The Adolescent Leadership Council : Group Mentoring for Youth with Chronic Illness

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Introduction

Up to 18% of all children have a special health care need, most of which involve a chronic physical condition. The frequency of childhood chronic physical illness increases with age, and teens (12-17 year olds) have a rate of chronic illness that is twice as high as younger children. There are significant negative consequences of having a chronic physical illness on the individual child and their family. These children miss three times as many school days and spend three times as many days sick in bed in comparison to their healthy peers. In addition, they are at increased risk of depression and other psychiatric illnesses and are more likely to get acutely ill. 30% of families affected by childhood chronic illness report at least one family member decreasing or stopping work as a result of the child's illness. There is also an increase rate of chronic illness in children who live in poverty and who are from minority groups.

According to a 2006 RI Health Department publication of Rhode Islanders 16-20 years old, 14% or 11,000 young adults in RI have a disability, which includes only part of the population of those with chronic physical conditions. In a national survey it was found that only 50% of youth with special health care needs had discussed the transition to adulthood with their pediatrician, and that only 15% had received support and guidance through this transition. In a 2004 survey of Rhode Island pediatricians the RI Health Department found that few pediatric practices had plans in place to support their patients with special health care needs as they transitioned to adult medical care and adulthood.

Adolescence and the transition to adulthood is a critical time for all young adults and in particular for those with chronic illness. In a longitudinal study from Great Britain of children with chronic physical conditions it was found that the greatest predictor of unemployment at age 36 was greater health problems from age 20 to 25 years old. In a study of 19-25 year olds from

Finland, those with chronic physical illnesses were less likely to be married, finish school, and live independently than their healthy peers. Clearly the transition to adulthood is a critical time for young adults socially, educationally, vocationally, and physically. However, there are few programs or strategies available to promote the successful transition to adulthood of adolescence with chronic physical conditions. This complex process requires the collaboration of parents, schools, doctors, and the young adults themselves.

Systematic Review

Mentoring programs for adolescents without chronic illness are common. Programs such as Big Brother/Big Sister provide formal mentorship to children throughout the country. Programs that specifically provide mentorship experiences to adolescent with chronic illness are less common. The purpose of this literature review is to identify mentoring programs that specifically serve adolescents with chronic medical illness. Key elements of such programs include

1) **Target Population:** High school students (13-19 years old) with childhood-onset chronic illness.

2) **Program structure:** Mentoring is a key component of this intervention and differentiates this program from other forms of peer support. Mentors are young adults with childhood-onset chronic illness, college students or other young adults from the community.

3) **Goals of the program**: Promoting successful adaptation, both in terms of medical care compliance and psychological adjustment are central goals of this program.

A systematic review of the existing literature is needed to describe existing programs that provide mentoring experiences to adolescents with childhood-onset chronic illness. Examination of these programs will help to inform the design, implementation, and evaluation of The Adolescent Leadership Council.

Methods

The goal of this literature review is to identify programs that address each of the three elements of TALC. Similar programs must serve adolescents 13-19 years old and match them with young adult mentors with a goal of promoting successful adaptation.

Search Strategy : A search was conducted using PubMed and PsychInfo, two online databases, to identify programs described in the medical and psychological literature. Search terms that were used included chronic illness AND "Adolescent"[MeSH],"Chronic Disease/therapy" [MeSh] & "Adolescent"[MeSH] & "Peer Group" [MeSH], "Chronic Disease/therapy" [MeSh] & "Adolescent"[MeSH] & "Social Support" [MeSH], "Chronic Disease/therapy" [MeSh] & "Adolescent"[MeSH] & "Social Support" [MeSH] & "Program Evaluation" [MeSH], "Chronic Disease/therapy" [MeSh] & "Adolescent"[MeSH] "Peer Group" [MeSH] & "Program Evaluation" [MeSH]. Each term was also combined with "mentor" and "mentoring." References were also reviewed to find additional articles. Titles and abstracts were reviewed in order to determine if an article met inclusion criteria.

Inclusion criteria:

    1)   The article is in English

    2)   The program is designed for adolescents 13-19 years old

    3)   The program involves mentors

    4)   The program is designed to promote adaptation broadly defined, not just provide education

Exclusion criteria:

    1)   Summer camps

2)   Support groups without a mentoring component

Summary of Mentoring Programs for Youth with Chronic Illness

<u>**Chronic Illness Peer Support Programme (ChIPS)**</u>

In 1993, the Centre for Adolescent Health at the Royal Children's Hospital in Melbourne, Australia established a program for adolescent with chronic illness (Olsson, Boyce, Toumbourou, & Sawyer, 2005). The program was designed explicitly to promote the adjustment of adolescents living with chronic illness, through peer support and mentoring.

The program has a strong leadership development component with all sessions led by a team including a social worker and a peer leader. The intervention has several components and different levels of involvement for participants. The starting level is an 8 week support group intervention with 6 to 8 adolescents with chronic illnesses meeting weekly the peer co-leader and an healthcare professional. The group discusses topics including school, hospital, family, medication, stress, recreation, relationships, sexuality and body image, in an effort to help the adolescent participants cope with their illness. The peer leader functions as a mentor sharing personal experiences and serving as a role model for participants.

Following completion of the 8 week session, some participants choose to participate in a broader ChIP-ERS (Chronic Illness Peer Support: Education, Recreation, and Social) program in which they can participate in social and recreational programming or get training to serve as peer mentors for the 8 week support group sessions. The social and recreational programming is run by the youth themselves and includes outreach to the community, including publishing a quarterly newsletter and an annual magazine. In addition, youth can choose to participate in social events including a summer camp and other group meetings. In this way, the ChIPS

program provides short-term mentorship for adolescents with chronic illness through the 8 week support group and provides an opportunity for a long term social and mentorship experience for those who participate in the broader ChIP-ERS community.

No formal evaluation of the program has been conducted. The article describing the program described potential mechanisms by which the program may help participants. Participation in ChIPS may help youth learn new coping techniques that will help them deal with influences of the social environment and may help them better understand personal stressors, while providing them with social support and helping to decrease isolation. The idea of helping others and reaching out to the broader community is an essential feature of ChIPS and one that is describe as important in helping youth with chronic illness decrease their social isolation.

TAKE CHARGE

The TAKE CHARGE program is an individual mentoring program for youth with disability. It was created as a research study in New Hampshire with the goal of promoting self-determination for adolescents 12-18 years old with physical disability through connection with adult mentors with physical disability (Powers, et al., 2001).

