REACH (RAPPORT, EMPOWERMENT AND ADVOCACY THROUGH CONNECTIONS AND HEALTH)
Dava Szalda, MD, Symme Trachtenberg, LISW, Lawrence Brown, MD, Natalie Stollon, MPH, Caren Steinway, MPH, Jaime DiIanni, MS
*The Children’s Hospital of Philadelphia*

**Purpose:** As over 90 percent of children with special health care needs are living into adulthood, there is need for education surrounding chronic disease management during educational, vocational and medical transitions. REACH is a one to two session group psycho-educational /mentoring program that has been run out of The Children’s Hospital of Philadelphia (CHOP) since 2003. The goal of REACH is to educate patients and families about the skills necessary and resources available for successful transition to adulthood.

**Methods:** REACH is supported by physicians and social workers interested in the transition process, though individual sessions for teens are primarily run by young adult peers who have successfully transitioned. The program caters to a diverse population with dozens of diagnoses and varied plans in adulthood. Specific sessions are aimed at preparation for college (REACH for College), preparation for work (REACH for employment), and REACH for Independence for youth 19 years and older. Other disease specific programs have also been conducted; for those with Autism, Epilepsy, Neurofibromatosis and Sickle Cell Disease. Adolescents with chronic illness and their parents are recruited to participate from outpatient clinics at CHOP and via social media. Mentors for REACH for College are young adults with chronic illness recruited from local undergraduate institutions or advocacy organizations in addition to former patients who have successfully transferred to adult providers. Mentors attend formal training prior to participation. Programming consists of a general session for teen participants and parents on the transition process presented by social work and medical teams from both pediatric and adult services. Then mentor led small group discussions for teens address social and medical transitions to adulthood. Parents simultaneously attend sessions on similar topics and have time with a panel of successfully transitioned mentors and parents. Presentations by undergraduate office of disabilities or vocational support representatives and disease advocates are included. The program is supported in part by LEND (Leadership Education in Neurodevelopmental Disabilities) and the Department of Social Work.

**Results:** Teens and parents found presentations, discussions and resources provided valuable and a shared sense of purpose as they plan for transition to employment, college and adult healthcare systems. Teens and parents cited presence of successfully transitioned mentors as a highlight of the program.

**Conclusions:** A group-mentoring program is a feasible method to communicate information and tools about transition planning for employment, college and transfer to adult centered medical care to teens with chronic illness and their parents. Expansion of the program to other institutions and additional disease specific groups may be worthwhile. Evaluation of transition readiness pre and post participation is also underway.

**Sources of Support:**
THE ADOLESCENT LEADERSHIP COUNCIL (TALC) OF HASBRO CHILDREN’S HOSPITAL
Jodie L. Neukirch, MS1, Jason R Rafferty, MD, MPH2, Christina Kiley Pastorello, MD2, Matthew Dean Willis, MD, MPH3, Cathleen Marie Adams, MD2
1Hasbro Children’s Hospital; 2Hasbro Children’s Hospital/Rhode Island Hospital; 3Warren Alpert Medical School of Brown University

Purpose: TALC is a non-categorical transition program founded in 2005 to serve dual purposes: provide psycho-social support to participants and education to participants and providers. Despite a large population of adolescents with chronic illness, few programs exist to support patients, their families, or providers. The goal of TALC is to decrease isolation in participants while educating and empowering them about transition issues. Participants provide educational opportunities to medical trainees and providers through programming and outreach activities.

Methods: TALC serves adolescents age 13 to 18 who live in Rhode Island, Massachusetts, and Connecticut. Participants must be diagnosed with a chronic medical illness and are recruited from inpatient hospital admissions, outpatient sub-specialty clinics, partial hospitalization programs, and through partnerships with community organizations. A positive youth development model is utilized, with mentoring occurring at all levels between medical residents, medical students, college students with chronic illness, and the adolescent participants. Regular council meetings focus on issues related to living with a chronic illness, including transition related skill building and leadership opportunities for participants. Concurrent programming is also provided for parents. Periodic social and art events occur throughout the year, and there is an overnight summer leadership camp hosted every summer. TALC has one permanent employee whose position is supported by the hospital, while fundraising supports the programming budget. The program was initially supported by grant funds.

