12th Annual Virtual Health Care Transition Research Consortium

Research Symposium

Wednesday, October 28, 2020
8:00 AM – 5:00 PM
Central Standard Time Zone (CST)

12th Annual Health Care Transition Research Consortium Research Symposium

Agenda

8:00 AM to 8:15 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 to 8:45 AM **Keynote Speaker**
Transition for youth from pediatric to adult-oriented healthcare: A smooth crossing or muddling through the swampy lowlands?
Imelda Coyne PhD, MA, BSc (Hons), HDip N (Hons), RSCN, RGN, RNT, FTCD, FEANS
Professor
School of Nursing and Midwifery
Trinity College
Dublin, Ireland

8:45 AM to 9:45 AM **Platform Session 1: Health Care Transition: International (Rita Nathawad, MD, moderator)**

1. *Prioritization of Transitional Care Interventions (TCIs) for Adolescents and Young Adults with Childhood Onset Disabilities: A Modified-Delphi and Consensus Meeting Approach*
2. *Implementing Mental Health Screening in an Outpatient Hemoglobinopathy Clinic – A Quality Improvement Project*
3. *An App-Based Transition Toolkit Targeting Youth with Chronic Health Conditions: A Feasibility Study to Improve Healthcare Transition and Outcomes (ApplyIT Study)*
4. *Health care transition: what about the healthy ones?*

9: 45 AM to 11:15 AM **Poster Session**

11:15 PM to 12:30 PM **Platform Session 2: Continuous Quality Improvement/Program Development/Models of Care**
(Moderator: Parag Shah, MD)

1. *Specialized primary care center for autistic adults is linked with increased provision of preventive care services*

2. *Utilizing Medical Students as Patient Mentors: An Intervention to Improve Transition Readiness in Young Adults with Sickle Cell Disease*
3. *Increasing Adolescent Patient Portal Access and Discussions About Confidentiality: A Quality Improvement Project*
4. *Continuity of Transition Services Promotes Long-Term Retention in Adult Care Among Young Adults with Sickle Cell Disease*
5. *Implementing a Structured health Care Transition (HCT) Process for Sickle Cell Disease (SCD) Using Quality Improvement: 18 Months Results of a SCD HCT Learning Collaborative*

12: 30 PM to 1:00 PM **LUNCH/BREAK**

1:00 PM to 2:00 PM **Break Out Sessions**

1. *Improving Transition of Care in Pediatric Rehabilitation*
2. *An Innovative, Multidisciplinary Approach to Healthcare Transition in a Pediatric Oncology Research Setting*
3. *Peer Mentorship for Young Adults with Intellectual/Developmental Disabilities (IDD) Transitioning to Adult Care*
4. *Self-advocacy and Empowerment for Young Adults with Chronic and Rare Diseases: Young Adult Perspectives*

2:00 PM to 3: 15 PM **Platform Session 3: Health Care Transition Considerations (Moderator: Thomas Walter Davis, MD)**

1. *Understanding the Long-Term Care Planning Experiences of Caregivers of Individuals with IDD*
2. *ED visits and hospitalizations are highest in transition-age patients empaneled in a primary care network at a major academic medical center*
3. *Designated Transition Programs Improve Satisfaction for Adolescents and Young Adults with Developmental Disabilities*
4. *Quality of Life, Family and Peer Support, and Transition to Adult Care in Youth with Gastroenterology, Renal, and Rheumatology Diseases*
5. *Pediatric Nurse Practitioner and Nursing Roles in Health Care Transition Planning: National Survey Findings and Practice Implications*
6. *Factors Influencing Chronic Condition Self-management During Middle Adolescence*

3:15 PM to 4:45 PM **Poster Session**

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Keynote	**Transition for Youth from Pediatric to Adult-Oriented Healthcare: A Smooth Crossing or Muddling Through the Swampy Lowlands?** *Imelda Coyne PhD, MA, BSc (Hons), HDip N (Hons), RSCN, RGN, RNT, FTCD, FEANS* It is estimated that more than 85% of children born today with chronic conditions will reach adulthood thus requiring a move to adult services. This has led to increasing focus over

the last decade on how adolescents with long-term conditions can be prepared for a smooth and seamless transition to adult healthcare services. Worldwide, many teams have researched different aspects of transition, such as youths' readiness to transition, their views and experiences as well as ways to improve the transition preparation in healthcare services. It is clear from existing evidence that we now have a growing body of research, policies, guidance, tools, benchmarks and a variety of transition programmes. Yet many youth experience abrupt transfer from pediatric to adult health services, feel unprepared, lack self-management skills and receive limited information about adult services. They continue to be 'the forgotten population' (a phrase used by Professor Betz more than 22 years ago).

In my presentation, I will speak to my work related to healthcare transition, lessons learned and implications for future research. Transition is a multifaceted area, so I am going to focus on the challenges and obstacles for youth. Adolescents need to be closely involved in the design of transition programmes and in the commissioning of services so that their views are heard, and services are responsive to their needs. Engagement with adolescents should be at all levels of healthcare provision and the culture of inclusion and participation should be embedded into the practices of healthcare professionals and organisations.

Platform Session 1: Health Care Transition: International Perspectives

Moderator: Rita Nathawad, MD

Presentation 1

Prioritization of Transitional Care Interventions (TCIs) for Adolescents and Young Adults with Childhood Onset Disabilities: A Modified-Delphi and Consensus Meeting Approach

Sarah Munce, PhD; Andrea Duncan, BScOT, MBA, OT Reg. (Ont); Dorothy Luong, MSc; Mark Bayley, MD, FRCPC

Background: Transitional care interventions (TCIs) and services have the potential to ensure needed continuity of care, reduce significant detrimental health outcomes associated with poor transition, and improve the quality of life of adolescents living with chronic conditions and disabilities as they age; however, the paucity of research in this area poses challenges in implementing interventions for research and evaluation. We sought to prioritize the TCIs found in the literature and determine the important implementation considerations (e.g., feasibility, barriers, facilitators, contextual factors) of these interventions to inform the development of a research agenda.

Methods: We used a modified-Delphi approach including two rounds of surveys followed by a face-to-face consensus meeting with individuals with expertise in transitional care (n=19).

Results: Experts rated 16 categories of interventions derived from a systematic review on importance, impact, and feasibility. Seven of the interventions received a mean score rating of ≥7 (out of 10) on all three rating categories. Participants then rank ordered the reduced list of seven interventions in order of priority and the top four ranked interventions advanced for further discussion at a 1.5 day-long face-to-face consensus meeting. Using the Template for Intervention Description and Replication (TIDieR) checklist as a guide , small groups focused on describing the components of the interventions and their implementation.

Conclusion(s): The face-to-face meeting highlighted that TCIs for these populations in particular are complex and multifaceted, and as a result, expert participants demonstrated resistance to focusing on one intervention only. However, the presence of an individual (peer or healthcare professional) playing the role of system navigator, educator, advocate, coach and case manager was considered the most ideal intervention.

Presentation 2	**Implementing Mental Health Screening in an Outpatient Hemoglobinopathy Clinic – A Quality Improvement Project** *James Bradley, MOT, OT Reg. (Ont);. Lucy Doan, Karen Leslie, MD MEd FRCPC; Lucy Doan, MN, NP-PHC; Melissa Young, PsyD; Melina Cheong, RN(EC), BScN, MN, NP; Emily Clarke, MN, RN(EC) NP-Paediatrics; Catherine Munns, Psy.D., C.Psych; Karen Leslie, MD MEd FRCPC; Lorber Sharon, MSW, RSW; Crosbie Jennifer, Ph.D., C.Psych; Irfan Mian, MD FRCPCP; Bridget Doan, PNP, MN, BScN (Hons), BSc (Hons); Erin Lawson, MPH, OT Reg. (Ont.)* **Background:** Over 20% of youth with a chronic physical illness may also have a mental health diagnosis, which can have a significant impact on quality of life.1 One of the barriers identified to successful health care transition planning for youth with chronic conditions includes addressing mental health concerns.2 Mental health screening was not included in routine care for the Hemoglobinopathies clinic at The Hospital for Sick Children. The purpose of this quality improvement initiative was to explore the feasibility of implementing a mental health screening program in this setting. **Methods:** The 4 Mental Health (4MH) screening project was piloted in the Hemoglobinopathies clinic from January 14 to March 12, 2020 following training of clinic staff. Patients aged 12-18 were initially screened with the Patient Health Questionnaire 4 (PHQ-4). A positive score ≥3 resulted in a clinical assessment by staff including the PHQ-9 and GAD-7. If the score on these questionnaires was ≥ 10 then a formal third level screening (risk assessment) was completed. Patients were asked to complete a brief questionnaire on their experience and a focus group was conducted with clinic staff at the end of the pilot. **Results:** Fifty four patients completed initial screening, resulting in 12 positive screens. Three patients scored moderate on the PHQ-9 and one scored severe. Three patients scored moderate on the GAD-7 and one scored severe. The majority of patients understood the purpose of the questions (89%), felt comfortable answering them (77%), and found it helpful to be asked(67%). Hemoglobinopathy clinicians became more comfortable with incorporating mental health screening into their practice over time. Staff requested more training with suicide risk screening. Time and patient-family dynamics were barriers to completing screening. **Conclusion:** This project demonstrated the feasibility of implementing routine mental health screening into standard clinical care in a pediatric hemoglobinopathy clinic. More staff training on third level screening and patient-family education about the purpose of screening were identified as important future steps.
Presentation 3	**An App-Based Transition Toolkit Targeting Youth with Chronic Health Conditions: A Feasibility Study to Improve Healthcare Transition and Outcomes (ApplyIT Study)** *Jan Willem Gorter MD PhD FRCPC; Grant, C., MD; Thabane, L., PhD; Arora, S., MD; Mondal, T., MD; Don Wauchope, A., MD; Punthakee, Z., MD ; Ronen, G., MD; Breakey, V., MD; Mahlberg, N., MSc; Hlyva, O, PhD; On Behalf of the ApplyIT Study Team* **Background:** When transition to adult healthcare is unplanned or poorly supported, patients and families experience adverse outcomes. The MyTransition app was designed to support youth through the transition process by promoting self-management and health advocacy. The app integrates a suite of tools including the Transition-Q©. **Methods:** Pilot mixed-methods Randomized Controlled Trial. Participants were randomized into 2 groups: use app with monthly support or continue with usual care. All participants completed a baseline visit as well as 3- and 6-month follow-up visits. **Results:** 36 participants with various health conditions and disabilities completed the final study visit (N= 15 intervention, 21 control). 26 participants completed qualitative semi-

	structured interviews (10 youth, 8 parents, 8 healthcare providers).Youth reported a variable use of the app. Clinicians indicated that the TRANSITION-Q can give them a quick picture as to where the youth are at in terms of healthcare self-management and transition readiness. Personal, familial, clinical, systemic, and temporal contexts shaped the app use. Facilitators for app use included: promoting from the study and endorsement from healthcare providers; flexible parent support and guidance; and positive perceived value. **Conclusion:** An app-based intervention holds a potential for raising awareness about transition, one's health condition, and self-management skills. Understanding how multiple contexts shape the app use and its perceived value by youth, families and clinicians is essential. This findings of the pilot RCT study will inform further development of then app and the design of a larger RCT to evaluate its effects.
	Health Care Transition: What About the Healthy Ones? *Joan-Carles Surís, MD, MPH, PhD* Research on transition is mainly devoted to youths suffering from a chronic condition. Nevertheless, all adolescents, at some point, will need to transfer to adult services. The aim of this presentation is to discuss transition among healthy youths using an exploratory Swiss study to illustrate it.
MORNING POSTER SESSION 1	
Poster 1	**A Multisite Project Investigating Navigation Service Advancement for Families in which a Child has a Neurodevelopmental Disability** *David Nicholas, PhD Lucy Lach, MSW, PhD; Wendy Mitchell, PhD, R.SLP* **Background:** This project has examined and advanced health and disability service access and navigational processes in three Canadian regions (Alberta, British Columbia and the Yukon) for families in which a child has a neurodevelopmental disability (NDD). **Methods**: We have sought 'Collective Impact' aims, based on tenets of Participatory Action Research (PAR). The regional teams identified key partners in disability and health sectors, who collectively determined system gaps and priorities for proactive change. **Results:** To date innovative changes have been implemented to navigation systems based on evidence that has been collected. For example, in Vancouver, the partners realized that after receiving an autism diagnosis at the Sunny Hill Health Centre for Children, many families were left wondering what to do next. Now, each family is automatically referred to Autism Information Services BC, an agency that guides them in taking their next steps. Meanwhile, the Yukon team hired a navigator in a remote community who is bridging gaps and connecting families with services, and learning new ways of navigating in rural /remote communities. In Edmonton, the team is co-developing, piloting and evaluating a peer/professional-based navigation program for parents, and contributing to a regional navigational resource. **Conclusion:** Based on PAR, regions have collectively developed and shared learnings, with key regional (and cross-regional) relationships being nurtured for both inquiry/learning aims and systems innovation. Backbone support by university partners has facilitated project evaluation, inter-regional communication and project coordination. A person in environment (ecological) framework illustrates key project elements linking research to action at micro, mezzo and macro system levels. Data collection processes (interviews, focus groups, instruments, process evaluation) and implementation and evaluation of 'pilots' as drivers of innovation will be conveyed, as will PAR considerations for systems-level capacity building. Implications and recommendations will be offered.

Poster 2	**Youth’s Experiences Transitioning into Post-Secondary Settings with Pre-Existing Mental Health Concerns: Results of a Scoping Review** *Kristin Cleverley RN, PhD, CPMHN(C); Tim Fricker M.Ed, PhD(c); Dr. Andrea J Levinson MD; Dr. Tony Pignatiello MD, FRCP(C)’ Emma McCann BSc* **Background:** As the number of students reporting mental health concerns steadily increases in post-secondary settings, it is essential to understand the mental health experiences and priorities of students as they transition into post-secondary (college and/or university) education. Given up to 75% of mental illness has its onset prior to age 18, a large proportion of youth are likely transitioning into post-secondary settings with a pre-existing mental illness. As such, there is an urgent need to understand the perspectives of this population in order to most effectively support student mental health needs Therefore, the aim of this scoping review was to synthesize existing literature on the experiences of young people with pre-existing mental health and/or addiction concerns as they transition into post-secondary education. **Methods:** Using an established scoping review methodology, this review examined 19 peer-reviewed and non-academic documents to identify themes in student perspectives on effective transitions into post-secondary settings for youth with pre-existing mental health concerns. **Results:** The review identified key themes in the transition process identified by students, including: change in living and learning environment, challenges managing illness independently, challenges managing medication, challenges navigating new systems of care, and loss of social support. **Conclusion:** The key themes identified in this scoping review can be utilized to support the development of post-secondary mental health transition strategies that specifically address student concerns. In order to further facilitate successful mental health transitions, these strategies must build on student experiences and continue to engage the student voice. Future research should engage student perspectives in the co-design of interventions to support youth with mental health concerns during the transition to post-secondary settings.
Poster 3	**The Transition Navigator Model: Engaging Stakeholders in the Co-Design of a Research Evaluation Framework** *Kristin Cleverley RN, PhD, CPMHN(C); Katye Stevens MHSc; Emma McCann BSc* **Background:** The transition from child and adolescent mental health services (CAMHS) to community or adult mental health services (AMHS) can be a negative experience for youth and their caregivers. Up to 60% of youth lack continuity of care during this period, leading to poor mental heath outcomes and wasted health care resources. The Transition Navigator Model is a promising intervention that introduces care navigators to more effectively facilitate these transitions. The NEAT (Navigator Evaluation Advancing Transitions) study partners with stakeholders to evaluate the Transition Navigator Model to generate evidence regarding the implementation and effectiveness of this intervention. **Methods:** Hospital leadership, youth and families, and transition navigators from three hospitals across the Greater Toronto Area were engaged in the co-design of the project and development of an evaluation framework. Stakeholders were also involved in ongoing clinical engagement at hospital sites, held research project roles (i.e., co-investigator), and collaborated on the selection of the measurement frameworks. **Results:** Stakeholder groups co-led the development of the qualitative and quantitative arms of the evaluation model for NEAT, including study documents, scripts, tracking tools and the selection of process and outcome measures. Foundational to this process was the co-creation of definitions of case complexity and the transition navigator role, including interventions and target population.