The study involved 20 adolescents with physical disabilities, with 10 participating in the intervention and 10 serving as a waitlist control group. The 5-month long intervention included weekly coaching session with program staff following the TAKE CHARGE manual and monthly community-based workshops for youth with successful adult mentors. Mentors and participants also worked together on community activities beyond the monthly workshops. Parents also received support with telephone calls and home visits from program staff. Parents also got to meet and interact with the mentors during monthly mentoring workshops.

Outcome measures included the Pediatric Adjustment and Role Skills questionnaire (PARS III), as well measures of empowerment and accomplishment, and a measure of disability-related self-efficacy designed for this study. Compared to the 10 participants in the control group, the youth with disabilities who participated in the intervention had increased psychosocial adjustment on the PARS III and higher levels of empowerment, however there was no difference in disability-related self-efficacy.

While promising, this study has several limitations related to its small sample size and the use of survey instruments that were not previously validated, other than the PARS III. In addition, this may be a select group of adolescents with disability who are able to participate in weekly sessions for 5 months and may not be representative of the more broad population of youth with physical disability. Still, this intense multi-component intervention demonstrates how mentoring from successful adults with disability can be paired with support from program staff and a curriculum to attempt to improve the psychosocial outcomes of adolescents with disabilities.

Diabetes Sponsor Program

A specific program pairing adolescents with diabetes, aged 12 to 16 years, with adults with diabetes was evaluated in a study published in 1992 (Daley, 1992). This program sought to promote positive health behaviors among adolescents with diabetes and to provide social support. The program involves bimonthly contacts between adolescents with diabetes and their sponsors. During these meetings the adolescent and sponsor would do activities in the community ranging from pure recreational activities such as going to a movie to educational activities, including attending a diabetes fair. The mentors served as diabetes role models during

these meetings, by taking care of their own diabetes actively during the meetings, such as counting carbohydrates when eating out at a restaurant.

The study involved 54 adolescents randomized to a control group or to participate in the intervention where they were paired with a sponsor and followed for 10 months. The adolescents were recruited from an urban diabetes clinic and considered to be at high risk of poor diabetes self-care. The mentors all had diabetes and ranged in age from 25 to 43. They were recruited through advertising at clinics and in the community. The mentors received training prior to the intervention and every 6 weeks met as a group with study staff to discuss progress of the adolescents and how to best support the adolescents.

Surveys were administered to adolescent participants before and after the intervention. There was a significantly greater increase in self-esteem in the intervention group as compared to the control group, but no difference in change in anxiety. Intervention participants had a decrease in average blood sugar (hemoglobin A1c), whereas the control group had an increase, but the difference was not statistically significant. Qualitatively, participants in the intervention reported that they enjoyed forming a relationship with an adult with diabetes. Many adolescents said that they hoped to be like their sponsor when they grew-up. The authors saw this as a potentially powerful effect of the program.

Diabetes Mentor Program Proposal

In 1997, Blake proposed a diabetes mentoring program that built on the program described above. The article did not describe the implementation of the program. Instead Blake, used the article to describe the rationale behind having mentoring programs for adolescent with diabetes. The program was designed to specifically address the needs of adolescents with a new

diagnosis of diabetes. Mentors between 21 and 40 years old would be recruited. Following a 3 session training mentors would be placed in a database and would be available to contact a teen, newly diagnosed with diabetes within 3 days. Evaluation would include measures of adjustment to diabetes and measures of general psychological distress. This program plan builds on the diabetes sponsor program, describe above, extending the model to adolescents newly diagnosed with diabetes (Blake, 1997).

Leeds Hospital Education Mentor Program

In 2004 a program to provide education mentorship for adolescents and young adults with cancer was developed in England, at a cancer clinic based out of the Leeds Hospital Teaching Trust (Pini, 2009). A position was created at the clinic for a learning mentor who would assist young adult cancer survivors with educational tasks ranging from working with their school to help the young adult complete their high school education to helping young adults apply to college. The program was evaluated after four years through an informal survey administered to patients and professionals.

The feedback from the questionnaire was positive overall from both patients and professionals. Several patients described how the education mentor helped them to complete their course of study and for others, the education mentor encouraged them to continue with their education through their cancer treatment. In 2008, the program increased the number of education mentors from one to three. No other data regarding program outcomes was provided. In addition, this program is different than the others described as there was no peer support component, as the education mentor was not a cancer patient or cancer survivor.

Analysis

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This review identified only a few programs specifically designed to provide mentoring experiences for adolescents with chronic illness. Two programs – TAKE CHARGE and the Diabetes Sponsor Program- had data that contrasted participants in the mentoring program with a comparison group. The other three programs were described without the presentation of any outcomes data. Even the outcomes data from TAKE CHARGE and the Diabetes Sponsor Program are limited by the relatively small sample sizes.

It is not possible the extent to which mentoring programs promote successful outcomes for adolescents with chronic illness based on the limited program evaluation data. However this review of programs described in the literature provides an opportunity to compare the salient features of mentoring programs and the ways in which mentoring programs can vary. Mentoring can be an intervention alone or in combination with other components and can take place in a group or individual setting. Programs can focus on specific illnesses, such as diabetes or provide services to adolescents with a diversity of chronic illnesses. The type of mentoring relationship can be designed to provide general support or to support for specific domains, such as educational support or support for self-management. Individuals identified as mentors can vary from adults with the same condition as in the Diabetes Sponsor Program, to a staff person without an illness in the Leeds Hospital Education Mentor Program. Finally, the context in which the mentoring relationship is formed and sustained can vary. For example, some programs are hospital based, while others occur primarily in the community.

Broadly these key features of mentoring programs can be divided into two categories, program design feature and factors influencing the development of the mentoring relationship. Program design features include the goals of the program, the site of program activity, whether or not the program is disease-specific, and whether or not there are other components to the intervention beyond mentoring. The program design features do influence the way in which the mentoring relationship develops, however there are other factors that contribute to the intensity and type of

mentoring relationship formed. The five programs identified have different program designs features and take different approaches to the development of the mentoring relationship.

The importance of program design can be seen in comparing the TAKE CHARGE program with the Leeds Hospital Education Mentor. TAKE CHARGE was a community-based program with direct matching of adults with disabilities with youth with disabilities. It had a curriculum implemented by staff and also involved the parents. The program was designed to promote empowerment and improve psychosocial outcomes for the youth with disabilities. The Leeds Hospital Education Mentor program had much different focus. The goal was to promote educational and vocational attainment. The program was designed to meet this narrow goal, as opposed to the broad goals of TAKE CHARGE. Instead of a multi-component intervention, the primary intervention was the involvement of an education mentor with young adult cancer survivors. The education mentor served as an advisor to the young adults and also a liason between the medical team and the education system. While both programs involved some elements of mentoring, the structures of the program made them dramatically different interventions.