Results: Since its inception, 117 adolescents, 123 parents, 55 college mentors, 34 medical students, and 52 medical residents have been involved with TALC programming. To determine if the goal of decreasing isolation was met, adolescent participants were administered the UCLA Loneliness Scale when they joined TALC and at the end of the program year. At intake, participants reported elevated scores in comparison to the general population. After participation in TALC, there was a statistically significant decrease in loneliness to below the mean standardized adolescent score. To determine if the goal of empowerment had been met, adolescents were administered the Transition Readiness Assessment Questionnaire (TRAQ). There was a small increase in the chronic condition management domain, and a significant increase in the self-advocacy domain post TALC participation. TALC consistently is rated as “extremely” or “somewhat” helpful in managing and coping with illness by adolescent and parent participants through annual program evaluations. TALC became the official youth advisory council for Hasbro Children’s Hospital the Fall of 2012, allowing participants to provide leadership through monthly feedback and large projects.

Conclusions: TALC is a novel transition program that brings together individuals involved in adolescent health care. Adolescent participants are empowered to become a part of their own care by involving them in the decision making structure of TALC and providing college age mentors as role models. Parents are encouraged to support their children’s growing independence. Medical providers are given
an opportunity to create longitudinal relationships with participants, enhancing their understanding of how to care for this population. Strong support from the hospital administration and resident training programs, a permanent employee, and a large network of volunteers has been essential to the success of TALC.

Sources of Support:

62.

PATIENT-DELIVERED PARTNER THERAPY FOR CHLAMYDIA: RECEPTIVENESS AMONG YOUTH
Ashley Vandermorris, MD¹, Leanne Kerr, MD², Sari Kives, MD³
¹The Hospital for Sick Children, University of Toronto; ²The Youth Centre

Purpose: Chlamydia, the most common bacterial sexually transmitted infection (STI) worldwide, disproportionately affects youth. Chlamydia infection has significant potential acute and chronic health implications, however up to 50% of men and 70% of women infected with Chlamydia are asymptomatic. Many individuals remain untreated, which likely contributes to high rates of Chlamydia reinfection as treated cases are re-exposed via untreated partners. Patient-delivered partner therapy (PDPT), a type of expedited partner therapy (EPT), involves an infected individual directly providing sexual partners with medication to treat STIs, without the partner requiring medical evaluation. It is an alternative to more traditional partner notification strategies which often fall short. PDPT has been shown to decrease rates of Chlamydia reinfection and to increase the number of partners treated. In 2009 The Society for Adolescent Health and Medicine (SAHM) formally endorsed EPT. There are a limited number of studies exploring attitudes and receptiveness of adolescents to PDPT. To our knowledge, no study has examined adolescents’ receptiveness to taking medication provided by a sex partner through PDPT. The objective of this study was to determine receptiveness to both providing and receiving PDPT among 15-24 year olds presenting to a youth-focused Community Health Centre (CHC) over 5 months.

Methods: An anonymous, confidential survey was administered to a convenience sample of 320 youth ages 15-24 presenting at a youth-focused CHC in Ajax, Ontario. The survey involved demographic questions followed by questions probing comfort with partner notification of Chlamydia and with PDPT, both if the respondent was the hypothetical index case or hypothetical partner. Participants ranked the likelihood of responding in a given manner on a 5-point Likert scale (5 = “for sure”; 1 = “no way”). Simple descriptive statistics were performed.

