

RILEY TEEN LEADERSHIP COUNCIL



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BACKGROUND

Youth with chronic illness are at increased risk for social isolation, low self-esteem/confidence, anxiety, and depression. In addition to the challenges inherent to their individual disease process, these psychosocial difficulties can compromise self care, self-advocacy, and transitions to adult care.

These issues can be addressed in medical homes that provide family-centered, culturally competent care. However, youth with chronic health conditions in Indiana are less likely to receive care in clinics that meet the full medical home criteria (48.5% compared to 61.7% of the general population).

AIMS

The purpose of the Riley Teen Leadership Council is to:

- 1) Improve confidence and preparation for transition in adolescents with chronic conditions
- 2) Increase understanding of the medical home model
- 3) Improve health care learners understanding of and comfort with youth who have chronic illness

METHODS

Positive Youth Development (PYD) programs are evidence based groups that encourage the development of character, confidence, social connectedness, competence, and compassion by nurturing participants' strengths. These programs include aspects of group therapy, effective role modeling, family/peer education, and opportunities for leadership which have been shown to target challenges faced by youth with chronic illness.

The Riley Teen Leadership Council is modeled after The Adolescent Leadership Council at Brown University, a successful PYD program for youths with chronic illness. Groups consisting of adolescents, their parents, and college aged mentors who also have chronic illness met once a month for 6 months. Groups were led by triple board residents with assistance from pediatric residents and psychology interns. The goal was to improve the teen participant's self-care, advocacy, transition readiness, and leadership skills with the help of mentors who also have chronic illness. Residents and interns participants had an opportunity to interact with youth with chronic illnesses in a non-medical setting. Teens, their families, and medical learners discussed aspects of chronic illness and learned about the medical home model. The capstone of the year was a community project designed and implemented by the adolescents.

PARTNERS

About Special Kids (ASK)

- A local parent led support group for families with children with special needs
- Discussed the concept of medical home
- Talked to parents about community resources and supports

Center for Youth and Adults with Conditions of Childhood

- A clinic dedicated to helping youths with chronic conditions transition to adult hood
- Discussed transitions preparation with both parents and youth

CURRICULUM

January	Introduction to group/discussion of diagnosis
February	Doctors and Hospitals: What is a medical home
March	Transition to adulthood: How do I find a medical home (ASK/CYACC)
April	Self: How do I take care of myself (CYACC)
May	Siblings/Project planning
June	Graduation/Project implementation

MEDICAL HOME



Question 1: I know what a medical home is
 Question 2: I understand the benefits of a medical home

PARTICIPANTS

- 5 teens and their parents
- 3 college aged mentors
- 2 psychology interns and 3 pediatric residents

Illnesses

- Cystic Fibrosis
- Lupus
- Crohn's disease
- Ulcerative colitis
- Juvenile arthritis
- Thyroid disease

PROJECT



For the leadership project, the teens made a video which depicted various aspects of living with chronic illness with the intent of educating medical trainees, peers, and others about the realities of living with chronic conditions.

TRANSITION READINESS

	PRE	POST
TEEN	3.38	3.53
PARENT	2.81	3.45

The Transition Readiness Assessment Questionnaire measures how often teens complete a variety of medical care and life skills tasks on their own (1= don't know how, 5=always).

DISCUSSION

Several families, mentors and trainees participated in the inaugural year of the Riley Teen Leadership Council. With the help of our community partners, participants better understood the importance of medical homes. As is to be expected, there was a larger increase in understanding among teens and their parents than among medical trainees.

However, we did not see the expected increase in transition readiness. There could be several reasons for this including the low number of participants, not enough focus on transition skills, or the limited time for this year's group.

Similarly, we did not see a change in resident attitudes towards chronic illness (data not presented). This could be due to a small number of participants or selection bias (residents who are already comfortable with chronic illness chose to participate in the group).

SUMMARY AND NEXT STEPS

PYD based programs can be an effective way to improve outcomes for youth with chronic illness, but may take more than 6 months.

Community based education and partnerships can help increase general knowledge of the medical home model. The program is in its second year with four teens returning and new teens and mentors joining the group. We are working to strengthen the mentoring portion of the program and creating partnerships with other programs around the country.

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