The approach to the development of the mentoring relationship also varied between programs. Programs such as the Diabetes Sponsor Program, the Diabetes Mentor Program, and TAKE CHARGE focused on "matching." In each program an adult mentor was paired with an adolescent with a chronic illness. This individual match was not only the starting point of the relationship, but was a central feature of the intervention. Each adolescent had their own mentor and this allowed them to form a strong bond with an individual. This individual matching approach to the development of mentoring relationships is based on mentors spending regularly scheduled time with their "mentee." In the case of TAKE CHARGE this was once a month and involved the mentor and participant working together on community projects, while for the Diabetes Sponsor Program, each pair meet twice a month and were free to participate in a wide variety of activities, ranging from purely recreational to more medically focused activities. The ChIPS program approach followed a

group-based mentoring approach. Participants in ChIPS were involved in a peer support group and had in this structured setting over the course of 8 weeks got to know a peer mentor. Then for those interested in continuing with this type of group mentoring, there was the option to join the larger ChIP-ERS community and to meet several other mentors. ChIPS approach to mentoring was to provide a broad community of potential mentors and allow connections to form in this community setting, more like the development of natural mentoring relationships, as opposed to the formal assigned mentoring relationships that characterized programs like the Diabetes Sponsor Program.

There are sound theoretical reasons to believe that mentoring should work the same for adolescents with chronic illnesses, as it does for other at-risk adolescents. However, as demonstrated in this review there is not sufficient data to make a judgment either in favor or against such programs. In addition, there is not a particular program design or approach to the development of the mentoring relationship that has been shown to work better for adolescents with chronic illness. In the general literature on mentoring and at-risk youth, there are lessons that can be applied to the design of mentoring programs for youth with chronic illness (Sipe, 2002). First, regardless of the overall program design, it is essential to design programs that provide support to the mentors and mentor training. A strong selection process and rigorous training are basic foundations to a mentoring intervention. Second, programs must promote the development of trusting relationships between adolescents and their mentors. The mentors need to be dependable, taking responsibility for maintaining the relationships, while balancing the need for learning and fun.

Conclusion

Mentoring programs for youth with chronic illness are well-suited to address the psychosocial needs of adolescents with childhood chronic illness. The few programs that have been described in the literature take a variety of approaches to program design and the formation of a mentoring

relationship. There is room for the development of mentoring programs for adolescents with chronic illness that build on what is known about mentoring programs for other at-risk youth.

Program Plan

<u>**Overview of the plan**</u>

   The Adolescent Leadership Council of Hasbro Children's Hospital (TALC) was established in 2005 at Hasbro Children's Hospital in Providence, RI. TALC is based on a program called Steps Towards Adult Responsibility (STAR) that was started in 1997 at Dartmouth-Hitchcock Medical Center and uses a group mentoring and leadership framework to promote the psychosocial development of adolescents with chronic physical illness. While the program has been ongoing for the past 5 years, the program does not have a formal program plan and there has not been any formal evaluation. This program plan describes the current program plan for TALC as of the 2009-2010 academic year.

   TALC's goal is to support adolescents with chronic illness in becoming successful adults in terms of educational, vocational, social, medical, and psychological outcomes. Chronic illness in adolescence is associated with social isolation and peer support has been found to be important for improving health outcomes. The program addresses social isolation by providing group peer support and mentoring. Adolescents with chronic illness meet together as a group with college students with chronic illness on a monthly basis and discuss different aspects of the illness experience. The college students with chronic illness are considered the mentors in this group mentoring program. TALC utilizes a non-categorical approach to chronic illness and brings together teens and college students with a diversity of medical conditions as there are common effects of childhood chronic illness across conditions.

   TALC is staffed by a full-time program coordinator who coordinates recruitment of patient participants, college mentors, and volunteer staff, as well as running monthly TALC dinner groups and other TALC programming. TALC dinner groups are the main program

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activity, however TALC also offers lower intensity program interventions, including a two

session medical transition program and clinic based medical transition nights. The main TALC

mentorship group which meets monthly for dinner is designed for 15 adolescents, 10 parents, 10

college mentors, 3-5 facilitators (i.e. medical students, pediatric residents, child life specialists)

for a total of approximately 40 people at a given meeting. Currently the program is funded by the

Rhode Island Foundation and March 2010 is the start of the third and final year of grant support

for the program coordinator position.

Context of Program Plan

Creating a program for adolescents with chronic illness involves many stakeholders,

particularly at the local level and requires being mindful of the variety of services already

available and potentially encroaching on other's turf. At the state and national level there is a

great deal of interest in adolescents and young adults with chronic illness. In Rhode Island the

Department of Health has an ongoing initiative to address health care transition in the Office of

Families Raising Children with Special Healthcare Needs. This office has been active in

collecting data and developing transition related materials for adolescents with a wide variety of

healthcare needs.(*Health Care Transition for Youth with Disabilities and Chronic Health

Conditions*, 2007) In addition, this office coordinates with programs at the Rhode Island

Department of Education which operates transition centers for youth with disabilities and the

Department of Human Services which operates vocational rehabilitation programs.

At the national level the Maternal and Child Health Bureau (MCHB) and organizations

including the American Academy of Pediatrics and the Society for Adolescent Medicine, have

all indicated that transition to adulthood and adult medical care is a health care priority for young

adults.("A consensus statement on health care transitions for young adults with special health

care needs," 2002; Draft 10-Year HRTW/Transition Plan," 2000; Lotstein, et al., 2009; Lotstein, McPherson, Strickland, & Newacheck, 2005; Rosen, Blum, Britto, Sawyer, & Siegel, 2003) Healthy People 2010 in objective 16-23 mentions that "transition services are needed to assist in the progression from adolescent health care to adult services and from school to work."("Healthy People 2010: Chapter 16 Maternal, Infant, and Child Health,") The MCHB in its 2001 survey of youth with special healthcare needs (YSCHN) found that only 15% of 13-17 year olds with special healthcare needs had met the core outcomes related to transition readiness.(Lotstein, et al., 2005) Clearly, the health care transition of young adults with chronic illness is a priority and at this time there are few programs that adequately address this need.

The greatest challenge to this type of program is engaging participants and medical providers. In particular, the structure of most medical systems does not fit well with a program that addresses adolescents with a VARIETY of medical conditions. Most pediatric services, especially those for children with chronic medical conditions are based out of particular specialty clinics and funded through separate funding streams. In this way, each group has duplicate services that are structured in different ways and there are groups of children with chronic illness who do not have access to psychosocial support services at all, while others have access to many.