Results: 328 individuals were approached for participation. 8 patients declined. 320 surveys were completed; 8 were excluded. Of the remaining 312 participants, the majority (83%) were female. Mean age was 19.2 years; 58.3% were under 19. 87.6% (n = 268) endorsed previous sexual activity; 86.6% (n = 233) reported previous sexual activity exclusively with opposite sex partners. The majority (63.5%) had 1 sexual partner while 4.5% had >3 partners in the preceding 60 days. 18.8% (n = 56) had Chlamydia previously. When asked about comfort providing PDPT to partners, 78.2% responded “for sure” or “yes”. When asked about taking PDPT, 63.2% of respondents expressed willingness (“for sure” or “yes”) if they were symptomatic, and 51% if asymptomatic. 92.3% would prefer treatment directly from a healthcare provider.
Conclusions: In this survey of 312 youth ages 15-24, a majority reported sexual activity. While most expressed comfort with the idea of providing PDPT to sexual partners, a smaller but significant proportion indicated comfort with taking a medication provided via PDPT if symptomatic. If asymptomatic, fewer were comfortable receiving PDPT. PDPT is thus an acceptable option to the majority of youth, however variations in comfort emphasize the importance of tailoring partner notification strategies to individual patients and of ongoing patient education.

Sources of Support: Janus Research Proposal Development Grant, College of Family Physicians of Canada.

63.

MULTIFACETED APPROACHES TO EARLY TRANSITION PREPARATION FOR FAMILIES – A CANADIAN PROGRAM
Joan Versnel, PhD
Dalhousie University

Purpose: You’re in Charge is designed to create an opportunity for families to start the conversations and actions that intentionally focus on the negotiation of responsibility for transition to adult health care services. Outdoor, arts-based and cooperative challenge activities are interwoven with education and skill-building exercises for parents, youth, and siblings – individually and collectively. Goal setting and action planning are supported by program personnel for four weeks following the camp experience. Healthcare professional students are recruited as volunteers to support the program and make it possible to have a zero-reject policy for developmental or behavioral concerns. Goals/Needs Addressed:

a) Youth with Chronic Illness learn to give a brief health history; recognize symptoms that need attention; identify barriers and facilitators for transition readiness; develop a goal and action plan to implement during the four week follow-up period; b) Parents learn about adolescent brain development and the implications of this on transition readiness; review the developmental trajectory for transition readiness; and develop a goal and action plan to implement during the four week follow-up period; c) Siblings are provided with an opportunity to discuss/reflect on the experience of having a sibling with a chronic illness; d) Youth Leaders are able to increase self-efficacy for their personal transition experiences and self-management of their own chronic illness through the experience of role-modeling; e) Healthcare Professional Students gain increased understanding of the impact on families who have a youth with chronic illness. You’re in Charge gives them a prolonged exposure in a variety of activities and daily routines.

Methods: You’re in Charge serves families with youth 12-15 years of age who have a chronic illness. Programming targets parents (professional and parental led); youth with chronic illness (youth led); and siblings (student led). It began as a pilot program to complement a province-wide adult chronic disease self-management program. You’re in Charge is held in a variety of community based settings with the core program usually offered at Camp Brigadoon – a camp specifically designed for children and youth with chronic illness. Financial support comes from the provincial Department of Health and Wellness. A multisectoral advisory council provides the program coordinator and youth leaders with support and
Results: On measures of Knowledge and Behavior related to Transition Readiness, statistically significant differences were found on all categories for both parents and youth after participating in the You’re in Charge program. These p values ranged from .046 to .0001

Conclusions: You’re in Charge is an evidence-based, early transition preparation program based on principles of youth engagement, grounded in theoretical models of transition and chronic disease self-management. Outcome data indicate that all groups of participants experience a shift in readiness for transition and transition support.

Sources of Support:

64.