	Conclusion: This project developed a novel model of evaluation for a promising intervention to address the major service gap between CAMHS and AMHS. The evaluation framework and definition of the transition navigator role co-developed for NEAT can be adapted outside of the current context and applied more broadly in the field of health care transitions. This process highlights key opportunities to engage stakeholders in transition research and evaluation.
Poster 4	**Factors Associated with Self-Management Independence and Quality of Life for Adolescents and Young Adults with Spina Bifida engaged in a Guideline-Based Transition Clinic** *Ellen Fremion, MD; Rachel Madey, BS; Kristen Stagers MS; Melissa Morrison-Jacobus, CURN; Larry Laufman, EdD; Heidi Castillo, MD; Jonathan Castillo MD, MPH* **Background:** To determine characteristics associated with self-management (SM) independence and quality of life among adolescents and young adults with spina bifida (AYASB) engaged in a SB transition clinic. **Methods:** Eighty-eight AYASB ages 14-20 completed the Adolescent/Young Adult Self-Management and Independence Scale II Self-Report/SB (AMIS II-SR/SB) and the QUAlity of Life Assessment in Spina bifida for Teens (QUALAS-T) during transition clinic visits. Demographic and clinical variables were collected from the electronic medical record. **Results:** Baseline scores for AMIS II total and the Condition SM (AMIS II-C) and the Independent Living SM (AMIS II-IL) question sets were 3.3 (SD 1.0), 4.3 (SD 1.4), and 3.1 (SD 1.1). Baseline scores for QUALAS-T family/independence (QFI) and bowel/bladder (QBB) subscales were 73.8 (SD 19.9) and 63.8 (SD 25.8). Older age was associated with higher baseline AMIS II total and AMIS II-IL scores (p=0.017, p=0.012). Private insurance and no cognitive impairment were associated with higher baseline AMIS II-C scores (p=0.009, p=0.004). Over time, AMIS II total significantly improved (p<0.001), but QFI and QBB did not. AYASB not on chronic intermittent catheterization (CIC) and those using urethral CIC significantly improved in AMIS II scores (p=0.001), but those using channel CIC did not. Public insurance and being ambulatory were associated with AMIS II-C improvement (p=0.006, p=0.047). **Conclusions:** This study supports a comprehensive transition care approach to improve SM skills for AYASB.
Poster 5	**The status of health care transition of patients with juvenile idiopathic arthritis in Ukraine**. *Julia Biliavska MD, PhD; Olena Oshlianska* **Background:** Organization of proper health care transition (HCT) of a patient with chronic conditions is a global problem, relevant not only in rheumatology. Maintaining continuity between both services during HCT of patient with juvenile idiopathic arthritis (JIA), especially treated with biologics, is fundamentally important. **Methods:** To evaluate current status of HCT of JIA patients in Ukraine on the base of survey of pediatric service specialists experienced in HCT. **Results:** A survey of 49 Ukrainian pediatric rheumatologists was conducted. It was established that HCT in Ukraine mostly starts at the age 18 and is equal to the patient transfer. 45 (91.8%) of respondents consider it mandatory to preserve the initial diagnosis (JIA) during HCT; 4 (8.2%) consider that transformation of JIA into one of adult diagnosis is possible. 30 (61.2%) specialists consider it appropriate to use JADAS27 at HCT for arthritis activity assessment with further transition to the corresponding adult indices; 15 (30.6%) consider it possible to use JADAS27 throughout the entire follow-up period; 4 (8.2)% suggested the simultaneous implementation of DAS28 at the transfer stage. 29 (59.1%) respondents are starting to prepare JIA patients for HCT immediately after biologics initiation,

	regardless of patient's age; 20 (40.8%) - starts HCT 1-2 years before age 18. Differences in therapeutic tactics were identified. 39 (79.5%) specialists prefer don’t change patient management during HCT. 25 (51.0%) respondents believe that the decision to taper biologics is possible after 2 years of stable remission; 10 (20.4%) specialists prefer to follow therapy without any changes during HCT. Regarding the patient’s readiness for transition, 26 (53.1%) of responders chose the need for a comprehensive procedure with involvement of both services specialists, parents, psychologist and results of a patient survey; 18 (36.7%) specialists consider that a pediatric rheumatologist can independently determine the patient’s readiness for HCT, while 4 (8.1%) believed that the results of one survey is enough. The main problem of proper HCT to the adult model of care 19 (38.8%) pediatric rheumatologists noted the lack of a collaboration between pediatric and adult care systems; 19 (38.8%) noted the complication of access to the rheumatologist in the adult model of care. **Conclusion:** In Ukraine, there is no unified approach to HCT of JIA patients. The main challenges are absence of a standardized approaches for diagnosis, disease activity assessment, therapeutic tactics. The implementation of a unified approach of HCT in Ukraine is extremely relevant.
Poster 6	**Pediatric to Adult Healthcare Transition Curriculum for Internal Medicine, Med Peds, and Pediatrics Residents: Improving Education to Improve Care** *Katherine Despotes, MD;Tyra Girdwood, BSN, RN; Michael Contarino, MD; Elisabeth P Dellon, MD, MPH; Jennifer Goralski, MD; Jacquelyn Baskin-Miller, MD; Diana M. Cejas, MD, MPH; Darragh Davis, BA; Maria E. Diaz-Gonzalez de Ferris, MD, MPH, PhD* **Background:** Chronically ill individuals experience longer lifespans and more adolescents are transitioning from pediatric to adult healthcare than ever before. However, there is great variability in transitional care education in U.S. residency training programs. We designed a healthcare transition curriculum for residents to assess current transition education standards within a U.S. academic center and to improve resident education on this topic. **Methods:** 19 Internal medicine, 20 pediatrics, 14 med peds, and 5 other (peds neurology and primary care pediatrics) residents answered an online baseline survey about their self-reported transition knowledge, clinical exposure to transitions, comfort with transition skills, and formal training in transitional care. Residents then attended 8 interactive, multidisciplinary lectures with experience in healthcare transitions. A patient panel with 3 chronically ill individuals and a family member provided perspectives and experiences of the transition process. **Results:** At baseline, residents indicated an overall lack of comfort in conducting transitional care like creating a transition plan, receiving a chronically ill patient from a pediatric provider, or discussing advance care planning with a patient. Approximately 68% of respondents indicated they had no knowledge of any transition readiness tools, and responses surrounding patient age at which transition discussion should be implemented varied widely. Only 15% of residents indicated that they had led a discussion about transition with a patient or their family, and only 22% indicated they had seen someone else lead a transition discussion. **Conclusions:** There is a current need for more healthcare transition related clinical experiences and education among internal medicine, pediatrics, and med peds residents. U.S. residency training programs could incorporate topics within our transition curriculum to enhance their residents’ healthcare transition knowledge**.**
Poster 7	**Associations Between Health Care Transition Preparation Among Youth in the US and Other Components of a Well-Functioning System of Services**

	Samhita M. Ilango, MSPH; Lydie A. Lebrun-Harris, PhD, MPH; Jessica R. Jones, MPH; Margaret A. McManus, MHS; Mallory Cyr, MPH; Marie Y. Mann, MD, MPH; Sara Beth McLellan, MPH; Patience H. White, MD, MA **Background:** Adolescents often drift away from health care during this developmental period, affecting their transition to adult health care. This study examines which components of a well-functioning system of health care services influence receipt of health care transition (HCT) preparation and whether that differs among youth with and without special needs. **Methods:** Data came from the combined 2016-2017 National Survey of Children's Health. Parents/caregivers reported whether youth ages 12-17 (n=29,617) received care within a well-functioning system of services and whether HCT preparation occurred. Unadjusted and adjusted analyses were conducted to examine associations, stratified by youth with and without special health care needs (YSHCN/non-YSHCN). Associations between individual components of a well-functioning system and HCT preparation were also examined. **Results:** 25.3% of YSHCN and 27.3% of non-YSHCN received care in a well-functioning system of services (p=0.1212), and 16.7% of YSCHN and 13.9% of non-YSHCN received HCT preparation (p=0.0040). Receipt of care in a well-functioning system of services was positively associated with HCT preparation among both YSHCN (aPRR=1.53, 95% CI:1.20-1.86) and non-YSHCN (aPRR=1.63, 95% CI:1.39-1.88). Regarding individual components of a well-functioning system, early and continuous screening for special health care needs was significantly associated with HCT preparation for both populations. For non-YSHCN only, receipt of care in a medical home was associated with HCT preparation. The remaining three components (family partnership in decision-making, continuous and adequate health insurance, access to community-based services) were not associated with HCT preparation for either population after adjusting for sociodemographic characteristics. **Conclusions:** Receipt of care in a well-functioning system of services, particularly receipt of early and continuous screening, is positively associated with HCT preparation among both YSHCN and non-YSHCN."
Poster 8	**The Experience of Being a Peer Mentor: What We Learned Along the Way** *Jacqueline Benavides, BA; Yesenia Berrones, BS; Constance M Wiemann, PhD* **Background:** Young adults with chronic health conditions who have made a successful transition to adult-based care are increasingly being recruited to serve as peer mentors to teach younger adolescents the self-management skills needed to make their own transition to adult care. The purpose of this project is to better understand the experience of being a peer mentor in a pilot intervention serving transition-age youth. **Methods:** Three young adults (22-24-year-old females) with chronic health conditions who transitioned to adult care from the same tertiary care children's hospital were recruited and trained to serve as peer mentors for a group-based intervention to promote the development of self-management and self-advocacy skills in adolescents/young adults 17-22 years of age. Each mentor was asked to reflect on their experience over a 6-14-month period. These reflections were then sorted into themes. **Results:** Four major themes emerged: (1) Personal growth: increased self-confidence and self-management awareness; (2) Emerging adulthood: developing a professional identity; (3) The power of shared lived experience in promoting meaningful connections; and (4) The importance of boundaries: becoming a confident peer mentor. While all three mentors acknowledged there were challenges, all felt the overall experience was positive given the changes they witnessed in their mentees and themselves over time. Having regularly scheduled supervisory meetings was important to all three mentors as it helped guide and ground their professional behaviors.

	Conclusion(s): The benefits of being a peer mentor include promoting personal growth and developing a professional identity. While peer mentors offer a unique perspective and approach to fostering self-management skills in adolescents/young adults with chronic health conditions, it is important they receive adequate supervisory support.
Poster 9	**Transition to Adult Healthcare: Creating a National Agenda in Canada** *Jan Willem Gorter MD PhD FRCPC; Dayle McCauley MSc* **Background:** Transition to adulthood can be a very challenging time. For youth with special health care needs, the challenges are often compounded as they navigate from a familiar, family-centred, paediatric healthcare setting to a more fragmented, patient-focused adult system. When transition to adult health care is either unplanned or poorly supported, young adults may experience negative health outcomes, costly hospitalizations and inequities in services: s. The social costs are also of concern with missed opportunities to attend post-secondary education, secure vocational opportunities (Tuchman et al., 2015) and be financially secure to live independently. It is well recognized (Hepburn et al., 2015; McManus et al., 2015; Major et al., 2015; Gorter, Stewart, Woodbury-Smith, 2011) that most adverse outcomes are preventable. **Method:** In Canada we identified the need for a collaborative nation-wide approach to overcome the fragmented services provided during transition to adult healthcare. Processes should happen in partnership with patients and families, together with paediatric-based and adult-based providers. By providing national opportunities to learn from each other, we can develop realistic solutions to promote the best possible health outcomes for patients and families. **Results:** In 2019, Children's Healthcare Canada (CHC) created "Child Health Hubs". The purpose of these hubs is to "connect individuals from member-organizations with 'like' peers from coast to coast to share information, ask questions, and exchange resources related to their position or role in their organization". Under the leadership of Dr. Jan Willem Gorter, a Child Health Hub in Transition to Adult Healthcare was formed. The vision for this hub is to "Create a knowledge (mobilization) network that seeks to bridge the gap between current treatment practices and evidence-based solutions for healthcare transition in Canada". The hub currently includes nearly 80 individuals from across Canada, including healthcare providers, researchers, young adults with special healthcare needs and parents. Over the past year we have hosted 11 online meetings and one in-person meeting. The inaugural in-person meeting at the CHC Conference in Ottawa on December 10th 2019 allowed our team to determine three deliverables for 2020: Conduct an Environmental Scan on the features of transition supports for people with special needs in Canada; Expand accreditation standards around transition; Plan a national conference on Transition. **Conclusion:** In summary, one year since its inception, the Canadian transition hub is well established and has an active membership, with various working groups. This demonstration poster will outline hub composition as well as the progress to date in the three deliverables listed above.
Poster 10	**Age of Care- Will Pediatric Providers Take On Young Adults** Ann Modrcin, MD, EMBA; Terri Hickam, MSW, LCSW, LSCSW, CCM Background: Pediatricians taking on the care of young adults as new patients poses questions surrounding best care, access, changing needs and transfer planning. Determining the best time to transfer from pediatric care to adult care providers comes with several challenges. Hospital ambulatory standards at this large pediatric health system are to care for patients through age 21. However, some specialists had established lower age levels and were refusing requests for consultations. This study sought to provide leadership with

	information regarding decision-making for acceptance or refusal of consultations and ongoing care for patients age 18-21. Methods: Division Directors were asked to complete a REDCap survey for each unique program within their Division. We explored practices, attitudes, and barriers related to the care of young adults. Sixty responses were received and analyzed. Common themes were identified. Results: Most providers were willing to offer consultations for young adults, with fewer willing to provide ongoing care. Efforts were made to recognize when exceptions were indicated. Exceptions were made based on the best interest of the patient medically, specifically ongoing adult-based verses pediatric-based care. Conclusion(s): If access for a young adult means that a new patient who is a child will not have access, providers are less willing to take on, or continue to care for young adults in their practice. In our large pediatric subspecialty setting, if one key specialty continues to care for a young adult, other specialists are more likely to also provide care, if the patients needs are best met in a pediatric setting. A common perception expressed by specialists is that they are reticent about taking on a new patient due to the fear that other needed specialists would refuse. This was not born out by our study.
Poster 11	**Parental Perspective of the Emerging Adult with Congenital Heart Disease** *Amy E.Delaney, MSN, RN, CPNP-AC/PC; Jeanna M. Qiu, AB: Christopher Lee, PhD, RN, FAHA, FAAN, FHFSA; Mei R. Fu, PhD, RN, FAAN* **Background:** The developmental stage of emerging adulthood (ages 18- 29 years) is a particularly important time for patients with congenital heart disease (CHD) to work towards independence and make decisions about their life goals, including CHD self-management. This integrative meta-synthesis examined the parental perception of emerging adults with CHD based on peer-reviewed and qualitative studies published from 2002 to 2020. **Methods:** Multiple electronic databases were comprehensively searched to retrieve 224 articles; 5 met inclusion criteria. An established quality assessment tool was used to assess the quality of the included studies. A meta-synthesis was conducted to analyze and synthesize the selected studies to develop new analytical themes. **Results:** The overall quality of the 5 included studies was adequate. Three themes that encompass the parental perspective of emerging adults with CHD were identified: 1) concerns about emerging adults' ability to be independent; 2) concerns about emerging adults' future; and 3) impact of CHD diagnosis on parents/family. Parents felt that emerging adults still relied on them for health management and were not socially or emotionally prepared for the adult world. Parents' perceived vulnerability led to fear that the emerging adults' disease status might negatively impact educational and employment opportunities and ability to be independent. Parents and families experienced a shared sense of trauma and guilt as a result of the uncertainty of the emerging adults' future. **Conclusions:** Parents of emerging adults with CHD have concerns about their children's ability to be independent and their future, leading to perceived difficulties in the transition to adulthood for patients. This review provides insights into clinical research and intervention. Research and intervention targeted towards understanding and helping to ease parents' concerns about their children's independence and future life choices may help to lessen the burden of this chronic illness on patients and parents/family.
Poster 12	**Development of a Transition Program for a Pediatric Renal Department: A Quality Improvement Approach** *Sahar Siddiqui, MD, MPH; Cortney Taylor Zimmerman, PhD* **Background:** Transition from pediatric to adult health care for patients with renal disease continues to be a challenging process that can lead to increased morbidity and mortality. Studies with other chronic disease populations have illustrated that a structured, well-defined