Each silo of specialty care is protective of its patients and loathes to share them with programming that is not tailored specifically for their patient population. In addition, there are many psychosocial support services that are available including social workers, child life specialists, summer camps, and fun programs like Make-A-Wish. In the context of so many other programs in the environment it is a challenge to design a program that is complementary and not in competition with these other groups and services.

Longitudinal group programming also faces a significant challenge related to geography and time. Both patients and program staff have to commit to meeting on an ongoing basis, which could be seen by patients and providers as an added burden. However, the hope is that participants will see the program as supportive and be willing to invest their time in participating. In addition, a group mentoring program must function differently if it is in an urban versus a rural environment. STAR, the model program from Dartmouth, has participants who travel 1.5-2 hours each way to participate in a monthly group. At Brown, which is located in the city of Providence, most participants come from within 30 minutes. However, there are unique travel challenges to having a program in an urban area, as participants might not have access to cars and it may not be feasible for participants to travel by bus to and from an evening program. Up front designing the program to meet the unique geographic and travel needs of the community is one important strategy to addressing this challenge. Rural areas may not have as many travel options like urban areas.

Creating a program that involves participants with a wide variety of diseases may be a source of strength in terms of financial resources, as there are a wide variety of funding mechanisms for each disease. At Brown, TALC is currently funded by a grant from the Rhode Island Foundation, but recently the program received a $15,000 grant to do programming in conjunction with the pediatric cardiology department. This funding will support the program coordinator's time and she will do some specific programming for the cardiology department, while also doing programming for children with a variety of other illnesses. Similarly, being a part of a medical center is a valuable way to get indirect support, such as office space, phone service, copying supplies and the support of grant writers.

There are limitations though that come from having a non-categorical approach and that is that many funding streams, including research funding from the NIH, are set-up to fund programs by disease. Other potential funding is from local foundations and from state or other governmental agencies that are interested in disease specific programs. In particular, the leadership focus is a strategy to make the program more attractive to funders as they could use the adolescent participants to advise them on salient issues.

The overarching strategy is to establish relationships with representatives from other groups working with the same population of children. This type of program is by necessity inter-disciplinary and requires support from individual providers all the way up to the top administration of the hospital or university. TALC has a core leadership group that involves representatives from each constituency: patients, parents, college mentors, pediatric residents, hospital staff, and university staff.

Goals and objectives

Goal 1: Increase positive outcomes for youth with chronic illness at Hasbro Children's Hospital transitioning into adulthood.

Objectives:

1) By Spring 2010, 50% of adolescent patients referred to TALC will have participated in at least one TALC program

2) By Spring 2010, there will be a decrease in loneliness and isolation, and increase in transition readiness among participants in the year-long TALC program

3) By Spring 2010, 100% of TALC program graduates will have graduated high school, 80% of TALC program graduates will either be in post-secondary education or working full-time.

4) In 2 years, Spring 2012, 80% of TALC program graduates will have made a successful transition to an adult medical provider.

5) In 3 years, Spring 2013, 50% of adolescent patients with chronic illness cared for at Hasbro Children's Hospital will meet the MCHB core transition readiness outcomes.

Goal 2: Increasee Medical students' and pediatric residents' understanding of adolescents with chronic illness and career choices to work with adolescents with chronic illness.

Objectives:

1) By Spring 2010, 90% of medical students and residents who participated in TALC over past academic year will report a positive attitude towards caring for children with chronic illness.

2) By Spring 2010, all pediatric interns who started in 2009 at Hasbro Children's Hospital will have received training from TALC program staff regarding chronic illness in adolescence.

3) By Fall 2010, 50% of physicians who participated in TALC programming over the past 5 years as medical students or residents will currently be working clinically with children with chronic illness.

4) By Fall 2011, three programs based on the TALC model will be started at other medical centers by physicians who participated in TALC as medical students or residents.

Relevant program theories

TALC is designed to promote individual behavior change and to change the environment surrounding the transition to adulthood and adult medical care for adolescents growing up with childhood onset chronic illness. The health belief model and social learning theory both guide the individual and interpersonal activities of TALC, while the community organizing model is the theory that informs the community change aspects of the program. In this way, TALC takes an ecological approach enlisting adolescents and their families in the process of changing their health care environment, while at the same time helping them to make individual behavior changes.

Social learning theory guides the group mentoring component of the TALC program. Mentors and peers provide an opportunity for observational learning. Adolescents and college mentors discuss the process of health care transition and gaining independence in terms of illness management. These discussions take place over the course of a year. During this time, participants witness others making behavioral acquisitions and can see the outcomes of these changes. This modeling is central to the program and the mentors also help to set expectations in a positive direction. Adolescent participants, also gain behavioral capabilities, such as when they learn to speak with doctors about their illness, by speaking with pediatric residents about their illness and watching others. Most importantly the social nature of this program provides the opportunity for positive reinforcement of steps towards adulthood. If a teen is quiet at the beginning of the program, but then becomes more engaged and outspoken over the course of the year, the other participants and mentors will provide positive reinforcement and encourage them to continue to behave this way.

At the individual level, the health belief model is a theory that guides TALC. First, few adolescents have thought about adult health care and the challenges of becoming an adult. The

program explicitly asks participants to examine their perceptions about their susceptibility to a poor health care transition and the barriers to inaction as compared to the benefits of preparation. TALC programming also provides "cues to action" as adolescents are prompted to speak with their parents and medical providers about the health care transition. TALC also promotes self-efficacy how, which both social learning theory and the health belief model incorporate as an important element of behavior change.

At the community level, TALC functions according to the principles of community organizing. TALC is designed to empower adolescents with chronic illness to take collective action to improve the system of care for adolescents with chronic illness. The group is a leadership program and for half of the year, participants engage in community outreach projects to engage the medical community, the community of adolescents with chronic illness, and the community at large. The adolescents are leaders and in collaboration with the college mentors, choose to focus on topics that are relevant to their lives and experience. The curriculum may be set-up for a discussion of school or friends, but the adolescents can choose to spend the whole time focused on that curriculum or to select other issues that are more relevant and devote their energy towards projects that address these issues. The true power of this intervention lies in the creation of a community that has the capacity to mobilize around the problems related to adolescents with chronic illness. Typically young adults with chronic illness do not get to know one another and are isolated. TALC brings together members of this community whom otherwise would not meet and generates the capacity for the community to act.