THE MAINE ADOLESCENT COUNCIL ON TRANSITION (ACT MAINE): A RESIDENT-DRIVEN, COMMUNITY ACCESS TO CHILD HEALTH (CATCH) GRANT FUNDED PROJECT TO IMPROVE THE QUALITY OF HEALTH CARE TRANSITION AND BUILD RESILIENCE IN YOUTH WITH CHRONIC ILLNESS AND THEIR FAMILIES

Jack C. Rusley, MD1, Jessica Hunt, BA2, David Buzanoski, MD2, Renata Arrington-Sanders, MD, MPH1, Jonathan T. Fanburg, MD, MPH3, Patrice Thibodeau, MD2

1Johns Hopkins University; 2Maine Medical Center; 3Maine Medical Partners - Pediatrics

Purpose: We observed youth with chronic illness (YCI) and their families struggle with transition to adulthood and noted a lack of resources to assist them in this process. Based on focus group feedback, we developed a resident-lead, positive youth development (PYD) program for YCI and their families.

Methods: A group of residents at an academic medical center in Portland, Maine developed and implemented the PYD program, mentored by faculty. A needs assessment was conducted using focus groups for pediatric sub-specialists (n=7), YCI ages 13 to 24 (n=4), and parents of YCI (n=4). Providers were recruited via email and participants were recruited via sub-specialist referrals and office fliers. Groups were recorded by note-takers, transcribed, and separated into themes. Findings were analyzed using a derivative thematic approach. Themes were used to develop the recruitment methods, meeting logistics, curriculum content, and advisory board. After the focus groups, YCI and parents were invited to participate in the PYD program. Residents facilitated seven 2-hour meetings with YCI and their parents, which included activities and discussions about health care transition (HCT), stress management, leadership skills, and communication with health care providers. To gather information for program improvement, quantitative and qualitative data were collected on attitudes and perceptions using written surveys before and after each meeting. The Maine Medical Center Research Institute IRB approved the project.

Results: All three focus groups identified key problems related to HCT. Parents discussed the tension they feel between keeping their child healthy and encouraging them to take on increased responsibility for their health. YCI included HCT in the context of other life transitions, such as transition to college and living away from parents. Providers focused on logistics of HCT (i.e., when and how to start the process) and the resistance from families to the HCT process. All groups identified the inherent resilience YCI possess but also noted significant stressors and barriers to well-being. Attendance at
monthly meetings was good (average of 2 to 3 teens and 2 to 3 parents per meeting). At the program’s conclusion, surveys and interviews indicated that both YCI and parent participants had developed new skills and behaviors they hope will help them cope more effectively with chronic illness. They also indicated a preference for a larger group size in the future.

Conclusions: This project demonstrates how a resident-driven CATCH grant can be used to develop a PYD program to address complex issues such as resilience, chronic illness, and health care transition. YCI, their parents, and sub-specialists describe different barriers to transition and require different approaches. These perspectives should be included in any transition program.

Sources of Support: American Academy of Pediatrics, Community Access to Child Health (CATCH) resident grant

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FROM IDEA TO REALITY: TRAPEZE, A SUPPORTED LEAP INTO ADULT HEALTH

Jane SW Ho, FRACP1, Madeleine Bridgett, MSW1, Lynne Brodie, RN2, Katharine Steinbeck, MB, ChB, DCH, FRACP, FSAHM3, Susan Towns, MBBS, FRACP, MMH, FSAHM1

1The Sydney Children's Hospitals Network; 2Agency for Clinical Innovation; 3University of Sydney

Purpose: To describe the development of a specialist service, Trapeze: a supported leap into adult health, for young people aged 14-25 years old with chronic conditions based in Sydney, Australia. The Ministry of Health provided funding to The Sydney Children’s Hospitals Network to develop, implement and evaluate an adolescent service based on principles of a chronic care program for older patients that addressed continuum of care in the community and avoidance of unnecessary hospitalisation. Trapeze strengthens primary and community care links, and complements an existing state-wide transition service which is primarily based in adult hospitals. Together, these provide an integrated transition model which is the only one of its type in Australia.

Methods: Data gathering to inform the model began with broad consultation with key stakeholders in government agencies, hospitals and the community; investigation of models of care in chronic conditions; and collection of baseline hospital data for adolescent-age chronic conditions associated with unplanned hospital admissions. The development of service infrastructure involved technology-based health records with real-time identification of referrals and immediate visibility of documentation. Young people provided service consultation and a multi-disciplinary workforce was engaged with broad expertise required to support the diverse chronic conditions of the adolescent age group. The initial communication strategy included presentations to key stakeholders, and tools to engage the target population, such as printed resource materials, website and social media development. All resources developed have had input from young people with chronic conditions, ensuring relevance and engagement. Education and advocacy pertaining to youth with chronic conditions were provided to different sectors in health care. Evaluation tools and processes were developed to be incorporated into normal work flow.

Results: Trapeze began clinical operations in January 2013. The service is located in the community between the two tertiary paediatric hospitals in Sydney, which are 26 miles apart. Staff regularly travel
between the two hospitals and conduct home visits. The service uses the HEADSS assessment, employing the commercial format TickiTR, to inform its coordinated care approach which focuses on primary care and general practitioner engagement. Youth engagement was optimised using face to face communication where possible, and regular contact by telephone, email or messaging. The established electronic medical record systems enabled automatic data collection for both clinical care and service evaluation.

**Conclusions:** We describe the development of a new adolescent chronic care service designed to prevent young people from falling through the health care gap, by engaging them early in paediatric care, improving their integration with primary care and community services, and providing skills and services to reduce unnecessary hospitalisations.

**Sources of Support:** No external funding applied.

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**BRIDGING THE GAP: A NEW MODEL OF TRANSITION CARE FOR YOUNG ADULTS WITH SERIOUS CHRONIC CONDITIONS**

Rachel Bensen, MD, MPH, Dana Steidtmann, PhD, Yana Vaks, MD, Elizabeth Malcolm, MD, MSHS, Donna Zulman, MD, MS and Arnold Milstein, MD, MPH

*Stanford University School of Medicine*

**Purpose:** Advances in medicine have enabled over 90% of children with serious chronic illnesses to survive into adulthood. This has created new challenges for adolescents and young adults who are transitioning to adulthood while coping with a chronic illness and transferring their care into a complex health care system that is designed for older adults. To meet these challenges, we designed a new method of care for the purpose of improving health outcomes and the care experience of patients, caregivers and providers, while lowering total annual per capita healthcare spending.

**Methods:** Our care innovation design method was adapted from one that had been successful in improving the yield from medical device design. It began with a detailed needs assessment accomplished by reviewing relevant research, communicating with medical systems nationwide that excel at providing transition care, and interviewing a broad range of stakeholders. Potential solutions were developed that could apply to youth with chronic illness regardless of the diagnosis. The solution underwent iterative refinement based on feedback from content experts, healthcare managers, social scientists, clinicians, patients/ families and researchers.

**Results:** A new model for transition care was developed that 1) prepares patients and families for adult care by (a) developing self-management skills and (b) treating anxiety and depression; 2) provides tele-mediated specialty and care coordination support to enhance ability of receiving health systems to accommodate complex young adults; and 3) offers navigation services through the transfer process to ensure a safe onboarding to adult-oriented care. These interventions are either assured or directly provided by a team of navigators and health coaches supervised by a social worker, nurse or advanced-practice provider. Assessments of medical fragility, patient activation, and psychosocial risk factors at intake and regular intervals will inform service delivery based on changing needs of individual patients.
and families over time. These assessments will be supplemented with very brief remote check-ins to facilitate early recognition of problems that may lead to health crises. Pilot tests of the care model are currently unfolding at several sites.

**Conclusions:** An innovative model of transition care with a focus on improving care while decreasing costs was developed and is in the early stages of implementation. An evaluation will measure user experience in addition to clinical outcomes, utilization, and a variety of process level measures. Key lessons learned to date include the importance of identifying sources of longitudinal data on outcomes and cost during program design as well as engaging providers across both the pediatric and adult health systems to collaborate in care delivery to this vulnerable population.

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67.

**ON TRAC—TRANSITIONING RESPONSIBLY TO ADULT CARE. A COLLABORATIVE PROVINCIAL INITIATIVE TO ADDRESS TRANSITION FROM GRASS ROOTS ENGAGEMENT TO HEALTH SERVICE POLICY**

Sandy R. Whitehouse, FRCP C, Susan J. Rabinovitz, MPH, Mary Paone, MSN, Dewey Evans, PhD

1Division of Adolescent Medicine Dept of Pediatrics University of British Columbia; 2Doctors of BC; 3BC Children’s Hospital

**Purpose:** ON TRAC (2011) is a Provincial Initiative in British Columbia (BC) Canada designed to improve health outcomes for transitioning youth with chronic health conditions/disabilities (CHC/Ds). ON TRAC’s goal is to achieve an integrated provincial process for transition preparation and transfer for youth ages 12-24 with CHC/Ds, ensuring young adults are engaged in their health care and attached to appropriate primary care and specialist services in the adult care system. ON TRAC was developed to address the multi-level challenges at transition/transfer for youth with CHC/Ds, including: clinical (differences in the complexity of conditions/resources required and provider practices/training); cultural (differences in expectations of providers and patients); personal (developmental and psychosocial needs and self-management requirements/capacity); and structural (differences in the organization and financing of care from pediatric to adult systems, access to specialists in non-urban areas, insurance coverage/benefits), and information transfer.

**Methods:** Using the Institute for Healthcare Improvement Triple AIM framework to ensure a systematic approach to change and ImProve Frameworks/PDSA cycles to guide planning, implementation, and monitoring, ON TRAC consists of 5 separately funded collaborative projects addressing policy change (Doctors of BC, Committee on Health Economics and Policy), clinical practice (BC Children’s Hospital (BCCH), Child Health BC), health system performance (Doctors of BC Shared Care and Specialist Services committees, BCCH, Child Health BC), and youth engagement (Vancouver Foundation Youth Voice Project). Strategies are targeted to achieve change in each of these domains and key stakeholders are engaged at every level to inform decisions, develop and test tools, and shape recommendations for
policy/system change A standardized repeated measures design using case studies is being used to evaluate the projects.

**Results:** In 2012 a provincial policy paper, Closing the Gap, laid out 10 recommendations for improving transition (Doctors of BC). Clinical Practice Guidelines, together with information transfer tools, have been developed to support pediatric, adult and community providers (including allied health) in preparing youth and families for developmentally-appropriate transition, transfer and post-transfer engagement. A new website, www.ontracbc.ca offers youth-specific tools using 6 developmental strategies for more independent health management behaviors. Family and health care provider tool kits are in development. The Shared Care Project has promoted the importance of a Medical Home for transitioning youth to facilitate continuity of care, and recommended changes in reimbursement to support primary care and attachment to Family Physicians. Condition-specific Transition Care Management Plans (TCMPs) have been developed through the Specialist Services Project to standardize transfer referral procedures, clarifying clinical management requirements and roles of primary and specialist providers in the adult care system. TCMPs will be available online. The Youth Voice project has directly engaged youth with CHC/Ds, providing skills-building training, online social mentorship, peer-led workshops, and education through creation of an effective, authentic Provincial Youth Advisory Committee. Youth leaders are involved in creating youth-friendly online tools.

**Conclusions:** ON TRAC has demonstrated the effectiveness of a comprehensive, structured approach to improving transition for youth with CHC/Ds. Integration of project components and engaging stakeholders across the transition trajectory provides synergy, maximizes impact, and supports sustainability and spread.

**Sources of Support:**