	transition process can improve patient outcomes and reduce hospital costs. This study describes the process of developing a transition program to address this critical gap in the renal department of a large children's hospital. **Methods:** Transition team comprised of champions from key stakeholder domains (physician, psychologist, social workers, child life, dietitian, quality of life coordinators and nurses) was formed to develop a process based on expertise. This team participated in transition needs assessment for the renal department. Part of this assessment involved physician faculty (n = 14), who rated ease of current transition process. Fishbone analysis was used to generate barriers to successful transition. **Results:** Barriers identified by the needs assessment included lack of standardized transition procedure, difficulty finding adult provider, and lack of insurance. Ease of transition was rated as 2.5 out of 5 (a 5 being easiest transition). To begin to address standardization, a transition policy was created and family letters and educational materials were designed. Patient and family surveys were developed for data collection pre and post transition to understand their perspectives. Collaborations were formed with a community-based organization to facilitate insurance access and with local adult renal providers willing to accept transitioning patients. The next step will include implementation, as well as measure of implementation and feedback within a pilot group of renal patients. **Conclusion:** The needs assessment highlighted areas to target for intervention, as noted above. Further, it was noted to be difficult to transition patients utilizing the current process. It is expected that implementation of the new standardized process will result in improved transition outcomes.
Poster 13	**Design of a Value-Based Payment Model for Young Adults with Intellectual and Developmental Disabilities** *Margaret McManus, MHS; Patience White, MD, MA; Samhita Ilango, MSPH; Annie Schmidt, MPH; Nathaniel Beers, MD, MPA, FAAP; Eric Levey, MD; Nadine Coy, MBA* **Background:** Medicaid and commercial payers are quickly moving to implement alternative payment methods in place of fee-for-service (FFS) arrangements. To date, there have been no tested examples of value-based payment (VBP) to incentivize a structured health care transition (HCT) process for youth or young adults with special needs. **Methods:** This 3-year project is funded by the WITH Foundation and operated jointly by The National Alliance to Advance Adolescent Health and HSCSN, a specialty Medicaid managed care plan that serves individuals from birth through 25 eligible for SSI in DC. A project advisory group was formed to design an 18-month VBP pilot to be conducted with 50 young adults, ages 18-23, with IDD. The group consists of a young adult with IDD, parent of a transition-aged youth with autism, lead physicians from pediatric and adult sites, and officials from DC Medicaid and Department of Disability Services. The pediatric site is DC's children's hospital, and two federally qualified health centers are the adult primary care sites. **Results:** The HCT intervention is the Six Core Elements, customized for use by pilot sites and HSCSN's care managers. A combination of two final pediatric visits and at least one adult visit will be offered to deliver the recommended HCT services. VBP options identified by the advisory group include recognition of selected FFS codes, a gift card to consumers for attending pediatric and adult visits, and pay-for performance for practices with evidence of completed visits, preparation of medical summary, review of care plan, and evidence of communication between clinicians. Performance measures aligned with the Triple Aim will be used: Got Transition's Current Assessment of HCT Activities (pre/post) and Consumer and Clinician HCT Feedback Surveys, and annual PCP visits and emergency department use. **Conclusion:** More collaborative partnerships with payers are needed to implement VBP transition pilots.

Poster 14	**The New Six Core Elements of Health Care Transition 3.0: Transforming Your Practice's Approach** *Patience White, MD, MA; Annie Schmidt, MPH; Jodi Shorr, MS; Samhita Ilango, MSPH; Dan Beck, MA; Margaret McManus, MHS; Laura Noonan, MD; Sarah Mabus, MLA* **Background:** Only 19% of youth with special health care needs and 14% of youth without special needs receive health care transition (HCT) preparation from their health care clinicians. To address this gap, the AAP/AAFP/ACP recommends the use of the Six Core Elements of HCT. A rigorous process was undertaken by Got Transition to update and create the Six Core Elements 3.0. **Methods:** Feedback from over 400 clinical, public health, and consumer experts for all three packages of the Six Core Elements was elicited via online survey over six months. In addition, Got Transition's HCT learning community and youth and family advisory groups, HCT experts from the 2019 HCT Research Consortium, and state Title V officials provided feedback. This update was also informed by HCT technical assistance requests. With consultation from Atrium Health's Center for Advancing Pediatric Excellence, implementation guides and quality improvement (QI) primer were developed as supplemental resources to the Six Core Elements. **Results:** External feedback reaffirmed the usefulness of the Six Core Elements and led to improvements to selected tools and measurement resources. Major additions include QI guidance, a clinician satisfaction measurement tool, and improvements in ease of use and customization of tools. The Six Core Elements 3.0, implementation guides with sample tools and useful resources, and QI primer were launched July 2020. **Conclusions:** With extensive external input and involvement of QI experts from Atrium Health, the Six Core Elements 3.0 are available for widespread use."
Poster 15	**Massachusetts Initiative to Improve Transition to Adult Healthcare for Individuals with Neurodevelopmental Disabilities (NDD)** *Susan Shanske, MSW; Jamara Polzin, BA; Lindsay S. Hunt, MEd; Sarah J. Spence, MD, PhD* **Background:** The 2018 report from the AAP, AAFP and ACP identifies "special populations", including individuals with developmental and/or intellectual disabilities, as facing additional challenges with healthcare transition above and beyond those of other adolescents and young adults1. Individuals with neurodevelopmental disabilities (NDD) require additional supports given their unique vulnerabilities. Studies highlight specific concerns, including lack of available adult providers with expertise in caring for individuals with NDD, and lack of care coordination resources to facilitate healthcare system navigation.1, 2, 3 Therefore, individuals with NDD may lack access to care and experience poorer health outcomes4. **Methods:** In spring 2018, invested pediatric providers gathered to address the most important needs for this population related to transition to adult healthcare in Massachusetts. Given that barriers are fairly well identified, the group determined the first step as creation of task forces to look at potential solutions to be presented at a statewide summit in fall, 2020. Philanthropic funding was utilized to hire team leadership, administrative support and a QI consultant. **Results:** Four major themes were identified: Workforce Development, Optimizing Clinical Care, Practice Management and Clinical Infrastructure, and Financing the Solutions. Steering committee members were solicited from across Massachusetts, representing stakeholder groups such as pediatric and adult providers, community agencies, payers, hospital administrators, educators, advocacy groups and families. Task forces were recruited to address the themes above; all are actively working on deliverables for the summit. Steering and task force members drafted a driver diagram and outcome measures to address the

	overall aim: Improve the quality of healthcare transitions for individuals with NDD in MA by ensuring that they have a comprehensive integration from pediatric to adult healthcare practices. **Conclusions:** This initiative facilitates a powerful collaboration with passionate stakeholders to identify best practices for improving the transition to adult healthcare for individuals with NDD in Massachusetts.
Poster 16	**Transition Contract Language for Medicaid Managed Care Organizations** *Margaret McManus, MHS; Annie Schmidt, MPH; Patience White, MD, MA* Background: The majority of Medicaid agencies do not include requirements in managed care contracts on pediatric-to-adult health care transition (HCT). In 2018, 10 of 37 Medicaid agencies that relied on risk-based managed care included HCT contract language; most often very general language. In contrast, 6 out of 7 states with specialty managed care plans for youth with special health care needs included HCT requirements. Methods: To assist state Medicaid agencies and managed care organizations (MCOs) in improving access to recommended HCT services, several HCT options were identified for specific managed care sections with specific language suggestions. These were informed by our state Medicaid managed care contract analysis, professional guidelines, evaluation studies on HCT, and quality improvement experience. Results: For each topic, options for consideration were developed. o Definition: Options for a stand-alone definition of pediatric-to adult HCT, expanding existing transitional care definition, or expanding other definitions (e.g., continuity of care). o Member Services and Education: Options for information/education about HCT and MCO approach, up-to-date directory about available adult providers for young adults with special needs, and assisting members experiencing access barriers related to HCT. o Provider Network: Options for conducting regular surveys of adult provider networks to assess availability for special populations, describing mechanisms to coordinate pediatric and adult providers, and establishing processes for transfer from pediatric to adult care. o Covered Services: Options for incorporating HCT into EPSDT, medical home, behavioral health, and health home services. o Care Coordination: Options for defining HCT approach in care coordination programs, conducting transition readiness assessments, and incorporating HCT into care plans. o Quality and Evaluation. Options for measuring implementation and outcomes of HCT and conducting HCT performance improvement projects. Conclusion: Using the contract provisions in this study would help expand access to HCT services for Medicaid-insured youth and young adults.
Poster 17	**Predictors of Obesity in Adulthood in a USA-Representative Sample of Emerging Adults With and Without Chronic Conditions: A Cohort Analysis** *Tyra Girdwood, BSN, RN; Maria Diaz-Gonzalez de Ferris, MD, MPH, PhD* **Background:** Transition into adulthood is marked by increased demands for responsibility and independence. Emerging adults with chronic conditions may be at an increased risk for poor outcomes during adulthood, like obesity. We sought to address the following research question: Does obesity during emerging adulthood, chronic condition type, and life expectancy perceptions predict obesity in adulthood? **Methods:** We analyzed a weighted sample of 14,800 individuals from waves III (2001-2002; aged 18-26 years) and IV (2008; aged 24-32 years) of the Add Health Study, a USA-representative longitudinal cohort. Chronic conditions were measured by self-report of having: (1) cancer, diabetes, or epilepsy; or (2) asthma (analyzed separately because less treatment burden/comorbidities). Life expectancy perception was measured by self-reported chance of living to age 35 in wave III. Socioeconomic status (SES) was based on self-reported parent

	education. Logistic regression models were conducted to examine potential predictors of obesity based on measured body mass index (BMI) >=30, or no obesity (BMI <30), in wave IV. **Results:** Our weighted sample included: 7,296 females (49.3%); 9,960 non-Hispanic White (67.3%); 2,353 non-Hispanic Black (15.9%); 1,776 Hispanic (12%); 6,423 had a parent with a college degree or higher (43.4%); 2,235 had asthma (15.1%); 740 had cancer, diabetes, or epilepsy (5%); 5,763 were obese in wave III (39%); and 3,138 were not almost certain they'd live to age 35 (21.2%). Being obese during emerging adulthood (p≤0.001), being non-Hispanic Black (p=0.01), having asthma (p=0.01), having cancer, diabetes, or epilepsy (p=0.01), and having worse life expectancy perceptions during emerging adulthood (p≤0.001) all were significantly associated with an increase in the odds of being obese in adulthood (wave IV), controlling for age, sex, and SES. **Conclusion:** In this USA-representative longitudinal cohort, having a chronic condition, being obese, and having poor life expectancy perceptions in emerging adulthood enhanced risk of being obese in adulthood.
Poster 18	**Supporting Peri-Transitional Young Adults during the COVID-19 Pandemic** *Leanne Langmaid MSN, RN; Colleen Huysman MSW, LCSW; Samantha Covelle MSN, FNP; Susan Shanske MSN, LICSW; Leah Ratner MD, MS; Ahmet Uluer, DO, MPH* **Background:** Young adults with chronic and complex medical conditions face systemic barriers and care fragmentation which leads to increased vulnerabilities. The BRIDGES Young Adult Transition Program at Boston Children's Hospital regularly provides transition consults to young adults with chronic and complex medical disease. In response to the COVID-19 pandemic, BRIDGES has developed a new approach to consults in order to further support peri-transitional patients, now facing new vulnerabilities as health care systems have been disrupted due to novel COVID-19. **Methods:** Patients considered for virtual visits met an inclusion criterion which consists of at least one pediatric onset illness and at least three chronic morbidities, actively managed by sub-specialists. Prior to the virtual visit, the BRIDGES multidisciplinary team meets for 30 minutes to conduct chart review and outline goals for visit. Visits are completed with an internal medicine - pediatrics physician, nurse practitioner, nurse transition coordinator and social worker. Four major themes are followed throughout 1) emergency and advance care planning, 2) COVID-19 related education, 3) medical and chronic care coordination and 4) management of psychosocial stressors. **Results:** Approximately 2-3, 60 minute visits are conducted per week. Quality improvement questionnaires are distributed via email after the virtual visit. To date, 14 questionnaires have been distributed assessing overall usefulness of visit and offering opportunity for feedback. BRIDGES also plans to disseminate questionnaires to our own team to collect feedback on provider experience, as there has been a marked increase in patient and family engagement through use of a virtual platform. **Conclusion(s):** Young adults with chronic and complex medical conditions will continue to need and receive individualized support to address unique needs related to their diagnosis, social situation and ability to advocate and navigate the healthcare system during the pandemic. COVID-19 has exposed the complexities surrounding fragmented health care systems, necessitating equitable solutions.
Poster 19	**A Series of Webinars to Assist with Transition Planning for Youth/Young Adults With Intellectual, Developmental, and Learning Disabilities during the COVID-19 Pandemic** *Ida Barresi, MA CCC-SLP; Rosa Seijo, MD; Erin Rivelis, PhD; Monica McQuaid, PhD; Miriam Brown; Joanne Siegel, LCSW; Karen Bonuck, PhD; Diana Rodriguez, LMSW*

	Background: Transition planning is a vital, though often confusing, component to one's educational planning. It serves as the link between the supportive services of high school and post secondary options including day programming, independent living, vocational training, and college. Transition planning is particularly important for youth/young adults with special needs. Though transition planning is mandated to occur, often times families do not have the necessary information to make meaningful decisions. **Methods:** This poster focuses on a series of webinars offered at Montefiore Medical Center's Rose F. Kennedy, Children's Evaluation and Rehabilitation Center (CERC). CERC is an inner-city, multidisciplinary, university affiliated UCEDD/LEND that serves a diverse, underserved population in the Bronx, NY, one of the poorest counties in the county. The COVID-19 pandemic has been and additional burden to the families of the Bronx. The Bronx has been a major pandemic hot spot with the highest rate of infection (30%/1000) in NYC. The webinars targeted a range of post secondary planning options conducted in collaboration with 2-year/ 4-year colleges, vocational training programs, ACCESS-VR, OPWDD and other governmental agencies. **Results:** Attendees completed a survey at the end of each webinar which will be analyzed for consumer satisfaction and suggestions for future webinars in a time when information is disseminated primarily online due to the COVID-19 pandemic. **Conclusion:** Youth/young adults and their families heard from 3-4 speakers during each of the three webinars with opportunities for questions and meaningful conversation both before and after the webinars.
Poster 20	**Transition to Adult Care Works: Experiences in the Era of COVID-19** *Lauren Ford, BSN, RN; Natalie Stollon MSW MPH; Adam Greenberg MSN CRNP; Christine Chamberlain BSN RN; Symme Trachtenberg MSW; Nicole Burrows BS; Dava Szalda MD MSHP* **Background:** Transitioning from pediatric to adult care for young adults with chronic medical conditions and intellectual disabilities presents a multitude of challenges. The COVID-19 pandemic has led to rapid changes in the access and delivery of care potentially causing lapses of care in this already vulnerable population. The goal of this project was to assess for lapses in care during the pandemic for recently transferred young adults with chronic medical conditions and/or intellectual disabilities that worked with a transition consult service. **Methods:** We contacted patients who worked with the Children's Hospital of Philadelphia's (CHOP) Adult Care and Transition Team (ACTT) to aid in their transition within the last three years. All patients were contacted by phone and asked 12 questions related to transfer of care and to COVID-19. Calls were made April – May 2020. Responses from patients and families were transcribed and evaluated by ACTT. **Results:** Seventy-six patients were called, and 29 (38.2%) participated. Patients were 19 to 26 years old at time of contact, and most (72.4 %) had both an intellectual disability and 2 or more chronic health conditions. Caregivers were primary responders (89.7%). All (100%) of the interviewed participants reported continued access to their medication and medical supplies during the pandemic. Furthermore, patients were able to connect with their healthcare providers when needed. Additionally, 6.9 % reported unmet community service needs, which was addressed by ACTT. **Conclusion:** During the pandemic, young adult patients that utilized ACTT had no lapses in care and few unmet community service needs. This project is limited by the lack of a control group. However, our findings suggest that the coordination of care by ACTT may have helped to alleviate lapses in care even after recently transferring to adult clinical care prior to the pandemic.
Poster 21	**Assessing Patient Self-Reported Transition Readiness in a Large Pediatric Rheumatology Center**

Mary Robichaux; Alexander Alexander; Priyanka Moolchandani, MD; Cristina Saez, MD; Ariel Coleman; JaLeen Rogers; Danielle Guffey; Anne Dykes; Miriah Gillispie-Taylor, MD; Tiphanie P. Vogel, MD, PhD

Background: Rheumatology patients need effective transition from pediatric to adult providers. Our clinic has developed a transition pathway, the BRIDGE (Baylor Rheumatology Initiative: Developing and Guiding Engagement), based on defined elements of transition and utilizing a transition planning tool to help with transition preparation. Our aim was to assess patient self-reported transition readiness over time.

Methods: The validated, self-administered Adolescent Assessment of Preparation for Transition (ADAPT) survey generates 3 composite scores (out of 100) for counseling on transition self-management and prescription medications, and on transfer planning. Return adolescent patients aged 14-19 years were surveyed regardless of diagnosis. Surveys were emailed via a REDCap database on the morning of clinic appointments between August-December 2018 and November 2019-May 2020. Surveys were scored and analyzed against demographics.

Results: 302 patients completed at least 1 survey. Most respondents were female (71%) and white (75%); 42% were Hispanic. Most were privately insured (57%) or covered by Medicaid/Children's Health Insurance Program (38%). The most common diagnosis was juvenile arthritis (30%). Average initial scores for all respondents were 37/100 for transition self-management, 66/100 for medications, and 17/100 for transfer planning. Initial scores in all three domains increased with older age at first ADAPT survey (p<0.001). Serial surveys were collected on 59 respondents. Scores for self-management increased by 17 over the year since the first survey (p<0.001), and increased by 16 for medications (p<0.001), and 23 for transfer planning (p<0.001).

Conclusion: Our clinic has developed a method to assess patient self-reported transition readiness. Our data indicates that participating patients improved over time in all domains measured by the ADAPT survey. Going forward, we plan to analyze outcomes of transitioned patients to assess the efficacy of our pathway. Our ultimate goal is to create a sustainable and successful BRIDGE between pediatric and adult rheumatology care.

Poster 22

Managing the Real World: Interagency Collaboration for Self-Management in the Holistic Transition to Adult Life for Youth with Disabilities

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Background: Transition to adult life and the adult healthcare system has historically been a challenge for transition-aged youth with disabilities. Increased demands for coordination, navigation, and decision-making with less support than is available in the pediatric system all contribute to transitions that find youth lost to follow up and reentering the healthcare system only when they reach crisis. Our team has developed an interagency collaborative program to build youths' capacity in managing their own appointments and agendas, using their healthcare transition as the tangible setting. Working together, Holland Bloorview Kids Rehabilitation Hospital (pediatric rehabilitation) and Yorktown Family Services (pediatric and adult mental health services) deliver client-driven programming to build and practice skills in the participants' own contexts.

Methods: Program of 5-10 participants is being run. Pre-post performance and satisfaction outcome measures will be assessed for clinically significant differences. Qualitative focus groups for staff and client participants will be conducted and analyzed thematically. Client satisfaction (CSQ-8) will be collected to understand program perceptions, and the Partners in Health Scale will be completed to explore perceived knowledge of healthcare participation.

Results: Results forthcoming in early fall upon completion of the program.

	Conclusions: Direct collaboration with and connection to adult sector institutions may contribute to early exposure and contextually-relevant capacity building for transition-aged youth with disabilities. A safe and intentional space in which to practice their self-management and receive constructive feedback to build positive experiences can help them become effective self-advocates and self-managers as adult healthcare consumers.
Poster 23	**Transition Backslide: Defining Demographic, Clinical, and Utilization Characteristics of Patients that Have Reengaged with a Children's Hospital after a Coordinated Transfer of Care from Pediatric to Adult Providers** *Adam Greenberg MSN, CRNP: Angelico N Razon MD, MPH, MSHP: Dava Szalda MD, MSHP:* **Background:** Measuring the effectiveness of a transition that is coordinated by a pediatric based transition of care service may be difficult when access to adult medical system utilization data is limited, particularly when the pediatric and adult medical centers are free-standing. A proxy metric for transition effectiveness may be unanticipated re-engagement with the pediatric system (PS) after transfer to adult care (e.g., refill request, office visit, emergency department (ED) visits). This retrospective descriptive study aimed to 1) quantify and define the demographic, clinical, and utilization characteristics of the patient cohort that reengaged with the PS; 2) determine indication for reengagement with the PS; 3) determine if this reengagement was planned; and 4) compare this cohort with patients that did not reengage with PS to identify risk factors. **Methods:** Patients were eligible for this study if their transition to adult care was coordinated by the PS service between July 1, 2017 and June 30, 2019. Patients were identified via a PS REDCap patient registry. Demographic, clinical, and utilization data were extracted from the PS electronic medical record through December 31, 2019. Anticipated versus unanticipated PS engagement will be determined by manual review of clinical documentation. **Results:** 90 patients met eligibility requirements. Demographic data extracted included age, gender, race, county of residence, and insurance type. Clinical information extracted included presence of an intellectual disability diagnosis, specialists seen, and active medications at time of referral to PS transition service. Utilization data captured ambulatory appointments, ED visits, and hospitalizations 24 months prior to date of referral to PS. Post transfer data extraction included encounter type (e.g., call, office visit, ED, etc.) and specialty contacted. **Conclusion(s):** Analysis of this cohort and comparison against the non-reengaged cohort is ongoing. Preliminary review of data suggests that many patients have reengaged with the PS after date of transfer.
Poster 24	**Transition Readiness Assessment in Turner Syndrome** *Benjamin Hoag MD; Joseph Cernich MD; Sarah Tsai MD; David Williams MPH* **Background:** Turner Syndrome is a genetic condition associated with learning difficulty within the visual-spatial, mathematics, and executive function domains. This complicates condition awareness and the ease of transition for this population. Our team conducted a Transition Readiness survey to determine the level of perceived transition readiness is this population and determine areas of deficiencies for future targeted improvement studies. **Method:** Turner Syndrome patients were surveyed electronically using a modified version of the Endocrine Societies Transition Readiness Assessment for Youths with Turner Syndrome. Of the original 29 eligible participants, 25 completed and submitted their survey. Patients ranged from 12 - 20 years of age, mean age 13.9 (SD ± 2.1). The survey consisted of 28 questions, divided into three sections: Self Care Importance/Confidence, My Health, and Using Health Care. Answer choices for the latter sections included "Yes, I know this", "I need to learn this", and "someone else needs to do this". Questions with "Yes, I know this" responses at or below the 80% threshold would be considered for potential interventions.

	Stata/SE 15.1 software was used for descriptive statistics. P-values ≤0.05 were regarded as statistically significant. **Results:** All questions in the “Using Health Care” section fell below the 80% threshold. Statistically significant associations were noted between patients’ age and the following survey questions: “I know where my pharmacy is and what to do when I run out of my medicines.” (p-value 0.0281), “I know that when I am 18 the rules about my health privacy change.” (p-value 0.0281), and “I have a plan so I can keep my health insurance after 18 or older.” (p-value 0.0336). **Conclusion:** For our study population, Utilization of Health Care represents an area of perceived deficiency in transition readiness and an ideal target for future interventions by our group.
Poster 25	**Transitional Care Interventions for Youth with Disabilities: A Systematic Review** *Ben B. Levya, BSc; Jessica Z. Songa; Dorothy Luonga, MSc; Laure Perrierb, PhD; Mark T. Bayleya, MD, FRCPC; Gail Andrew, MDCM, FRCPC; Kelly Arbour-Nicitopoulos, PhD; Brian Chana, PhD; C.J. Currand, BHA, MA, CHE; Gina Dimitropoulose, PhD, RSW; Laura Hartmand, PhD, MScOT; Lennox Huang, MD, FAAP, CPE; Monika Kastner, PhD; Shauna Kingsnorth, PhD; Anna McCormicki, MD, FRCPC, PhD; Michelle Nelson, PhD; David Nicholase, PhD, RSW; Melanie Pennerb, MD FRCPC; Laura Thompsond, MScOT; Alene Toulany, MD, FRCPC; Amanda Wooa, MScPT, MHScHA, CHE; Joanne Zee, BScPT, MSc, MCPA; Sarah E. P. Muncea, PhD* **Background:** Transition from the pediatric to the adult health care system is a complex process that should include medical, psychosocial, educational, recreational, and vocational considerations. This systematic review aims to synthesize the evidence on transitional care interventions to improve the quality of life for adolescents and young adults with childhood-onset disabilities, including neurodevelopmental disorders. **Methods:** Four electronic databases (MEDLINE, EMBASE, PsycINFO, and CINAHL) were searched. Included studies examined transitional care interventions for adolescents and young adults (12 to 24 years of age) with childhood-onset disabilities. Studies were experimental, quasi-experimental, and observational studies published in the last 26 years. Two reviewers independently completed study screening, data extraction, and risk of bias assessment. **Results:** Fifty-two studies were included. Five studies reported on quality of life, but statistically significant improvements were noted in only one of these studies. Significant improvements were also found in secondary outcomes including disability-related knowledge and transitional readiness. Transitional care interventions targeted patients, families and/or caregivers, and health care providers, and exhibited great heterogeneity in their characteristics and components. Inconsistent reporting on interventions between studies hindered synthesis of the relationships between specific intervention characteristics and outcomes. **Conclusions:** Although there is limited evidence on the impact of transitional care interventions on quality of life for youth with childhood-onset disabilities, there is indication that they can be effective in improving patient and provider outcomes. The initiation of transition focused care at an early age may contribute to improved long-term health outcomes in this population.
Platform Session 2: Continuous Quality Improvement/Program Development/Models of Care	
Presentation 1	**Specialized Primary Care Center for Autistic Adults is Linked with Increased Provision of Preventive Care Services**

	Brittany N. Hand, PhD, OTR/L; Daniel Gilmore, BS, RDN, LD; Daniel L. Coury, MD; Amy R. Darragh, PhD, OTR/L; Susan Moffatt-Bruce, MD, PhD, MBA; Christopher Hanks, MD; Jennifer H. Garvin, PhD, MBA, RHIA **Background:** While the patient-centered medical home is linked with increased provision of preventive services among other populations, there is a paucity of literature testing the effectiveness of medical homes in serving the healthcare needs of autistic adults. The objective was to compare the preventive service use of patients at a patient-centered medical home specifically designed for autistic adults (called the Center for Autism Services and Transition "CAST") to US national samples of autistic adults with private insurance or Medicare. **Methods:** Retrospective cohort study of medical billing data was accessed. The study sample included CAST patients (N=490) who were propensity score matched to Medicare-enrolled autistic adults (N=980) and privately insured autistic adults (N=980) on demographic characteristics. The median age of subjects was 21 years old, 79% were male, and the median duration of observation was 2.2 years. The primary outcome measure was the utilization of any preventive service, as defined by the Medicare Learning Network and AAPC. Secondary outcome measures included utilization of specific preventive service types (i.e., general health and wellness services; screenings; counseling and therapies; vaccinations; and sexual/reproductive health services). **Results:** CAST patients had significantly greater odds of receiving any preventive service than Medicare-enrolled (OR=10.3; 95% CI=7.6-13.9) and privately insured (OR=3.1; 95% CI=2.3-4.2) autistic adults. CAST patients were also significantly more likely to receive screenings and vaccinations than either Medicare beneficiaries (screenings OR=20.3; 95% CI=14.7-28.0; vaccinations OR=5.5; 95% CI=4.3-7.0) or privately insured beneficiaries (screenings OR=2.0; 95% CI=1.6-2.5; vaccinations OR= 3.3; 95% CI=2.6-4.1). **Conclusions:** Our findings suggest that patient-centered medical homes with physicians who are knowledgeable about autism, like CAST, are a promising solution to improve healthcare delivery for the growing population of autistic adults.
Presentation 2	**Utilizing Medical Students as Patient Mentors: An Intervention to Improve Transition Readiness in Young Adults with Sickle Cell Disease** *Adrienne Viola, PhD, MPH; Richard Drachtman, MD; Amanda Kaveney, MD; Ashwin Sridharan, MD; Beth Savage, PhD; Katie Devine, PhD, MPH* **Background:** Advances in medical care have resulted in nearly 95% of all children with sickle cell disease (SCD) living to adulthood. Standardized transition programming does not currently exist, resulting in high rates of mortality and morbidity among young adults (YA) during the transition period. Mentoring and social support have been used to impact health behavior change. Medical student mentors can offer specialized support for YA. Guided by the Social-Ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) framework, the objective of this study was to examine the needs of YAs living with SCD to develop a medical student mentor intervention to improve transition outcomes for YAs with SCD. **Methods:** 24 AYA with sickle cell disease and 9 medical student mentors enrolled in the program. Feasibility and acceptability of the intervention was assessed through enrollment rates, reasons for refusal, retention rates, engagement with the intervention, satisfaction, and reasons for drop-out. The preliminary efficacy of the intervention among patient participants was assessed for changes in transition readiness, health related quality of life, self-efficacy, SCD knowledge medication adherence, and health literacy. Among medical student mentor participants, changes in attitudes towards chronic illness and SCD knowledge were explored.

	Results: Patient participants demonstrated adequate retention (75.0%) and adherence to the intervention (88.3%) and rated the intervention components highly. Patient participants demonstrated significant improvements in transition readiness (p=0.001), self-efficacy (p=0.002), medication adherence (p=0.02), and health literacy (p=0.05). Medical students also demonstrated significant improvements in SCD knowledge. **Discussion:** A medical student mentor intervention for transition from pediatric to adult care for young adults with SCD is both feasible and acceptable to patients and medical students. Preliminary evidence suggests such an intervention may provide dual benefit for both patients and students.
Presentation 3	**Increasing Adolescent Patient Portal Access and Discussions About Confidentiality: A Quality Improvement Project** *Margaret Fennell; Ariel L. Reinish, MD; Marybeth R. Jones, MD, MHPEd* **Background:** Adolescents and their parents can use online patient portals (e.g., MyChart) to engage in their health during health care transition, especially as the "21st Century Cures Act" rules have mandated increased record transparency. However, parent/guardian proxy access can compromise confidentiality, thereby inhibiting access to important adolescent health care services. During well child checks (WCCs) at the Golisano Children's Hospital Pediatric Practice, providers aimed to increase documentation of their conversations with teenagers about confidentiality and portal proxy status from less than 1% to >80% of WCCs over 6 months in an effort to improve portal access, while protecting adolescent confidentiality. **Methods:** Baseline (Fall 2019, n = 203), cycle 1 (Winter 2020, n = 327), and cycle 2 (Spring/Summer 2020, n = 147) chart reviews assessed primary outcome measures (documented conversations about confidentiality and proxy status) and balancing measures (including portal enrollment) during annual adolescent (ages 12-17 years) WCCs. Cycle 1's intervention added note template prompts to discuss and document confidentiality and proxy status, educated providers via faculty meetings and clinic-wide emails, and supplied templated patient instructions regarding confidentiality policy statements and portal information. Cycle 2's intervention re-educated providers and adjusted the prompts based on participant feedback. **Results:** Adolescent portal enrollment increased from <3% at baseline to 5% (cycle 1) and then 10% (cycle 2). Rates of documented confidentiality discussions increased to 88% of visits (cycle 1) and remained high (84%) after cycle 2. Proxy status discussions increased to 45% (cycle 1) and then 68% (cycle 2) of visits. **Conclusions:** Our interventions increased documentation of conversations with adolescents about confidentiality and proxy status and increased MyChart enrollment. Telehealth utilization related to COVID-19 may have contributed. As telehealth evolves, protecting confidentiality remains a priority for adolescent health engagement.
Presentation 4	**Continuity of Transition Services Promotes Long-Term Retention in Adult Care Among Young Adults with Sickle Cell Disease** *Kristin E. Howell, MPH; Anjelica C. Saulsberry-Abate, MD; Joacy Mathias, PhD, MSc; Jerlym S. Porter, PhD, MPH; Jason R. Hodges, PhD, MA; Kenneth I. Ataga, MD; Sheila Anderson, RN; Vikki Nolan, DSc, MPH; Jane S. Hankins, MD, MS* **Introduction:** During transition from pediatric to adult care, young adults with sickle cell disease (SCD) experience increased acute healthcare utilization and mortality. The St. Jude SCD Transition to Adult Care Program uses a co-located pediatric-adult care delivery model during young adulthood (ages 18-25 years). We tested the hypothesis that individuals who participated in the co-location model, in which pediatric provider involvement continued during young adulthood, had greater retention in adult care compared to those who received only pediatric transition services.

	Methods: This study consisted of 364 participants of a longitudinal SCD cohort study, Sickle Cell Clinical Research and Intervention Program, who transferred from pediatric to adult care during the years 2007-2017. Participants were excluded if they did not transfer in time for a full 12 (n=53) or 24 (n=91) months of observation. Retention was defined as continuation with a pediatric provider for ≥12 or ≥24 months post-pediatric care. Logistic regression estimated the association between co-location status and retention at 12 and 24 months. **Results:** In the 12-month analysis (n=311; 51.5 % male; 63.0% HbSS/HbSβ0-thalassemia), those in the co-location model (n=163) had a 47% decreased odds of abandoning care compared to those in the non-co-location model, when controlled for year of last pediatric visit (p=0.045). In the 24-month analysis (n=273; 52.0% male; 62.6% HbSS/HbSβ0-thalassemia), those within the co-location model (n=134) had 52% decreased odds of abandoning care compared to those in the non-co-location model (p=0.046). Reasons for care discontinuation included voluntary care abandonment (12 months: n=82, 24 months: n=87) and death (12 months: n=4, 24 months: n=5). Exclusion of individuals who died <12 or <24 months post-pediatric care yielded similar findings. **Conclusion:** Continuity of providers from pediatric to adult care may increase long-term retention in adult care. Longitudinal monitoring of adult outcomes is critical to identifying the efficacy of transition services.
Presentation 5	**Implementing a Structured health Care Transition (HCT) Process for Sickle Cell Disease (SCD) Using Quality Improvement: 18 Months Results of a SCD HCT Learning Collaborative** *Ifeyinwa (Ify) Osunkwo; Cheryl Courtlandt MD; Patience H White, MD; Laura Noonan MD; Charity G Patterson PhD; Peggy McManus, MHS; Jennifer Cornette MA; Raymona Lawrence DrPH; and all ST3P-UP Study Investigators and Study Coordinators* **Background:** A SCD HCT learning collaborative (SCD-LC) engaged 14 pediatric and adult paired sites (including community participation) using a standardized quality improvement (QI) process. Monthly virtual meetings provided coaching on clinical recommendations, QI methods, and practical implementation of Six Core Elements of HCT (6CE). **Methods:** Implementation of 6CE was measured across 14 clinical sites (each site comprised of both pediatric and adult clinics) who care for 1625 individuals aged 16-25. Clinical programs varied: 12 urban, 2 rural; 12 academic, 2 non-academic; 6 small, 8 large. The HCT Process Measurement Tool (HCT-PMT) assessed 6CE implementation adherence using iterative QI strategies at baseline (2018), 12 months (2019) and 18 months (2020). Pre-post results were compared for overall group and by type of practice. The 24-month data will be available and presented at the HCTRC Symposium. **Results:** All 14 sites made substantial progress towards implementing a structured HCT process within 18-months. Overall HCT-PMT scores increased over time from 19.4 (SD 14.1) at baseline to 61.5 (SD 25.7) at 12-months and 76.2 (SD 21.6) at 18-months (p<0.0001). Pediatric site scores increased significantly from 24 (baseline) to 71.2 (12 months, p<0.0001) to 85.0 (18-months, p<0.0001). Adult site scores also increased from 15 (baseline) to 51.8 (12-months p=0.0003) to 67.6 (18-months, p<0.0001). Pediatric sites scored higher at 18 months compared to adult sites (p=0.0471). Although the change over time for pediatric sites was higher than that for adult sites, it did not reach statistical significance (p=0.35). Large sites showed increased scores from 21 (baseline) to 59 (12-months p<0.0001) to 75 (18-months, p<0.0001) while small sites increased from 20 (baseline) to 66 (12-months p=0.0007) to 76 (18-months, p=0.0001). **Conclusion:** All 14 pediatric and adult sites reported significant progress with adherence to a structured HCT process aligned with the 6CE within 18-months using quality improvement.
LUNCH	
Breakout Sessions	

Breakout Session 1	**Improving Transition of Care in Pediatric Rehabilitation** *Didem Inanoglu, MD; Rishi Shah, MSHM; Ashley McCool, MHA* **Goals:** This is a multidisciplinary/ interdisciplinary session where a medical provider (pediatric rehabilitation specialist), a quality improvement consultant, and a transition care administrator will provide small group discussions including clinical models of care and research, quality improvement methodologies, and pediatric to adult health care transition theories. The patient education materials and process tools created for this program will be shared with the participants through case presentations. **Learning Objectives include:** 1. Understand pediatric to adult health care transition processes 2. Identify strategies for improvement in health care settings 3. Introduce learning tools, resources, and best practices 4. Discuss opportunities for future implementation and research **Intended audience:** This session is targeted for different levels of learners and clinicians interested in process improvement, health care transition, and program development. This workshop will start with a five-minute introduction on current state and content. It will then include three breakout sessions, each twenty-minutes long, discussing health care transition theories, clinical implementation and research, and QI methodologies led by facilitators from different disciplines. Small group exercises will be used to engage learners. The workshop will then conclude with a ten-minute case study from the pediatric rehabilitation clinic at Children's Health and UT Southwestern demonstrating practical applications. Learners will have an opportunity to ask questions throughout the sessions and at the end.
Breakout Session 2	**An Innovative, Multidisciplinary Approach to Healthcare Transition in a Pediatric Oncology Research Setting** *Sandra Jones, DNP, APN, CPNP* **Goals/Significance:** There are approximately 375,000 adult survivors of childhood cancer in the United States. Lifelong surveillance for childhood cancer survivors is imperative and guidelines have been developed to detect subsequent malignant neoplasms and/or other late effects to allow early detection and treatment. Short and long-term complications as well as late effects from treatment can lead to significant physical and psychosocial adverse effects. Addressing healthcare transition, health maintenance and surveillance prior to the end of treatment may be an effective method to equip adolescents and young adults with the knowledge and tools to independently advocate for their own healthcare. Enhancing and building healthcare transition skills such as the ability to communicate their cancer history and treatment can assist other providers in managing their healthcare and impact the quality of care received. Compliance with survivorship programs is essential to maintain health, detect secondary cancers and obtain early treatment which in turn may decrease morbidity and mortality. Ensuring adolescents and young adults remain engaged in healthcare and encouraging them to embrace health promotion may lead to continual engagement in healthcare. **Learning Objectives include:** 1. Discuss the importance of a comprehensive, multidisciplinary approach to healthcare transition for childhood cancer survivors 2. Describe challenges faced by adolescent and young adult childhood survivors from a medical and psychosocial perspective 3. Describe an innovative program to prepare families, adolescents and young adults for healthcare transition and entry into survivorship programs 4. Take home messages:

	• Late complications from therapy can significantly impact morbidity and mortality of childhood cancer survivors. • Many adolescent and young adult (AYA) survivors have inadequate knowledge related to their disease and health management. • Many are noncompliant with recommended surveillance guidelines and health promotion practices that could improve long term health outcomes. **Intended audience:** Physicians, primary care providers, nurses, nurse practitioners, social workers.
Breakout Session 3	**Peer Mentorship for Young Adults with Intellectual/Developmental Disabilities (IDD) Transitioning to Adult Care** *Ellen Fremion, MD; Jordan Kemere, MD* **Goals:** Peer mentorship programs to enhance transition knowledge/skills have been described for adolescents and young adults with chronic conditions. However, such programs specifically for individuals with IDD are limited. Funded by a grant from the Texas Council for Developmental Disabilities, we have developed a group mentorship curriculum that can be done in a live group setting as well as virtual meeting that addresses topics for young adults with IDD including: making a medical summary and finding an adult doctor, insurance and home/community based services navigation, physical/emotional self-care, education/employment, and independent living/transportation. **Learning Objectives:** 1. Describe formats for in-person/virtual group mentorship for young adults with IDD. 2. Evaluate measurements of success and lessons learned from our initial pilot program. 3. Explore ways to make a peer-mentorship program sustainable through community partnerships. **Intended Audience:** Clinic providers, young adults with IDD or chronic conditions, families, teachers, community advocates
Breakout Session 4	**Self-advocacy and Empowerment for Young Adults with Chronic and Rare Diseases: Young Adult Perspectives** *Snetha Dave* **Goals:** As young adult patients, there are topics that we want providers to know about and to address, themes such as navigating the education system, the workplace, insurance. This breakout session is led entirely by young adult patients and will include core themes of what entering adulthood looks like beyond the medical setting. The session will be based on the development and evolving work of the Health Advocacy Summit, a first-of-its-kind nonprofit organization dedicated to improving the lives of young adults with chronic and rare diseases by focusing on state events, online programming, and health equity. During the era of COVID-19, HAS has created a Keep High-Risk Students Safe campaign to ensure that high-risk students are safe as well as has conducted weekly virtual meetings discussing a wide range of topics of concern to young adult patients. HAS is focusing on core topics such as vocational rehabilitation, mental health, and health policy. HAS is led entirely by young adults diagnosed with invisible chronic and rare diseases. This breakout session will be led by the Health Advocacy Summit executive director, Sneha Dave, 22 years old, and a couple of additional strong young adult patient advocates. **Learning Objectives:** 1. Learn the various complexities of growing up with a chronic condition beyond the medical setting. 2. Learn about the various social situations young adults may encounter with their condition, and how they learn to overcome.

	3. Learn how to advocate for health equity specifically for young adults with chronic and rare diseases. **Intended audience**: Interdisciplinary health care professionals.
Platform Session 3: Health Care Transition Considerations	
Presentation 1	**Understanding the Long-Term Care Planning Experiences of Caregivers of Individuals with IDD** *Caren Steinway LMSW MPH; Vanessa Chicas; Matthew Schwartz; Charmaine Wright, MD MSHP; Michelle Cornacchia, MD;Thomas Davis, MD; John Berens, MD; Ilka Riddle, PhD; Jason Woodward, MD MS; Jack Chen, MS; Sophia Jan, MD MSHP* **Background:** Children with intellectual/developmental disabilities (IDD) are expected to outlive their caregivers. Although many caregivers of individuals with IDD worry about their relative's future, few develop solid long-term care (LTC) plans. The goal of this project was to identify targets for LTC planning interventions for caregivers of individuals with IDD. As a result, we hope to build a long-term care planning website intervention in order to help families plan the lifespan for individuals with IDD. **Methods:** Between April 2018 and October 2019, focus groups were conducted across five states with caregivers of individuals with IDD. Participants completed a survey that included demographic questions, Waisman Activities of Daily Living Scale (W-ADL), and Scales of Independent Behavior-Revised, Problem Behavior Scale (SIB-R). Caregivers then participated in focus groups and were asked about perceived barriers and facilitators of LTC planning and suggestions for tools to promote LTC planning among families like theirs. Focus group recordings were transcribed verbatim and coded using the constant comparative method to identify major themes. **Results:** Forty-nine caregivers participated in focus groups (mean age, 55.9). Individuals with IDD ranged from 7-40 years old (mean, 22.7); 83% had ≥ 1 problem behavior. The mean W-ADL score was 1.1, meaning that most individuals with IDD need assistance with activities of daily living. Focus groups revealed multiple facilitators and barriers to planning, which are especially prominent when services are lost during transition to adulthood. Suggestions for online tool characteristics included: a resource database; accurate LTC planning information; and a timeline to help with knowing when to plan for certain things. **Conclusions:** Interventions for LTC planning may improve quality of life, independence, and personal choice of adults with IDD and their caregivers. Information gathered will be used to develop an online planning tool to aid as an intervention to the planning process.
Presentation 2	**ED visits and hospitalizations are highest in transition-age patients empaneled in a primary care network at a major academic medical center** *Kanwarabijit Thind, Jack Wiedrick; Reyna Lindert, Adrienne Kovacs, Alison Martin, Rachael Roberts, Reem Hasan. MD, PhD* **Background:** Transition to adult care is a vulnerable time period for patients with pediatric-onset medical conditions. We used a population-based approach to describe the characteristics and utilization of transition-aged primary care patients across a healthcare system. **Methods:** We analyzed retrospective data from patients ages 12-29 from 10 primary care clinics within our hospital network. We determined the prevalence of 11 target pediatric-onset medical diagnoses: intellectual/developmental disability, seizure disorder, congenital cardiac disorders, sickle cell disease, cystic fibrosis, type 1 diabetes, inflammatory bowel disease, rheumatologic disease, history of or active cancer, history of transplant, and technology dependence. Utilization outcomes included Emergency Department (ED) visits and hospitalizations. We performed t-tests and chi-square statistics to examine whether healthcare utilization varied between diagnostic groups.

	Results: Of 19,989 patients, 1975 (9.9%) had ≥1 target diagnosis. Compared to those without a target diagnosis, patients with diagnoses were more likely to have public insurance, an assigned care manager, and elevated risk scores (all p<0.01). Patients with diagnoses were also more likely to have ED visits (24% vs. 15%; p<0.01) and hospitalizations (10% vs. 4%; p<0.01). Compared to 12-17 year old patients, 18-23 year old patients with a target diagnosis had 72% more ED visits (p<0.01). 98 patients ages 16+ underwent transfer from a pediatric to an adult clinic. Patients with diagnoses who had completed transfer had 57% more ED visits and 110% more hospitalizations compared to those who had not transferred care. **Conclusions:** Our results demonstrate significantly greater use of high cost healthcare services for patients in the transitioning 18-23 year age group and for patients with complex medical conditions. These findings prompt systems-wide processes to improve health and decrease unnecessary utilization in this patient population.
Presentation 3	**Designated Transition Programs Improve Satisfaction for Adolescents and Young Adults with Developmental Disabilities** *Rachel Cowley, BS; Ellen Fremion, MD; John Berens, MD; Kristen Staggers, MS* **Background:** National surveys have shown that adolescents and young adults with developmental disabilities (AYADD) often do not receive optimal transition preparation. While structured transition programs have been shown to improve clinical outcomes and transition satisfaction for youth with various chronic conditions, there are limited studies for AYADD. Objective: This study aims to identify factors associated with transition satisfaction for AYADD with medical complexity. **Methods:** 408 AYADD or their families completed GotTransition.org Transition Feedback Surveys at their first visit to an adult medical home clinic. Demographic, clinical, and referral source type (community, affiliated pediatric hospital system, or a designated transition clinic program within the pediatric hospital) data were collected from the electronic medical record. Linear regression models were used to determine factors associated with survey responses. **Results:** AYADD referred from a designated transition program felt more prepared for transition than those referred from community sources (OR 4.43; 95% CI: 2.19, 8.96). Those with increased medical technology dependence also experienced increased transition satisfaction, with the odds of feeling very prepared for transition being 1.31 times higher (95% CI: 1.04, 1.66) for each additional technology required. Latinos (adj. OR 1.94, 95% CI: 1.03, 3.63), and African Americans (adj. OR 2.43, 95% CI: 1.22, 4.84) were more likely to feel prepared for their transition compared to Non-Latino Caucasians. Finally, the median time between pediatric and adult visits for patients who felt very prepared to transition was 2.2 months shorter than those who did not feel prepared. **Conclusions:** For AYADD with medical complexity, transitioning from a designated transition clinic was associated with higher levels of transition preparation satisfaction. Further research is needed to explore the effects of designated transition clinics on other outcome measures such as biometric health measures and cost/acute care utilization.
Presentation 4	**Quality of Life, Family and Peer Support, and Transition to Adult Care in Youth with Gastroenterology, Renal, and Rheumatology Diseases** *Courtney Zimmerman, PhD; Beth Garland, PhD; Constance Wiemann, PhD* **Background:** Pediatric patients with chronic diseases have lower health-related quality of life (HRQOL) than their healthy peers. Little is known about family and peer support, and the potential impact on transition to adult healthcare. The goal of this study is to examine the role of HRQOL and both family and peer support in adolescents' feelings about leaving pediatric care for adult care among adolescents struggling with chronic diseases.

	Methods: 135 adolescents (17-22yrs) with Gastroenterology (GI), Renal, or Rheumatology disease completed questionnaires as part of a larger study examining health, relationships, and the transition to adult-based care. Questions assessed current HRQOL (i.e., number of days health prevented activities, Centers for Disease Control), peer and family support, and feelings about transition. Data were analyzed using linear regression (SPSSv25). **Results:** Adolescents reported generally poor HRQOL. In the multivariate model, lower HRQOL (= .25, p<0.01) and less peer connectedness (= -.18, p<0.05) were associated with worse feelings about transition (R2 = .13, p<0.001). While, family support was associated with negative feelings about transition (r = -.18, p<0.04) at the bivariate level, it did not retain significance in the model (= -.12, p= 17). **Conclusion(s):** Results are concerning as the transition from pediatric to adult healthcare is a milestone that every patient must attain. At this stage of development, peers tend to be more important supports than parents, which might explain the lack of independent relationship between family support and feelings about transition in a model that included peer support. This study highlights potential targets for intervention such as improving HRQOL (e.g., via acceptance and commitment therapy) and increasing peer support (e.g., social skills training, family facilitation) to improve feelings about transition to adult care for pediatric patients with chronic diseases.
Presentation 5	**Pediatric Nurse Practitioner and Nursing Roles in Health Care Transition Planning: National Survey Findings and Practice Implications** *Jennifer Disabato, DNP, RN; Jennifer Mannino, PhD, RN; Cecily Betz, PhD, RN, FAAN* **Background:** The four domains identified in the Health Care Transition Research Consortium's framework for research and practice and Got Transition's Six Core Elements of pediatric to adult HCT served as a foundation for development of a validated tool, Nursing Roles in Health Care Transition Planning (NR-HCTP) used in the study. The purpose of this study was to address a gap in current knowledge specific to the roles and responsibilities pediatric nursing professionals perform in pediatric to adult health care transition planning (HCTP). Research questions included, 1) What extent are nurses involved in HCTP for youth and young adults (YYA) with Chronic Illness and Disability (CID)? 2) What HCTP activities are nurses providing to YYA with CID? 3) What are the associations between selected professional demographic characteristics of nurses, and provision of HCTP services? **Methods:** A quantitative descriptive design using the NR-HCTP survey reflected 13 HCTP role activities; whether these were included in the pediatric nursing professionals' job description, self-reported levels of HCTP knowledge, and ratings of importance of the 13 elements. A volunteer sample of 1,814 Pediatric Nurse Practitioners and pediatric nurse certificants from the Pediatric Nursing Certification Board, or members of the Society of Pediatric Nurses completed the survey. **Results:** Over 64% of respondents performed HCTP activities related to complex chronic illness management. Only 18% reported specialized training in HCTP. Highest-ranking items about perceived importance were educating and supporting disease self-management and speaking with families about complex needs. Predictors of perceived importance included role, inclusion of transition planning in a job description, percentage of time in direct care, caring for patients 14 years and older, and level of knowledge about HCTP. **Conclusion:** The findings identify specific elements that can support future HCTP role development, job descriptions and specialized interdisciplinary HCTP training.
Presentation 6	**Factors influencing chronic condition self-management during middle adolescence** *Eileen Williams, BS; Lauren Bretz, MD; Cassandra J. Enzler, MPH; Cortney J. Zimmerman, PhD; Albert C. Hergenroeder, MD; Beth H. Garland, PhD; Jean L. Raphael, MD, MPH; Constance M. Wiemann, PhD*

	Background: Despite the AAP's recommendations that transition preparation begin by age 14, much of the published literature on healthcare transition has focused on the development of self-management in older adolescents (≥ 17 years). The goal of this qualitative study is to learn how middle adolescents with chronic health conditions perceive and learn about self-management, and how that process is facilitated or inhibited by family members, peers, and healthcare providers. **Methods:** Twenty adolescents ages 14-16 with renal (n=5), gastrointestinal (n=5), hematologic (n=5) or rheumatologic (n=5) diseases, and twenty parents, completed individual semi-structured interviews to discuss the adolescents' current level of self-management. Questions assessed healthcare management responsibilities, attitudes, and skills; motivation to develop self-management; specific processes through which adolescents progress toward increasing self-management; and the impact of social support. Five coders analyzed transcripts using Thematic Framework Analysis. **Results:** Preliminary findings indicate that youth self-reported higher levels of independent self-management than described by their parents, frequently presenting a narrow scope of understanding of their illness and focusing on short-term consequences and motivations, which is characteristic of adolescents in this stage of development. Common motivations to self-manage included pain aversion and a desire to engage in typical adolescent activities. Barriers to self-management include adolescents' lack of motivation to learn skills that parents already perform, parental reticence to turn over responsibility to their adolescent, and systemic challenges associated with being a minor. Adolescents and parents described a variety of learning processes, including observational learning, hands-on learning, and direct instruction by parents or healthcare providers. **Conclusion(s):** Middle adolescents' attitudes and approaches to self-management were largely informed by typical developmental processes and cognition. Future interventions to improve self-management should address barriers identified by parents and adolescents, while incorporating instructional methods appropriate for this developmental stage.
POSTER SESSION 2	
Poster 1	**Acceptability, Feasibility, Reliability and Preliminary Validity of the Self-Report Version of the AMIS II (Adolescent/Young Adult Self-Management and Independence Scale II)** Kathleen Sawin, PhD, CPNP-PC, FAAN; Eileen Sherburne, PhD, ACNS-BC, FNP-BC, CRRN, WCC **Background:** Adolescents/Young Adults (AYA) with spina bifida (SB) often have major challenges performing complex self-management behaviors (SMB). Most lag 2-5 years behind their typically-developing peers. Clinical assessment of the level of self-management in these AYA should specifically-distinguish between the behaviors the individual knows how to do and the behaviors they actually execute independently. However, there are few instruments that measure actual incremental performance of SMB (what the AYA actually does independently). The AMIS II, an Interview with established reliability and validity, addresses this gap. However, AMIS II takes trained professionals to implement and 15-20 minutes to administer. Multiple investigators have indicated a self-report version would enhance data collection in practice and research. Both a Generic (28 items) and a SB-specific (36 items, AMIS II SR-SB) version of the AMIS II have been developed. This study is evaluating the new AMIS II SR-SB. **Methods:** A descriptive preliminary psychometric study consisting of two REDCap web-based or paper surveys for 25 AYA and a parent and a follow-up telephone interview with a subsample is being implemented in one clinical site. Surveys include the AMIS II SB-SR, a demographic/ clinical form, and three instruments for concurrent validity. The telephone interview includes a measure of clarity, relevance and the participant's assessment of what age AYA with SB are expected to achieve the behaviors. Frequency, reliability (internal and

	test-retest), item analysis and Pearson’s correlations will be conducted. This approach is similar to the approach we used in assessing the clarity and relevance of the interview items when developing the AMIS II interview version. **Results:** Pending **Conclusion:** Establishing the acceptability, feasibility, reliability and preliminary validity of the AMIS II SR-SB can facilitate evaluation of self-management in clinical practice. Using REDCap provides the opportunity for multiple sites to collaborate in a larger study of this instrument.
Poster 2	**Barriers and Facilitators to Patient and Caregiver Satisfaction With a Specialized Primary Care Center for Autistic Adults: A Qualitative Study** *Lauren Harris; Jennifer Garvin, PhD, MBA, RHIA, CPHQ, CCS, CT, FAHIMA, FAHA; Brittany Hand, PhD, OTR/L* **Background:** Patient-centered medical homes (PCMHs), where a primary care provider coordinates a patient’s healthcare needs, have been associated with greater satisfaction with care among caregivers of autistic children. There is, however, little research to date that analyzes the extent to which PCMHs meet the needs of autistic adults. **Methods:** We conducted a phenomenological qualitative study. Participants included 9 autistic adults and 12 caregivers who received medical care through a specialized PCMH designed to remove barriers to care for autistic adults, called the Center for Autism Services and Transition (CAST). Participants completed a 30-60 minute interview about barriers and facilitators to their satisfaction with care. Interviews were recorded and transcribed for qualitative analysis using NVivo 12 software. **Results:** Major themes that contributed to satisfaction with CAST were: (1) CAST physician knowledge about autism, for example explaining procedures in terms the patient understands; (2) rapport, which is non-autism-specific strategies to build patient-provider relationships; (3) tempo of the appointment, where patients and caregivers felt that they spent little time waiting and more time with the physician; and (4) negative experiences with previous/non-CAST physicians, which often stemmed from the physicians’ lack of knowledge about autism. Barriers to satisfaction with the care received at CAST were: (1) lack of access to care, such as appointment unavailability; and (2) patients’ difficulty communicating, particularly with regard to expressing mental health needs. **Conclusion:** A PCMH specifically designed to remove barriers to care for autistic adults is a promising solution for a mode of healthcare delivery that better meets this populations’ needs. These findings highlight the specific components of CAST with which patients and caregivers are satisfied (e.g., knowledgeable physicians, rapport with providers, tempo of appointment) as well as identify opportunities for continued improvement (e.g., increasing accessibility of appointments and developing strategies to improve patient-provider communication).
Poster 3	**Identifying Cultural and Socio-Economic Barriers in Long Term Care Planning** *Christine Cummings MD; Caren Steinway, LMSW MPH; Sophia Jan, MD MSHP* **Background:** The lives of individuals with intellectual/developmental disabilities (IDD) continue to extend into adulthood as medicine continues to advance. Despite this, long term care (LTC) planning is often neglected, causing uncertainty in the health, financial, and legal welfare of individuals with IDD. Resources available to families to help LTC are not individualized to a family’s values, culture, and socio-economic status. **Methods:** Semi-structured in-depth interviews were conducted with families, siblings, and individuals with IDD to gain an understanding of the cultural and socio-economic barriers families face when LTC planning for individuals with IDD. Participants were asked to report current socio-economic status, education level, and race/ethnicity. Previous semi-structured interviews with this population identified the following domains of LTC planning: caregiving,

transportation, housing, health management, financial management, and legal management. Participants were asked to expand on barriers to planning in any of these domains. Participants were asked additional questions regarding their cultures, values, and finances. Additionally, they were asked to compile a comprehensive “wish list” for LTC in an ideal setting.

Results: From October-December 2019, ten in-depth interviews were conducted. Participants identified with at least one of the following: non-white (4,40%), English as a second language (1,10%), education equivalent to or less than a high school diploma (2,20%), or income less than $50,000 annually (7,70%). Interviews revealed a web-based tool would help facilitate planning if viewers felt there were photos of individuals of diverse backgrounds and disease states; availability in multiple languages; and peer collaboration. Participants stated financial security in the short term (i.e. social security assistance), but lack of LTC in most of the domains, particularly legal and financial management.

Conclusions: LTC planning is a challenging process for families with children with IDD. Cultural and socio-economic factors play a large role in a family’s ability to be receptive to the resources provided.

Poster 4

Bridging the Gap: An Introduction to Pediatric to Adult Care Transition Curriculum for Medical Students

Kayla Erspamer, BA; Reem Hasan, MD, PhD

Background: Few formal curricula exist to teach trainees about pediatric to adult transition. We sought to create and implement a medical student-focused session to teach pediatric to adult transition concepts and to report on the preliminary curriculum evaluation and student assessment outcomes.

Methods: First-year medical students enrolled in a one-hour interactive, video-based session on pediatric to adult care transition. The first session occurred in May 2020 and future sessions are scheduled in coming months. A pre-curriculum and post-curriculum survey was completed prior to and after each session. Associations with the phrase “transition of care” were gathered via a word cloud generator prior to and after the session. We used Qualtrics survey software for survey administration, and results were analyzed using descriptive statistical methods and Fisher’s exact test.

Results: Nine medical students attended the May 2020 session. Nineteen words were associated with transition care in both the pre-curriculum and post-curriculum word clouds. Only the word “continuity” was present in both. This was the most popular association pre-curriculum, whereas “communication” was the most popular association post-curriculum. There were more words associated with teamwork and education in the post-curriculum word cloud. The post-curriculum survey revealed that 67% of students could define health care transition to a patient/guardian compared to 13% during the pre-survey (p=0.05). 89% could explain the differences between pediatric and adult models of care after the session compared to 13% before the session (p=0.003). All nine students recommended this session to others. Results from the August and October sessions will be analyzed prior to the 12th annual HCTRC Research Symposium.

Conclusion: Medical students are interested in learning about health care transition and an hour-long interactive session can increase knowledge about this important topic.

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Poster 5	**Healthcare Transition for Young Adults with Tuberous Sclerosis Complex: An Interdisciplinary Approach** *Whitney Herge, PhD; Steven Sparagana, MD; Ashleigh Kinney, LCSW; Catherine Thompson, BS, CCRP* **Background:** Tuberous sclerosis complex (TSC) is a rare, complex genetic disorder characterized by the growth of benign tumors throughout the body. TSC presentations may range from mild (e.g., facial growths) to severe (e.g., epilepsy, kidney and lung growths, cognitive impairment, behavioral dysregulation) and often include both physical and psychological/psychiatric symptoms (collectively termed Tuberous Sclerosis Associated Neuropsychiatric Disorders [TAND]). Symptoms may fluctuate over time, often making management and intervention difficult. Given the multisystemic nature of TSC, appropriate transitional care from pediatric to adult settings is paramount. In recognition of this need, Scottish Rite for Children (SRC; Dallas, TX) recently began a program development initiative to improve the healthcare transition of its TSC patients. **Methods:** SRC treats approximately 170 patients with TSC annually (ages 0-27). In an effort to improve patients' transition to adult care, an interdisciplinary taskforce was assembled, including a Pediatric Neurologist, Physician Assistant, Nurses and Clinic Coordinators, Psychologist, and Social Worker. Consistent with recommendations from Got Transition and the Child Neurology Foundation, a model was established, such that patients age 12+ were scheduled for an annual Transitional Care Appointment; appointments combined standard surveillance/treatment with assessment of patient/caregiver transition readiness, education regarding the patient's symptoms/intervention needs, as well as transition-related goal setting and transition planning. **Results:** To date, 22 patients have participated in Transitional Care Appointments (ages 12-22). Of those, two have transitioned to adult providers. Early qualitative feedback suggests that patient families are open and receptive to proactive transitional care planning. Families have also expressed satisfaction with having their child's interdisciplinary needs met in a single setting, particularly when concerns related to TAND and decision-making capability arise. **Conclusion(s):** Formal transitional care planning appears critical for young adult patients, particularly those diagnosed with complex multisystemic disorders like TSC.
Poster 6	**Development of an Electronic Health Record On-Demand Report to Identify Patients for Adult Transition Interventions and Transition Planning Tool Utilization** *William C. Anderson III, MD; Jennifer Disabato DNP CPNP-PC, AC* **Background:** Many youth and young adults (YYA) at academic pediatric healthcare institutions are seen by more than one specialty team. Lack of timely communication between teams, the patient, caregivers, and care delivery settings about readiness and timing of transfer can lead to gaps in care and poor outcomes. The electronic health record (EHR) based Transition Planning Tool (TPT) in EPIC allows providers to track pediatric to adult transition preparation over time and between specialties, but it does not proactively identify patients who would benefit from its use. **Methods:** Pediatric to adult transition leaders worked with clinical application analysts to develop an on-demand report for weekly clinic resource planning and tracking the utilization of the TPT to target provider and team education. Elements of the report include criteria for inclusion (age and follow up encounter indicating ongoing care) medical complexity level, treating clinic, primary diagnosis, date of last appointment, TPT use, and date of last TPT use. With report development, clinic TPT use and number of patients with transition planning initiated can be monitored.

	Results: The initial clinic trial of the report will begin in summer 2020, with data available for Quarter 3 which will serve as a baseline for tool functionality. Measures reported will include TPT completion in report-identified patients; report utilization in clinics; and TPT engagement across the institution. **Conclusion:** Use of the EHR for on-demand reports to support proactive planning and monitor use of EHR integrated transition tools to target interventions has been limited. This novel reporting tool has potential implications both for increasing provider engagement in transition planning and for measuring pediatric to adult transition and transfer success over time, to improve the experience for YYA.
Poster 7	**Exploratory Investigation of Types of Academic and Health-Related Accommodations Provided to Transition-Aged Students with Spina Bifida** *Cecily L. Betz, PhD, RN, FAAN; Alex Van Speybroeck, MD, MPN; Sharon Hudson, PhD; Kathryn Smith, DrPh, RN; Nithya Rajeev, BS; Adam Skura* **Background:** Health-related accommodations are essential supports/services for adolescents and emerging adults (AEA) needed to facilitate their full inclusion and participation in school and academic performance. Students who do not receive the needed health-related accommodations may be hindered from performing as needed to be academically successful and reach their academic potential. The purpose of this study is to explore the types of academic and health- related accommodations by grade and school levels provided to AEA with spina bifida (SB) **Methods:** The sample consists of 192+ AEA with SB ages 9 to 21 years of age enrolled in the Movin' On Up health care transition (HCT) program. Phase 1 consisted of data extraction from the charts of AEA with SB enrolled in the program using the HCT Health Related Accommodations Questionnaire. Phase 2 involved reliability checks of all data extracted from the charts of AEA in the sample. Phase 3 is currently underway involving data inputted into REDCap database. Phase 4 will involve data analysis of the types of academic and health-related accommodations by grade and school levels provided to AEA with SB. **Results:** We anticipate to present preliminary data; frequencies/percentages will be reported for type of academic and health-related accommodations; correlational analysis will be conducted to explore the association between type of accommodations listed and selected demographics listed in the tools. COVID-19 has currently impacted our current project activities (Phase 3 and Phase 4); however we anticipate we will have data on 192+ AEA with SB to report. **Conclusions**: We anticipate that conclusions pertaining to the need to more closely monitor the provision of health-related accommodations in the school setting given our preliminary work to date.
Poster 8	**Examination of Rates of Hospitalization of Adults with Spina Bifida Using Los Angeles Data Resource (LADR) Aggregated Patient** *Cecily L. Betz, PhD, RN, FAAN; Juan Espinosa, MD; Sharon Hudson, PhD* **Background:** Individuals with spina bifida have much higher healthcare utilization rates compared to their peers without spina bifida.1 The lack of preventative care provided to this population has led to higher rates of hospitalizations and hospital readmissions.2 Within individuals with spina bifida, these rates begin to increase as individuals reach adulthood. As adults with spina bifida get older, they are less likely to see a primary care physician and are more likely to be hospitalized.3 The current project analyzes aggregated LADR data in order to better understand the hospitalization rate of adults with spina bifida in Los Angeles. **Methods:** Cohort discovery will be completed using LADR and de-identified data will be collected on 529 adults with spina bifida receiving care in the greater Los Angeles area. Eligible participants will be recruited into the study, which will involve the completion of an

	investigator-designed survey and interview. In addition to collecting demographic information, the survey will collect information on insurance status as well as the utilization of healthcare, support services, and technology. The interview will focus on the participants' health concerns, employment, education, social relationships, and recreational interests. **Results:** Based on preliminary data collection, of the 529 adults with spina bifida receiving care in the LA area 175 receive care at UCLA, 1 receives care at City of Hope, 57 receive care at USC, and 296 receive care at Cedars Sinai Medical Center. We will be reporting the complete results after gaining access to the data. **Conclusions:** We will be presenting and analyzing the results once we are able to access the data.
Poster 9	**Barriers Identified in a Transition Navigator Intervention for Youth with Sickle Cell Disease** *Jenai Jackson; Lynn F Davidson; Ellen J Silver1; Makeda Mallea; Karen Ireland; Rosy Chhabra; Kerry Morrone; Caterina Minniti;, Deepa Rastog; Maya Doyle; Ruth EK Stein; Suzette Oyeku; Deepa Manwani; Laurie J Bauman* **Background:** Transition to adult care is a high-risk period for young adults with Sickle Cell Disease (SCD). Inadequate transition planning may result in reduced quality of care and patient satisfaction, increased acute care utilization, avoidable morbidity, and death. **Methods:** We developed and implemented an intensive, goal-oriented, protocolized intervention delivered to 17-20 year olds with SCD over a period of 6-12 months by a trained TN in person and by phone. Youth completed surveys at enrollment and program completion including the Transition Readiness Assessment Questionnaire (TRAQ). Barriers to transition were identified through patient self-report and TN observation, and documented on a Barriers checklist. **Results:** Of 56 participants, 76.7% met with the TN >3 times and 64.3% worked with the transition navigator □ 6 months. There was significant improvement in total TRAQ scores (p<0.0001). Significant differences were seen between participant's and TN's identified barriers regarding lack of appointment availability (p=.004), parent/family's reluctance to let go (p<.0001, difficulties finding new provider (p<.0001). The most common barrier listed by both the youth (47.4%) and the TN (56.1%) was "relocating for college.", with particular challenge identified for participants dependent on public insurance accepted to college out-of-state. **Conclusion:** Our data demonstrate that participation in the TN intervention is feasible and associated with improved transition readiness. Some barriers of great concern to participants were seen as minimal barriers by TN, which may indicate lack of familiarity with negotiating the healthcare system or insurance, highlighting why having a navigator through this challenging time is vital. To minimize multiple transitions simultaneously (medical, educational, and geographic, for example), individualized transition plans and flexible institutional transition policies are both needed. . Further study is needed to determine if this intervention improves transfer to and success with adult care, reduces barriers to transition and morbidity.
Poster 10	**Filling the Gap: Understanding Transition Needs of Minority Youth with CHD** *Ayesha Masood,BS;;Donna K Lovick BSN RN CCCTM; Nicole S Broussard LCSW; Deborah Thompson PhD; Keila N Lopez MD MPH* **Background:** Young adults with congenital heart disease (CHD) often have gaps in care during the transition period between pediatric and adult care; these gaps are often pronounced in minority youth. The transition needs of minority youth with CHD are largely unknown. The goal of our study was to conduct a needs assessment of minority youth with CHD to determine barriers and preferences during the transition period.

	Methods: IRB approval was obtained. Demographic and CHD severity information was collected from youth with CHD who were recruited from cardiology clinics. Individual interviews were conducted surrounding feelings and deterrents during the transition process until thematic saturation was achieved. Transcription, coding, and content/thematic analysis were conducted (NVivo 12). **Results:** Ten interviews were completed, with 90% of participants from minority groups (n=9; 2 non-Hispanic Black, 6 Hispanic, 1 Asian). For minorities, 40% (n=4) had severe and 50% (n=5) had moderate CHD complexity, and approximately 70% had public insurance. The top 3 transition needs identified were: (1) Lack of knowledge surrounding transition skills (78%); (2) Desire to improve CHD knowledge via teen CHD support groups (67%) and private discussions with a transition nurse (78%); (3) Gaps in knowledge surrounding reproductive health (44%) and communicating with peers about CHD (33%). Two-thirds wanted information through a mobile application or website, with capabilities to message their medical provider (100%), have a checklist to monitor their transition progress (89%) and communicate with other teens with CHD (78%). **Conclusion:** Minority youth with CHD expressed a distinct need to connect with other CHD teens both in person and via e-health, and to have private communication surrounding reproductive health and other topics with healthcare providers. E-health platforms, with various communicative features, were identified as a helpful way to improve the transition process. Further research is needed to develop programs to meet these needs.
Poster 11	**Impact of Perceived Barriers on Patient Attitudes Towards Transition and Transfer** *Megan Drovetta, LCSW; Jordan Sevart, APRN; Alaina Linafelter, PharmD* "Title: Impact of Perceived Barriers on Patient Attitudes Towards Transition and Transfer **Background:** Transferring to adult care is a daunting time and may be impacted by a variety of barriers. Being able to identify obstacles and discuss solutions may create a smoother transfer process. To our knowledge, no research has evaluated perceived barriers towards transition and its potential impact on patient outcomes. We aimed to evaluate the link between patient-reported barriers and attitudes towards transition and transfer. **Methods:** Sixty-four young adults (M = 18.76 years, SD = 1.27) were seen in a Young Adult IBD Clinic, which targets transition planning among young adults with Inflammatory Bowel Disease (IBD). As part of standard care, patients completed questionnaires on perceived transition barriers; perceived confidence, importance, motivation, and readiness towards transition and transfer; IBD self-efficacy; and allocation of treatment responsibility. Descriptive statistics (e.g., M, SD) were used to summarize patient-reported data. Cross-sectional linear regression was used to evaluate the association between perceived barriers and attitudes towards transition and transfer. **Results:** Not knowing who to transfer to (59.4%), not knowing how to transfer (45.3%), and not understanding insurance costs/plan/coverage (42.2%) were the most commonly endorsed barriers. On average, out of 13 total barriers, patients endorsed 3.39 barriers (SD = 2.29). Perceived barriers significantly predicted transfer confidence (F (1, 63) = 31.22, p = .000, R2 = .335), transfer motivation (F (1, 63) = 12.08, p = .001, R2 = .163), and transfer readiness (F (1. 63) = 15.77, p = .000, R2 = .203). Perceived barriers did not predict attitudes towards transition, IBD self-efficacy or allocation or treatment responsibility. **Conclusion(s):** Perceived barriers, such as insurance and how/who to transfer care to, impact patient attitudes towards their care and can be used as intervention targets to facilitate transition planning.
Poster 12	**Primary to Subspecialty: A Multi-Component Approach to Health Care Transition** *Erin Benekos, MSN, RN, NP-C, CPHON; Wendy N. Gray, PhD; Lauren Partain, LCSW; Erika Jewell, LCSW; Hanae Kim, MHA; Anne Carpinelli MD; Kenneth Grant MD; Alexandra Roche MD; Michael Weiss, DO; Mary Zupanc MD*

	Background: The increasing number of youth with chronic health conditions surviving into adulthood has necessitated the need for pediatric to adult care transition policy in health care settings. In response to this, transition research in each disease group is developing in its own silo, with resultant disparities among various pediatric populations. All youth, including those with disabilities, require education, support and advanced planning, assuring the greatest success of seamless transition. **Methods:** The SUCCEED Program at CHOC Children's is a system-level reform to facilitate and promote the health care transition process for all youth with and without chronic conditions. Transition programming is woven into patient care, both primary and subspecialty, and aligns with the Got Transition 6 Core Elements. We present our overall program, including our structured educational curriculum, to standardize our process of preparing youth and their families for adult care. Our risk stratification tool illustrates how transition services within a standardized system are tailored to patient needs. In addition, our novel specialty transition clinic supports youth whose needs may exceed what can be provided within the time constraints of scheduled primary and subspecialty care visits. **Results:** We present an overview of key features of our developing program, including our standardized educational curriculum and specialty transition clinic. Our program's alignment with Got Transition's 6-core elements and our multi-component plan for evaluating the success of our program using the Triple Aim framework will also be presented. **Conclusions:** A systematically implemented program to address transition to adult care may help to reduce health care disparities in youth with conditions less commonly researched in the transition literature. Creation of a hospital-wide transition program, with the ability to stratify patients by risk level, may result in tailored care to ensure that all patients receive the level of support they need.
Poster 13	**Center for Healthy Adolescent Transition: A Lean, Institution-wide System for Transition** *Courtney Porter MPH, CPH: Ellen Iverson MPH; Rachel Cuevas; Jennifer Baird PhD, MPH, MSW, RN, CPN; Roberta Williams MD* **Background:** For children and adolescents living with special healthcare needs, pediatric tertiary care hospitals often become patients' medical homes, addressing primary and sub-specialty medical needs, case management, and psychosocial support. Challenges patients face as they graduate into adult-oriented care systems are well-known and have led to widespread recognition of the need to prepare patients and families for adult care before transfer of services occurs. Though there are promising emerging models of transition focused on specific patient populations, slower to evolve are hospital-wide initiatives that provide commitment and resources for transition across all sub-specialties and conditions. Building upon existing models, the Center for Healthy Adolescent Transition (CHAT) is an institution-wide system to support and prepare adolescent and young adult (AYA) patients as they transition into adulthood and the adult healthcare system. **Methods:** Our evidence-based framework includes proactive education/coaching for patients and families; building capacity of our teams to integrate transition preparation into patient care; using innovation and technology to support patients and providers; coordinating transfers to the healthcare and benefits systems that change as patients enter adulthood; and evaluating outcomes. For sustainability and alignment with hospital strategic goals, we identified a formal reporting structure to leadership in the clinical, strategy, and research departments. **Results:** We have piloted a multi-faceted approach to build team capacity, including a clinic-level assessment, digital instruction modules and toolkit, and education on AYA health topics. Hospital-wide policy and standardized clinical documentation have been developed. A

	Navigation Hub has been developed as centralized support for navigating insurance and benefits systems and transfer to adult providers. **Conclusion(s):** CHAT is designed as a system for transition that serves as a model for pediatric health services delivery and that is broadly adoptable and sustainable through clinical reimbursement and research funding. "
Poster 14	**Transition Planning Tool Use Within the TCH Rheumatology Clinic** *Danna Bernard; Monique Maher, MD; Tiphanie Vogel, MD, PhD* **Background:** The prevalence of autoimmune disease in the pediatric population is increasing, and studies have shown that many chronic conditions are at great risk of becoming uncontrolled around the time of transition. In the Department of Rheumatology at Texas Children's Hospital (TCH), we have implemented a formalized transition pathway. This pathway is executed via an electronic medical record-based flowsheet called the Transition Planning Tool (TPT), which is utilized during clinic visits. **Methods:** Data was extracted from the EPIC electronic medical record (EMR) regarding Best Practice Advisory (BPA) activation and TPT use for 1567 individual clinic encounters. This data was used to calculate the frequency of TPT use and BPA acknowledgment in the TCH Rheumatology Clinic for 2019 by month and by provider. For encounters in which the BPA was activated but the TPT was not opened, the provider gave an explanation as to why. **Results:** Increase in utilization of the TPT over time was statistically significant (p<0.001). TPT use plateaued around July 2019, with usage at 45% of eligible patient visits, up from 16% of visits in January. When both use and acknowledgement are considered, the TPT was included in 95% of patient visits in July, up from 24% in January. The most common acknowledgement for providers who did not use the TPT was the clinic being too busy (32% of acknowledgements). **Conclusions:** The data suggests that a BPA which incorporates the TPT into provider workflow is a promising means to promote transition planning. As many providers cited time constraints as a key limitation in utilization of the TPT, it is important to use an intuitive tool. However, there will always be days in which it is challenging to make time to use the TPT. As such, dedicated transition support may be helpful in achieving standardized transition readiness and planning.
Poster 15	**Long-Term Follow Up of Childhood Kidney Transplant Recipients: A Single Center Review** *Irma Guardiola, RN, BSN; Celine Castro, RN, BSN, CPN; Irene Gamez, RN, BSN; Iliana McGurn, LCSW; Daniel Ranch, MD, MBA* **Background**: Kidney transplantation is the best treatment for children with renal failure. Early graft failure rates have decreased markedly, but long-term graft survival has not improved in parallel. One known risk factor for graft loss is the transition of care from a pediatric center to an adult team. This fragmented process results in many former pediatric transplant recipients becoming lost in adult practices, making it difficult to truly know their long-term outcomes. Our aim was to determine the outcomes of our patients who had been transitioned to adult care, and to uncover the factors associated with poor outcomes. **Methods:** Our team reached out to 85 former patients transplanted at our center from 2001–2016 who had transitioned into adult care. Those contacted were asked to participate in a telephone survey to obtain information on their medical health, education, employment, psychosocial health, and feedback regarding their transition process. **Results:** We were able to contact 20 of 85 patients; median f/u time 10 years, median age 25.1 years. Nineteen participated in the survey. Partial information for an additional 8 patients was available from chart review. Total cohort: 13 patients still had a functional graft; 13 patients had lost their graft. One patient was re-transplanted. Two patients had died.

	Surveyed patients: 11 had hypertension, 4 had diabetes mellitus, and none had cancer. Seven reported mental health issues, with anxiety/depression being most common. The majority still lived with their parents, and 8 were still in school. Seven had jobs, and 7 were receiving disability benefits only. Monthly income ranged from $100-$2000/month. Two patients reported being divorced, and 1 had children. Finally, thirteen recalled receiving transition education, and 12 felt it was beneficial. The theme of the comments was that it improved knowledge. **Conclusions:** Long-term outcomes of childhood kidney transplant recipients are still not well-known, due to poor follow-up. A significant number of our patients lost their graft after transition, and possible risk factors include mental health and financial issues. Transition was well-received but may not have helped them to actually perform tasks needed to be a successful adult patient. Transplant centers should continue to advocate for more resources to fully support a successful transition into adulthood.
Poster 16	**COVID-19 and Patient Navigation: Transitioning Pediatric Patients Living with HIV (PLWH) to Adult-based Care** *Educardo Ocampo, MA; Gayatri Mirani, MD; Sara Aguirre, LMSW; Albert Hergenroeder, MD; Susan Gillespie, MD, Ph;, Gloria Sierra, MPH; Mary Paul, MD* **Background:** The main goal of patient navigation in the pediatric HIV field is to aid PLWH transition to adult care using a designated patient navigator (PN). Due to the COVID-19 pandemic, patient navigation and patient transition processes have suffered. **Method:** The patient navigation process facilitating transition from pediatric to adult-based care for PLWH at the Texas Children's Hospital is as follows: 1. Transition need is identified six months prior. 2. PN provides adult care options at the patient's last visit. 3. PN assists with scheduling first appointment, gathers documents, and portable medical summary. 4. PN reviews transition tool to evaluate knowledge of patient's medical condition. 5. PN is available before, during, and after the first appointment. 6. PN ensures patient has a follow-up appointment and medication(s). 7. PN repeats the process for second appointment. 8. PN services conclude once the patient has a third appointment; transition is marked successful. Due to the current pandemic and the restrictions placed on visitors to clinics, the PN no longer accompanies transitioning patients to appointments. **Results:** Eleven new referrals of PLWH were made to the PN between August 2019 and May 2020, with 36% successfully transitioning. Seven are still in the transition process. Because of COVID-19 restrictions, the PN is no longer accompanying patients to adult clinics (steps 5 and 6 cannot be completed), resulting in patients leaving the adult clinic without seeing a provider (1), not receiving medications/labs (1), and missing appointments (2). **Conclusions:** Linkage to care is a key component of ending the HIV epidemic in the US. The role of PN is essential in the effective transition of pediatric PLWH to adult care. The COVID-19 pandemic has placed system-wide restrictions that negatively affect the transition process.
Poster 17	**Addressing gaps in provider education and resource awareness among internal medicine physicians to improve healthcare transition for young adults with chronic childhood conditions** *Rahela Aziz-Bose, MD; Kelsey Ripp, MD; Sarah Capponi, MD; Chandler Villaverde, MD* **Background:** As more children are living into adulthood with chronic health conditions that might once have been life-limiting, transitioning from pediatric into adult care becomes increasingly important. Internists report significantly more discomfort caring for young adults with chronic childhood conditions (ACCCs) than other young adult patients (Okumura, 2008). This project aims to understand and address barriers to an optimal transition from pediatric to adult care related to provider education and resource access.

	Methods: A needs assessment of adult providers was performed at an academic outpatient clinic in Philadelphia. The survey assessed comfort with and perceived barriers to providing comprehensive care for young adults with and without chronic conditions, focusing on perceived gaps in resources and education. The survey was distributed via Redcap to 68 providers with 19 total responses, a response rate of 28%. **Results:** Of total respondents, 6 (32%) were attendings, and 13 (68%) were residents. 63% of respondents trained in internal medicine, with the remainder in internal medicine/pediatrics. 100% of respondents selected either "agree" or "strongly agree" when asked about comfort caring for young adults without chronic health conditions. When asked about comfort caring for ACCCs, 32% selected "neutral" and 32% selected "disagree" or "strongly disagree". Major barriers include inadequate patient exposure and provider unfamiliarity with community resources. Insurance, government benefits, tube feeding and TPN, durable medical equipment, and tracheostomy care were identified as areas of discomfort in counseling. Resources identified as most helpful were: subspecialty providers, day programs, vocational training, and the guardianship process. **Conclusion(s):** Information on the prioritized resources was compiled into a website for providers directing them to community and health-system resources specific to ACCCs. Next steps include 1) a post-intervention survey to understand provider use of the website and impact on comfort caring for ACCCs, and 2) continuing to share and update resources.
Poster 18	**Development of a telehealth-based transition to adult care program: A pilot study** *Wendy Gray, PhD; Erin Benekos, N; Lauren Partain, LCSW; Erika Jewell, LCSW; Karina Chavez, MSW; Ana Koh, LCSW; Anne Carpinelli, MD; Kenneth Grant, MD; Mary Zupanc, MD; Michael Weiss, DO* **Background:** In the advent of COVID-19, the healthcare field has had to adapt the way it provides services to youth with special health care needs. Transition to adult care is no exception. We have developed, and are currently testing, a telehealth-based, data-driven, transition from pediatric to adult care intervention. **Methods:** Patients with pediatric inflammatory bowel disease (N=10) or epilepsy (N = 10) were recruited for our pilot program. Eligible patients were recruited during a regularly scheduled telehealth visit with their subspecialty provider. Families completed online validated self-report measures of transition readiness and disease knowledge. Afterward, families participated in a telehealth transition visit with a nurse practitioner and a licensed clinical social worker. The transition visit included a brief targeted intervention informed by self-report measures, clinician assessment of transition readiness (UNC TRxANSITION Index), and an educational intervention based on each patient's age and transition needs. Following the transition visit, families completed a brief program satisfaction questionnaire. **Results:** Data collection is ongoing, with 19 out of 20 patients enrolled and all data collection expected to be complete by the end of August 2020. As part of the evaluation of our program, we will present feasibility and acceptability data and transition readiness outcomes. Feasibility will be assessed by percentage of visits completed, length of visit, and billing and insurance reimbursement rate. Acceptability will be assessed via family program satisfaction ratings. A summary of transition readiness outcomes and educational interventions delivered will also be provided. **Conclusions:** Pending results, we plan to expand this transition program over the next year to include adolescent and young adult survivors of childhood-onset cancer and patients with type 1 diabetes. Over the next several years, we will continue to expand our pilot to include other chronic illnesses, and ultimately, all primary care and subspecialty care clinics.
Poster 19	**Epilepsy Transition Educator Project: Medical Student Experiences** *Sara Peterson; Emily Walsh, MD; Inna Hughes, MD, PhD; Marybeth Jones, MD, MHPEd*

	Background: Transition-aged patients with epilepsy (ages 18-25 years) are at increased risk for poor health outcomes. A novel medical-student-as-patient-educator (MSTE) educational program has established ‘value-added’ roles for medical students to learn systems-based care and collaborative practice, and thereby improve health care transition (HCT) counseling and support for teens and families. **Methods:** In 2019-2020 academic year, medical students (n=5) were enrolled as MSTEs and were trained to assist patients with goal-setting in the domains of Using Healthcare, Taking Medications, and Understanding Medical Conditions. Under the direction of a student coordinator (S.P.) and supervising physician (I.H.), MSTEs were paired with transition-aged patients. MSTEs provided written and verbal reflections on their patient encounters and offered suggestions to improve the program. **Results:** Five patients with epilepsy (ages 16-20 years) expressed interest in the program. Three out of five patients were contacted and paired with a MSTE; two were lost to follow-up. All patients expressed a goal of understanding and retelling their healthcare history. Other goals included creating an online health portal account, remembering to take medications, and knowing medications and dosing. MSTEs described successes in stimulating patient engagement in the program, navigating communication methods, motivational interviewing, and helping teens explore their reluctance in self-management. Challenges included COVID-19 disruptions, difficulty contacting patients, and initial relationship-building. MSTEs shared an experience with patients of being frustrated with the healthcare system and collaborated to troubleshoot some of the system’s complexities. **Conclusions:**MSTE experiences in this novel HCT program can increase understanding of patient goals surrounding transition, identify areas for resource development, and offer insight into how this model may be adapted for individuals with developmental disabilities or expanded into other specialties. Additional qualitative data from patients and families will further contribute to the assessment of the feasibility and sustainability of this transitional program.
Poster 20	**Development and Evaluation of a Program to Train Young Adult Peer Mentors** *Demonica L. Jones, MPH, MSW; Casandra Enzler, MPH; Rachel Wolfe, PhD; Jean L Raphael, MD MPH; Albert H Hergenroeder, MD; Sarah E Graham, MPH; Constance M Wiemann, PhD* **Background:** The use of peer mentors to help facilitate transition to and engagement in adult healthcare for adolescents with chronic conditions is frequently discussed; however, training and mentor readiness have not been formalized for healthcare transition. The purpose of this study was to 1) describe the development of the mentor training program and recruitment, 2) review pilot data evaluating the acceptability and feasibility of the training, and 3) provide lessons learned from the process. **Methods:** The training curriculum was developed utilizing local and national experts in medicine, psychology, public health, and development. Two investigators attended a mentor training workgroup specific to adulthood transition. Peer mentors were recruited through job postings and recommendations from healthcare professionals at an urban pediatric hospital. Applicants submitted responses to essay questions asking about lived experience prior to being interviewed. Acceptability and feasibility of the trainings were evaluated using surveys completed by mentors following training, behavioral coding, and exit interviews. **Results:** Five peer mentors were recruited and participated in the training. The mentor training program included presentations on mentoring, group dynamics, research ethics, and Motivational Interviewing (MI) skills. Discussions and role plays occurred for MI and the intervention curriculum. Mentors participated in two pre- and post-MI training simulations, which included immediate feedback/de-brief, personal review and self-evaluation, and individualized supervision. Full description of the components and standardized patient

	training and script materials will be presented. A majority of mentors rated each component of the training program as meeting their needs. Qualitative statements will be presented offering more detailed responses to the curriculum components. **Conclusions:** The development of this mentor training program formalized empirically-based skills, including interpersonal skills, boundary considerations, and managing groups. The training was considered useful and important; improvements included additional/ongoing MI training and practice, better defined goals/objectives, and increased guidance on personal disclosure.
Poster 21	**Educational Intervention with a CKD Self-Care Manual in Young Adults Incidents in Dialysis at the Hospital General de Mexico** *Juliette Britto, RN; Mara Medeiros MD, PhD; Elba Medina MD, MSc; Guillermo Cantú MD, PhD; María Ferris MD, MPH, PhD; Rafael Valdez-Ortiz MD, PhD.* **Background:** Young patients with a chronic condition face various challenges early in their illness and it is frequently assumed that they are already self-sufficient and must face and take on their challenges. However, it has been observed that in this age group many of them are unprotected, vulnerable and face the transition from pediatric to adult health care with poor knowledge and self-management to face chronic kidney disease (CKD). The implementation of the Self-Care Manual as a tool to promote self-management can have a positive impact on the quality of life and the biopsychosocial environment of young patients with CKD. **Methods:** A Quasi-experimental study was carried out in 17 incident young adult patients on dialysis at the Hospital General de México. The intervention with the CKD Self-Care Manual was implemented in 6 individual weekly sessions and the change in knowledge and self-management skills was evaluated with the STARx and T.R.A.N.S.I.T.I.O.N questionnaires. **Results:** The mean age was 24.1 ± 3.4 years and 76.92% were men. A significant difference is observed in the pre and post scores of the questionnaires that evaluate knowledge and self-management (p <0.05), with a difference of 6.76 (95% CI 2.09 - 11.43) in the STARx questionnaire and 2.788 (95% CI 2.16 - 3.40) in T.R.A.N.S.I.T.I.O.N. **Conclusions:** The CKD Self-Care Manual as an educational intervention improved the scores of the STARx and T.R.A.N.S.I.T.I.O.N questionnaires. It is essential to focus efforts on strategies to improve self-management, given the repercussions it has on indicators of CKD morbidity and mortality, especially in socioeconomically vulnerable groups, where the burden of disease appears to be harder. Follow-up should be extended to assess possible changes in clinical outcomes and indicators of adherence to treatment in dialysis patients**.**
Poster 22	**Transfer of Care: Impact of Transition Coordinator** *Michael Regier, MSW LCSW; Kathryn Hassell, MD* **Background:** Adolescence is a time of competing interests and stress. For those with sickle cell disease (SCD) managing one's health adds another dimension for adolescents and young adults (AYA). One important aspect of healthcare is attending clinic visits. However, this may lapse, particularly when transferring from a pediatric to adult setting. **Objectives:** To assess the impact of a sustained relationship between AYA and transition coordinator (TC), extending from the pediatric to adult setting, on attendance to post-transfer clinic visits. **Methods:** Colorado Sickle Cell Center conducts a formal transition program anchored on a TC's contact with AYA from ages 12-26, providing transition skills assessment, coaching and facilitation of transfer of care, accompanying the youth to adult visits as requested. Use of various transition tools are individualized by the TC. As a metric of transfer success, attendance to the first 3 recommended visits post-transfer is tracked using the electronic medical record and/or AYA self-report.

	Results: Since July 1, 2017 twenty-four AYA left pediatric care; 2 moved out of state. Twenty of the remaining 22 (90%) completed their first visit, 14 within recommended time. Twelve (55%) completed 3 visits, 8 doing so within recommended schedule. Of the 8 who did not complete 3 visits, two completed visits on time, 1 completed one of 2 visits late, 2 were lost to care after first visit, and 3 were living out of state; follow up data were not obtained. Of the 2 who did not complete their first visit, 1 is delayed but scheduled and 1 was lost to care. **Conclusion:** Transition and transfer of care can be overwhelming for AYA with SCD, each with unique strengths, fears and areas to improve. A key element of success may be sustained engagement with a TC before and after transfer.
Poster 23	**Adult provider perspectives on transition and transfer to adult care: A multi-specialty, multi-institutional examination** *Wendy Gray, PhD; Hanae Kim, MHA; Mary Zupanc, MD; Kenneth Grant, MD; Michael Weiss, DO* **Background:** Transition programs have largely developed in subspecialty silos, limiting our ability to identify programming needs and barriers that transcend all illness populations and medical specialties. When adult providers are included in transition research, they generally represent one specialty area or one health care system. Although this research is helpful in guiding smaller-scale, subspecialty-specific interventions, its generalizability to larger-scale efforts is limited. As our hospital provides care for over 2 million children across a four-county catchment area, our patients transfer to primary care and specialists across a number of healthcare systems. Thus, in order to develop a transition program that transcends all illness populations, medical specialties, payment models, and healthcare systems, we need to incorporate the broader perspectives of our adult care colleagues. **Methods:** Twenty adult providers representing 3 hospital systems in the specialty areas of family medicine, internal medicine, endocrinology, gastroenterology, and neurology participated in one of 6 semi-structured focus groups exploring the barriers and needs surrounding transition to adult care. **Results:** Data collection is ongoing with all groups scheduled to be completed by late July 2020. Data will be analyzed via directed content analysis. Commonalities across specialists, as well as specialty-specific needs, and recommendations to improve both transition and transfer will be identified. **Conclusions:** Understanding cross-specialty commonalities related to transition to adult care will inform the development of a hospital-wide, condition agnostic, structured transition program as well as a streamlined transfer of care process.