TALC operates at several levels within the ecological framework. Social learning theory and the health behavior model are used to guide aspects of the intervention that relate to

individual outcomes. Participants take part in a community organization effort to improve the outcomes of young adults with chronic illness in Rhode Island.

Implementation

The program implementation requires the coordinated efforts of the TALC program coordinator, volunteer staff, mentors and adolescent participants in order to achieve the programs objectives. The program has a leadership team that meets regularly to coordinate recruitment efforts, training sessions, dinner groups, and leadership activities throughout the year.

Leadership Team

The leadership team is central to the implementation of the TALC program. This leadership group includes representatives from the key stakeholders including adolescent patients with chronic illness from the hospital, college student mentors from Brown University, staff from the hospital, staff from the university, several residents and the program coordinator.

The core leadership group plans the logistics of each meeting, including the meeting place, food, and topic. Operationally, this planning is often carried out by the program coordinator who meets regularly with different members of the leadership group. The TALC manual is an 80 page document describing the program curriculum in detail. The leadership group also works on developing plans for funding and recruitment of participants. The main focus of the leadership group is to situate the TALC program in the local community and form strong bonds between the program, the hospital, and the university. These bonds allow for patient recruitment and provide a source of mentors, as well as provide options for meeting

space, either on university campus or at the hospital. Further involvement by other community members is also possible.

Recruitment

Recruitment is essential for the implementation of the TALC program. Adolescent patients from the hospital and college mentors with chronic illness need to be rectuited. In addition, volunteer staff including medical students, residents, and other hospital staff need to be recruited to participate. The volunteer coordinator is primarily responsible, in conjunction with other hospital staff involved in the leadership group, for reaching out to different segments of the hospital and community in order to recruit adolescent participants. Methods of recruitment include distribution of letters and pamphlets to physician offices, notifying both providers and patients of the program and providing contact information. The program coordinator has an office in the hospital, with a phone and email access. The program coordinator meets with interested patients and families at the hospital, called either by the patient's doctor or by the family. In addition, the hospital has started a medical transition clinic and the program coordinator is involved in this clinic as well. In addition, the program coordinator would communicate with disability support staff at the Brown University and other local colleges to facilitate recruitment of the college student mentors.

Mentor training, adolescent orientation, and volunteer staff training

The program coordinator in conjunction with medical staff conducts a 2 session training for the mentors, so that they are prepared to facilitate group discussions about medical problems with the adolescents. The format of this training follows the mentor training section of the TALC

manual. Adolescents are invited to a program orientation prior to the first dinner group meeting where they can meet other participants and experienced mentors and be introduced to core ideas such as medical transition, teen leadership, and community outreach. Volunteer hospital staff also go through a brief training to prepare them to function as group facilitators and to clarify their roles at the meetings.

Dinner Groups - Core Program Activities

The monthly dinner groups are the core program activity. The leadership group works with the program coordinator to set the dates of the dinner groups for each semester. The program coordinator is responsible for ordering food and materials for the meetings and coordinating with participants regarding attendance. Parents, adolescents, mentors and volunteers are asked to RSVP, so that an accurate plan can be made for activities and food. The program coordinator is responsible for organizing parking vouchers for participants and for reserving space for the meetings.

Each monthly dinner group includes 30 minutes at the beginning for dinner and informal conversation with all participants, teens, parents, mentors, and staff eating together. Then the parents go to a separate room for their discussion facilitated by a pediatric resident, while the mentors and staff facilitate a discussion with the teens regarding the topic of the meeting. Usually the time is divided into a large group discussion of the topic, followed by small group activities related to the topic, and ending with the group coming back together to share the results of the small group discussions. For example, when the group discusses doctors, the topic is introduced to the large group and then each small group comes up with a list of suggestions for

doctors and adolescent patients on how to communicate more effectively. Each small group then shares their list with the large group at the end of the session.

Other program activities such as social events and an end of the year ropes course or picnic are organized by the program coordinator in conjunction with the leadership group. A summer leadership camp lasting 4 days and 3 nights is held on the Brown University campus for up to 15 adolescent leaders and 4 college mentors.

Leadership Activities

Each semester the group of adolescents and mentors decides on specific leadership activities that they would like to pursue. Production of an annual newsletter is one leadership activity that is used to facilitate recruitment of participants. Other potential leadership activities include art projects, group presentations, or working with the hospital administration to address adolescent patient concerns.

Participants

The leadership group consists of 2 adolescent patients, 2 college mentors, 2 medical/hospital staff and a representative of the university staff, as well as the program coordinator. The current program goal is to have 20 teen members of the leadership group, with patients, 10 parent participants, and 5 college mentors. In addition, there are at least 4 pediatric resident facilitators and a child life specialist who regularly attend meeting programs.

Other TALC Activities

The program coordinator and TALC volunteer staff also are involved in other activities including short term programming and education. The program coordinator runs a semi-annual program called Adolescents Coordinating Their Transition Now (ACTT Now!!) which serves as an orientation for the main TALC program. In addition, the program coordinator runs clinic transition night programs. These programs are one night events that allow individual pediatric sub-speciality clinics to use TALC staff and materials to run a medical transition program for their own patients. The TALC coordinator is also directly involved in education, meeting with all pediatric interns each year to discuss transition and also conducting education sessions with medical students.

Budget

Non-staff program costs	
Meeting Costs	
Meeting supplies	
$100/meeting x 10 meeting/year	$1000
Food for dinner meetings	
$10/person x 40 x 10/year	$4000
Other program costs	
Summer Leadership Camp	$5000
Outreach production	
Advertising	$2000
Newsletter printing costs	
$2/newsletter x1000	$2000
Other art supplies	$1000
Logistical costs	
Office space	Donated by hospital?
Phone	Donated by hospital
Office supplies	$1500
Meeting space	Donated by hospital or university
Program coordinator salary/benefits	
Salary 100%FTE	$45,000
Benefits (salary x 0.33)	$15,000
Total:	$76,500

7. Logic model

Resources	Activities	Outputs	Short- & Long- Term Outcomes	Impact

Data regarding medical, educational, vocational, and social outcomes of young adults in the community.
 	
Community Participants
  - College mentors
  - Adolescent patients
  - Hospital staff facilitators (Residents, etc)
 	
Institutional support -
 -Hospital/College Space
 -Hospital nterest in adolescent patient input
 	
Leadership team
  -Coordinator (staff or volunteer)
  -Clinical supervisors
  -Hospital Representative
  -College Representative
 	
Funding (min. $2,000/yr)
  -Dinner group funds
	Recruitment
	  - College mentors
	  - Adolescent Patients
	  - Resident/Staff Facilitators
	
	Mentor Training
	
	Participant Orientation for parents and teen participants.
	
	Monthly Dinner Group Meetings
	
	Quarterly Leadership Activities (presentations, consultations, etc)
	
	Art and Outreach
	  - Newsletter Production
	  - Summer Camp
	  - Pre-teen outreach
	  - Meet with doctors
	
	Social Events
		Year 1:
		Program participation
		  10 college mentors
		  15 Adolescents
		  10 Parents
		  4 Residents
		  2 other staff
		
		10 group held meetings/year
		
		2000 newsletters distributed
		
		Two local presentations
		
		Educational activities with pediatric residents
		
		Completion of group initiated leadership activity
			Adolescent
			 - increased knowledge about medical transition
			- decreased isolation
			- improved attitude towards illness
			- better adherence to medical regimin
			- adults with chronic illness identified as mentors
			- graduate high school
			- consider attending college
			
			Parent
			- increased knowledge about medical transition
			- decreased distress over child's illness
			- Networking with other supportive parents
			
			College Mentors
			- improved attitude towards illness
			- decreased isolation
				Higher educational attainment for adolescents with chronic illness
				
				Adolescents with chronic illness better able to follow medical regimens as adults
				
				Established hospital-wide system to support medical transition for young adults with chronic illness
				
				More College mentors pursue health related careers
				
				Hospital transition coordinator position fully funded
				
				Mentoring is broadly available for adolescents with chronic illness

-Activity funds			Pediatric Residents, Hospital Staff - Increased knowledge about medical transition - Better understanding of experience of chronic illness - Actively seek out opportunities to work with adolescents with chronic illness	throughout the community. Pediatricians routinely trained to address medical transition.

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Sustainability of the program

The future of TALC at Hasbro Children's Hospital is a central concern as the sustaining grant funding for the program coordinator position runs out in less than a year. For this reason extensive planning has gone into developing a business plan and to continued fundraising. Including the 3 years of grant funding from the Rhode Island Foundation TALC has raised $212,297, including over $30,000 in 2009 separate from the main foundation grant. (Appendix A) This history of successful fundraising is an important part of TALC's sustainability plan, as it demonstrates to the hospital administration that the program can bring money in from outside funders.

Sustainability for TALC involves ensuring sustained funding for the program coordinator position, sustained involvement of resident leaders, sustained recruitment of patient participants and mentors, and a sustained commitment from the leadership of the hospital to provide office space and other material support. These broad areas of sustainability can be broken into financial/logistical needs, manpower needs, and patient recruitment/retention needs.

First and foremost, the program coordinator position is vital to the continue vitality and growth of the program. The goal is for this position to become a line-item in the hospital budget. From the hospital administration point of you, the TALC program coordinator is worth funding because of the TALC programming, but also because she can serve as a point person on adolescent transition issues throughout the hospital. In addition, the TALC program brings much needed positive publicity to the hospital through news coverage and the TALC program coordinator is able to bring in grant funding for the program. (Appendix B) Other than grants it is possible that in the future there may be ways for the hospital to bill for TALC services. Discussions with the insurance providers and the state's Medicaid program are ongoing.

Staffing and leadership are also vital components of sustainability. Towards this end TALC has established a community advisory board that includes representatives from all program constituencies : patients, parents, hospital staff, and Brown University staff. Continuity of pediatric resident leadership is also vital. Fortunately many of the residents involved in the program are in a combined program in pediatrics, psychiatry, and child psychiatry which lasts 5 years. Since residents in this program are at Brown for 5 years, they can be involved with TALC for several years and gradually assume leadership roles. The founders of the program graduated the residency in June 2009 and the program made a smooth transition to the current leadership group of residents.

The most important part of sustainability is the continued involvement of patients and college mentors. Ongoing recruitment is needed to ensure that the program has both college mentors and teen participants. Over the past 2 years the program has reached a point where program graduates are now becoming college mentors. This is the ideal model for sustainability of mentors. Continued work with pediatric clinics and the inpatient hospital is a way for the program to continue to recruit adolescent patient participants.

The final piece of sustainability relates to college students and physicians who had been a part of TALC or of the original STAR program from Dartmouth, going to other medical centers and starting similar programs. To date, similar programs have been started following the TALC manual at other medical centers including the University of Wisconsin and the University of Virginia. The common factors at each of these sites are that the programs are based out of academic medical centers with pediatric residency programs and in close proximity to a major university. The program has been designed to utilize the resources of each group. The academic medical center provides a stable patient base, while the pediatric residency program provides

volunteer man power, and the university has a large group of successful young adults with

chronic illness who are interested in reaching out to others.

Program Evaluation

The Adolescent Leadership Council (TALC) was first funded in 2005 with a $3,000 grant. As of the winter of 2010, the program has received approximately $200,000 in grants and has a full-time program coordinator. Program evaluation at this time is essential to determine whether the program components are producing the desired outcomes and justify the need for further funding and support. The program coordinator position has another year of funding and after that time the goal is for Hasbro Children's Hospital to incorporate the program into the hospital's annual budget. With the incredible growth in the program over the past 2 years, program evaluation at this time is a part of quality improvement.

The program evaluation will be based on guidelines from the Kellogg Foundation and the CDC.(U.S. Department of Health and Human Services. Centers for Disease Control and Prevention Office of the Director Office of Strategy and Innovation, 2005; van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004) The Kellogg Foundation's work on logic models provides a framework for setting up the evaluation team and for creating a strategy for evaluation. The TALC evaluation is going to be an outcomes evaluation, designed to understand the short and long term effects of program participation.(van Dyck, et al., 2004) Relevant inputs will also be examined but the main focus of this evaluation is on the outcomes.

In designing the program evaluation, the first step is to define the evaluator.(Issel, 2009) There are advantages to having an external evaluator, however, I plan on conducting the evaluation and will be an internal evaluator. I am clearly an internal evaluator, asI both founded the program and was the program director for 4 years. While I stepped down as program director in July 2009, I continue to advise the program staff. In some ways it would be useful to have an external evaluator who could examine the program in a less biased manner and objectively

develop a program plan to answer specific questions.(Issel, 2009) However, as an internal

evaluator, I have the advantages of knowing the stakeholders well and having spent years

developing the program and speaking with stakeholders regarding their priorities.

A strong evaluation is often one that is collaborative.(Issel, 2009) The most important

quality for an evaluator of TALC is the ability to speak with all participants, ranging from

thirteen year old children to hospital administrators. I think that having the support of an external

evaluator as a consultant would be useful. In some ways working on this evaluation plan as part

of a class at the UNC School of Public Health is a way to have external feedback on the TALC

program evaluation.

TALC has stakeholders in three broad categories: Participants, Staff, and Funders. The

CDC program evaluation guide describes the importance of engaging all stakeholders in order to

increase the credibility of the evaluation and provide a framework for the results of the

evaluation to be useful to the program.(U.S. Department of Health and Human Services. Centers for Disease

Control and Prevention Office of the Director Office of Strategy and Innovation, 2005) Each group has

different concerns. Participants include teens, parents, and college mentors are more concerned

with the context of the program and how it fits into their lives, ranging from the location of the

program activities to the way the program is integrated with other services. In addition, this

group is concerned about short and long term outcomes, as the main reason that they participate

is that they are hoping to benefit from connections to the group. TALC program staff include the

pediatric residents and other staff who run the program. This group is likely most concerned with

implementation outcomes, such as the number of participants, retention, and volunteer

participation. The financial support for TALC has come from several foundations, the Rhode

Island Department of Health and Hasbro Children's Hospital. The short and long term outcomes

are of most interest to these stakeholders both in terms of the medical and transition outcomes of young adult participants and in terms of the resident and community education regarding young adults with chronic illness.

TALC has a community advisory board that has representatives from these groups of stakeholders and so working with this board on the evaluation plan is one way to seek stakeholder input. In addition, meetings with stakeholders will be held. The competing interests of stakeholders is one potential challenge to this evaluation, as participants want the program to provide high quality programming for them, which may be counter to funders desire to fund a program that serves large numbers of participants. A more significant challenge is related to the fact that pre-participation data has already been collected in the Fall for the 2009-2010 program and so the post-program data will be collected in May, but the data being collected has not been informed by this program evaluation process. Finally, the program is relatively small and without a comparison group, so there will be challenges in analysis and interpretation of the data.

Evaluation Design

The program evaluation for TALC is based on the CDC's guide to program evaluation titled, "Introduction to Program Evaluation for Public Health Programs."(U.S. Department of Health and Human Services. Centers for Disease Control and Prevention Office of the Director Office of Strategy and Innovation, 2005) Specifically this evaluation will focus on process and short-term effectiveness measures of the TALC program. The evaluation will also examine the program in terms of its effects on individuals and its effect on Hasbro Children's Hospital in the long term. This evaluation will utilize pre-test/post-test design.(Issel, 2009)

This TALC evaluation will require the examination of participants in the program as well as patients who were referred but who did not participate, to fully understand the implementation

of the program. Examining records will provide details regarding who participated and the number of meetings attended, but it is important to also gather qualitative data from the non-participants in order to understand the barriers to the program and improve implementation.

For participants a single group outcome evaluation will be conducted using measures that were collected before participation and at the end of one year of participation. Data to be collected include measures of loneliness, isolation, attitude towards illness, and readiness to transition to adult medical care. There is not a control group and so this data will only indicate the degree to which an individual patient has changed over time.(Issel, 2009) Parents will also be evaluated to see if there has been a change in their own loneliness and their attitude towards their child's illness. Participation in TALC would be only one of many factors that could be related to any observed changes. Still, such data is useful to examine the potential effect of the program on important markers of adaptation for young adults with chronic illness.

In addition to examining the short-term process and effectiveness of TALC, it is important to examine long term outcomes such as educational and vocational success in adulthood, as well as transition to adult medical care. A survey of TALC participants who completed the program, TALC graduates, will be conducted to assess the longer term effects of participation in the program. The long term impact of the program also will be evaluated by examining the readiness to transition to adult medical care of adolescents cared for by pediatric sub-specialists at Hasbro Children's Hospital in 3 years.

TALC also has a goal related to educating medical students and residents regarding the experience of childhood chronic illness. For this reason, a similar evaluation of short and long term effectiveness will be conducted. This evaluation will follow the Kirkpatrick Model, focusing on the attitudes and behaviors of medical trainees who participate in the

program.(Kirkpatrick & Kayser Kirkpatrick, 2009) The evaluation will first focus on Level 2 from the Kirkpatrick model, particularly the attitudes towards chronic illness of medical students after participation in the program. Second, the evaluation will examine Level 3, by examining the behavior of medical student and resident participants after participation. This will be evaluated by surveying this group of participants after they have left Hasbro Children's Hospital and moved on to the next step in their career. This survey will assess the degree to which these participants are working with children with chronic illness and their attitude towards children with chronic illness and whether or not they have started similar programs at their new home medical centers. We will also examine the proportion of interns who participate in TALC training session to see the degree to which TALC programming is reaching medical trainees beyond those who participate in a long-term way.

This TALC program evaluation will assess the program implementation and effectiveness over the short and long term using qualitative evaluation of participants and non-participants, surveys of teens, parents, and graduates, and surveys of medical students and resident participants and graduates. The goal will be to produce an evaluation report that will be useful to stakeholders and can lead to program improvement.(van Dyck, et al., 2004)

Evaluation Methods

Both qualitative and quantitative program evaluation methods will be employed in the evaluation of the TALC program. The main sources of data will be program record review, qualitative interviews with participants and non-participants, surveys of participants, and surveys of program graduates. The diversity of data collected will describe both the implementation and effect of the program.

Program records will be reviewed in order to establish the proportion of referred patients who participated and how many meetings they attended. In addition, the records will identify important data such as age, referral source, disease, and source of medical care, all of which will be part of assessing the process by which patients get referred to TALC and ultimately become participants in the program. This review will also identify the non-participants who will be contacted regarding barriers to their participation and reasons behind choosing not to participate.

At the beginning of the program most participants agree to participate in a TALC IRB-approved research protocol and complete several surveys, including the Child Attitude Towards Illness Survey (CATIS), UCLA Loneliness survey, and the JAX Hats transition readiness survey.(Austin & Huberty, 1993; Russell, 1996; Sawicki, et al., 2009) This same set of questionnaires will be administered after one year of participation in TALC. Parents also complete two questionnaires, the UCLA Loneliness survey and the Parent Experience of Child Illness survey at the beginning and end of the program.(Bonner, et al., 2006) These surveys constitute the primary pre and post test assessment. All participants also complete a program satisfaction survey at the end of year.

A TALC graduate survey is planned for the summer of 2010 which will be delivered using an online survey platform to all TALC graduates from 2006 through 2010 and will include questions regarding their current educational and vocational status, and about their current health care situation (whether or not they see pediatric or adult doctors). A similar graduate survey will be conducted with the medical student and resident graduates of the TALC program aimed at assessing the degree to which they are currently working with children with chronic illness and their attitude towards childhood chronic illness.

The impact of TALC on Hasbro Children's Hospital will be evaluated in 2 to 3 years through a survey of adolescents seen by pediatric sub-specialists. This survey will examine the transition readiness of pediatric patients with chronic illness. A long term objective of TALC is to improve the hospital wide transition planning process and such a survey would provide evidence that TALC is a part of improving the transition readiness of adolescents with chronic illness at Hasbro Children's Hospital.

Dissemination plan

Following the evaluation of the TALC program dissemination activities will be conducted at the local and national level. First the results of the evaluation will be shared with the TALC program coordinator and TALC community advisory board, so that they can use the information to improve the program. Second there is a plan to share the results of the evaluation with a diverse group of stakeholders including TALC participants, parents, college administrators and hospital staff. These activities share the common goals of providing stakeholders an opportunity to comment on the results and allowing them to use the information early on, prior to it being incorporated into a formal report. Third a report will be distributed to all stakeholders, including grant agencies as part of the dissemination process. Finally the results of the evaluation will be written up for submission to a peer-reviewed journal.

The primary goal of dissemination of the results of this evaluation is to improve the quality of the TALC program. Through consideration of the results of this evaluation, the program staff will be able to make changes so that TALC can better meet its patient service mission and physician training mission. The secondary goal of dissemination is to describe the TALC program so that it can be implemented in other settings. As part of the national

dissemination the results of the TALC program evaluation will be presented at the Pediatric

Academic Society national meeting and also at Pediatric Grand Rounds at Duke University

Medical Center, as well as at other medical centers that might be interested in implementation of

a program like TALC.

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<div align="center">**Discussion**</div>

As of the last evaluation in 2008, 20 teens, 17 parents, 14 Brown University student mentors, and 6 pediatric residents participated in the monthly TALC program. TALC reached many more people through its outreach programs described below. In 2005, 8 teens participated in the program and through semi-structured interviews conducted before and after their participation it was found that participation in the group decreased isolation, improved the teen's attitude towards their illness, and improved their relationship with their parents. 100% of parents and teens reported that they had benefited from the program and 66% of teens reported that their parents had benefited from the program, even if their parent had not come to the parent council. In 2006 we have had 15 teen participants (with 3 returning from the previous year) and 10 parents. The program is ongoing and the program evaluation described above is critical

The teens participating in the program have twelve different medical conditions ranging from cancer to diabetes to sickle cell disease to lower extremity cerebral palsy. In 2005 63% of the group were caucasian, 25% were African immigrants, and 12% were African American. This year, 2006, 50% are caucasian, 19% are Hispanic, 19% are from Africa, and 12% are African American. Geographic areas represented in 2005 included 37% from urban Providence or Pawtucket and 63% from suburban towns.

In addition to providing support for individual group members, TALC has been engaged in community leadership and outreach. Group members have done presentations at local schools and we have a small TALC style group that members support at a local high school. The group produced a mural in collaboration with an artist from New Urban Arts that was displayed in a Pawtucket Art Gallery and written about in the Providence Journal and that will be in a second show in May 2007. The group produced a newsletter of which 1500 copies were distributed to

patients at Hasbro Children's Hospital and at community pediatric practices. TALC has also played an active role in the education of pediatric residents at a variety of conferences and through their involvement in TALC meetings. In a survey from April 2007, 100% of pediatric residents had heard of TALC and many reported that the best way for them to learn about chronic illness was from patients like those in TALC in a non-hospital setting. The group has also presented at Pediatric Grand Rounds, Child Psychiatry Grand Rounds, and to the 2nd year medical students at Brown Medical School. Finally, the group has received a national award as an advocacy project from the American Academy of Pediatrics.

The goal for TALC going forward is to improve the lives of adolescents with chronic illness in Rhode Island and promote their successful transition to adulthood. Over the next years, if the project is successful we hope that, 1) over 100 teens with chronic physical illness will have participated in TALC programming helping to prepare them for the transition to adulthood, 2) a sustainable leadership and service corps of TALC will be thriving, 3) college age mentors from several different colleges throughout Rhode Island will be involved in TALC programming, 4) pediatric residents and pediatricians in the community will be better prepared to address the challenges posed by the transition to adulthood for adolescents with chronic illness and 5) there will be a system to support adolescents with chronic physical illness as they transition to adulthood.

TALC is an innovative program that brings together three groups that often do not communicate well, namely doctors, parents, and adolescents. The program plan and evaluation describe in this paper would allow the expansion of the program and the demonstration of the value of group mentoring for adolescents with chronic illness. TALC can serve individual adolescents, while also serving as a model for the development of programs across the country.

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Appendix A: Evaluation of Goals and Objectives

Goal 1: Increase positive outcomes for youth with chronic illness at Hasbro Children's Hospital transitioning into adulthood.

Short-term process - Objective 1: By Spring 2010, 50% of adolescent patients referred to TALC will have participated in at least one TALC program

Evaluation question	Participant	Evaluation method
How many patients participated in at least one TALC program?	Program coordinator	Record review
What are the methods used to refer patients to TALC? (physician, hospital consult, therapist, self, etc.)	Program coordinator Teen, Parent participants	Program records review Teen/Parent Survey
How many were patients referred in 2009-2010?	Program coordinator	Record review
What programs did participants participate in?	Program coordinator	Record review
What were barriers to referred patients actually following through and participating in a program?	Program coordinator Teens who did not participate in program	Record review Non-participant survey Program staff
Were changes made to address the barriers?	Program coordinator	Program staff
What facilitated patients who were referred attending a program?	Program coordinator Teen, parent participants	Record review Teen/Parent Survey

Short-term Outcome - Objective 2: By Spring 2010, there will be (1) a decrease in loneliness and isolation, and (2) an increase in transition readiness among participants in the year-long TALC program

Evaluation question	Participant	Evaluation method
		ALL ARE PRE-POST
Part (1) Loneliness/Isolation		
Was there a decrease in loneliness as measured by the UCLA loneliness scale over year?	Teen participants Mentor participants Parent participants	UCLA loneliness survey
Can participants identify a mentor, ie an important adult, other than their parents who has made a positive difference in their life?	Teen participants	Response to single item question regarding mentor (only POST)
Was there an improvement in attitude towards illness as measured by the CATIS over year?	Teen participants Mentor participants	Child Attitude Towards Illness Survey (CATIS)
Was there a change in the degree to which participants would choose to keep their illness over the year?	Teen participants Mentor participants	Response to single item question regarding keeping illness
Part (2) