levels of self-reported importance and confidence (Likert scale of 0-10) when initially establishing with a transition program, while a secondary aim is to understand whether demographic characteristics (age, sex, gender identity, race, ethnicity, language, and insurance type) may be predictors of higher levels of importance or confidence around health care transition. **Methods:** Retrospective chart review data for AYAs (n=6450) from Children's Mercy Kansas City, Cleveland Clinic, Henry Ford Medical Group, and Ravenswood Family Health Center will be managed in REDCap and exported to SPSS for descriptive analysis. **Results:** Results pending as the study is in progress **Conclusions:** Data have been collected as part of QI efforts, and as a convenience sample are not generalizable to every health care system. However, by identifying initial perceptions of importance and confidence to indicate engagement of AYAs in health care transition programs, this may guide others working in HCT.
Poster 3	**Clinician Experience in Eight Health Systems Incorporating Health Care Transition (HCT) into Their Practice** *Ariadne Lie, MD; Julie Corder CNP; Carrie Cuomo DNP, CPNP; Lauren Galpin MD; Reem Hasan MD, PhD;Terri Hickam MSW, LCSW, LSCSW; Marybeth Jones MD, MS; Lisa Lestishock DNP, CPNP; Dina Parekh MD; Carolyn Reynolds APRN, MS; Emily Rosenthal MD; Patience White MD, MA* **Background:** Health Care Transition (HCT) programs aim for high-quality care by utilizing the quadruple aim approach: maximizing a positive youth/young adult and family/caregiver experience, improving overall health outcomes, improving health care utilization and reducing health care costs, and improving clinician experience. Although HCT literature includes many studies of youth experience, health outcomes, and utilization of care, there is a paucity of evidence examining clinician experience with incorporating HCT into their practice. Among health systems engaged in a HCT Learning Collaborative, we aim to describe perceived experiences of clinicians and staff with HCT process implementation. **Methods:** Representatives from eight health systems (University of Rochester Medical Center, Children's Mercy Kansas City, Cleveland Clinic, Oregon Health & Science University, Walter Reed National Military Medical Center, Kaiser Permanente Colorado, Ravenswood Family Health Center and Intermountain Healthcare) collaborated to combine Got Transition Clinician Feedback surveys for Pediatric, Family Medicine/Med-Peds and adult clinicians into one electronic survey. The final survey is designed to elicit clinician feedback about HCT processes, leadership support, and resulting clinician experience. The target study population includes all clinicians and staff participating in HCT implementation efforts at eight participating health systems. The survey will be disseminated via RedCAP in 2022. Responses will be categorized using a 5-point Likert scale and analyzed using descriptive statistics and Fisher's exact test. Overall satisfaction and correlations between the clinician and staff experience and other characteristics of the clinicians, staff and the health system will be reported. **Results:** Results pending as the study is in progress. **Conclusions:** Understanding the experience of a diverse group of clinicians working in a variety of health care systems allows other health systems and practices to better support their providers in improving the HCT process for their youth and young adults as they move from pediatric to adult health care.
Poster 4	**The Impact of a Dedicated Health Care Transition Program on Post-Transition Chronic Care Management and Utilization for Young Adults with Spina Bifida** *Sujal Manohar, BS, BA, Xiaofan Huang, MS, Melissa Morrison-Jacobus, CURN, Jonathan Castillo, MD, MPH, Heidi Castillo, MD, Ellen Fremion, MD* **Background:** A structured health care transition (HCT) process is critical to ensuring continuous access to preventative health and chronic condition management for adolescents and young adults with spina bifida (SB) as they transfer from pediatric to adult care. While various pediatric HCT clinical models have been implemented to prepare for HCT, the impact of these models on adult care outcomes is less well known. **Methods:** A retrospective chart review was completed of adult SB patients within a single-center medical home for adults with intellectual and/or developmental disabilities. We compared the chronic management outcomes of being on a bowel and bladder regimen and having a skin ulcer at the first adult visit, and the health care utilization (outpatient, emergency room, and hospitalization) in the first year post-HCT between young adults with SB who did (HCT group) and did not (non-HCT group) participate in a SB HCT preparation program in the pediatric hospital setting. **Results:** 162 patients with SB transferred from the pediatric hospital and established care at the medical home between 2009 and 2021. Patients in the HCT group (n=68) were more likely to have a bowel management program (p=<0.001) at the time of establishing care. In the first year after HCT, patients in the HCT group also had higher numbers of adult subspecialty visits (p=0.01) compared to the non-HCT group. There was no statistically significant difference between the groups regarding the bladder management regimen, the presence of a skin ulcer, rates of emergency room and hospital utilization, and primary care visits post-HCT.

	Conclusions: Our results indicate that HCT programs may support being on a bowel regimen and engagement in outpatient subspecialty adult care post transition for adults with SB.
Poster 5	**Impact of a Structured Transition Program Including the Assistance of a Virtual Transition Visit** *Tara Shores, BSN, RN, CBC; Pam Finn, APRN; Toby Rockefeller, MD; Brian Birnbaum, MD* **Background:** Young adult patients are lost to follow-up as they age out of pediatric care. Patients and families are nervous and unfamiliar how to navigate the process of transitioning care to an adult provider. ACHD colleagues reported many patients do not seek cardiac care until symptomatic. Our heart center began closer collaboration with two local experienced ACHD programs. Allowing two of our providers to establish clinics at these facilities. A unique virtual transition clinic was launched between these programs to reduce barriers. **Methods:** Previously, no process in place to track patients ready to transfer. We provided a list of local adult cardiologists to schedule with yet no knowledge of appointment status. New process involves structured transition education program starting at age 15. Between ages 18-21 when deemed ready to transfer, an order is placed and our ACHD transition coordinator is notified. The patient is added to our spreadsheet to track their transfer process. Process involves contacting patients, scheduling a virtual appointment with the pediatric ACHD team and adult ACHD team (piloted with one adult facility.) This appointment covers their specific cardiac anatomy, surgical history, medications, insurance, and specialty considerations. They schedule their first appointment with their new provider at that time. They have the option of the ACHD coordinator attending their first appointment. The ACHD coordinator is notified by the adult team if they attended their appointment. **Results:** From commencement of this program there have been 56 patients referred for transfer. 9 completed transfer, 23 scheduled, 18 awaiting scheduling and 6 unreachable. Of the currently scheduled 6 have been piloted with our virtual transition clinic. Feedback from patients and families has been very positive. **Conclusion:** Assisting patients in navigating the transition process has resulted in successful handoffs to adult cardiologist. Patient and families have expressed high satisfaction in the new process and improved transition.
Poster 6	**A Novel Approach to Transition Readiness Assessment– An All-Specialities Inclusive Rubric Based on Age-Appropriate Outcomes and Growth Measures** *Myoung Hyun Choi, MD; Erin Hickey, MD* **Background:** In the current literature, assessment of transition readiness of pediatric patients with complex congenital or early acquired conditions is based on surveys consisting of Likert-scales or dichotomous questions. These screening tools are then used repetitively in intervals to gauge transition readiness. While useful in measuring the patient perception in transition readiness at the time of administration, these surveys are not formative and often subjective, limiting the tool's ability to provide shared insight from both the patient and physician and inform future directions to improve transition readiness. In light of these findings, we devised a novel growth-based, objectives-driven rubric that provides a conduit through which patient and provider can establish a shared understanding of the patient's abilities as well as needs in successful transition and transfer to adult care. **Methods:** We performed literature review and devised six key focus-areas crucial to transition in any specialty. For each focus area, we created five levels of ascending proficiency and delineated specific abilities that qualify them as novice to expert. **Results:** We designed a rubric with six age-appropriate focus areas that provide formative, growth-based assessment of transition readiness with the ultimate goal of scaffolding patients to be able to manage their health conditions independently and also make informed, inquiry-based, and shared decisions with their physicians. **Conclusion:** We intend to apply for IRB exemption for the rubric to be used in pediatric specialty clinics at the University of Illinois Health System and survey physicians on their perception of the quality, specialty-specific usability, and comparative efficacy relative to existing transition readiness tools for long-term use.
4:00 PM Wrap Up	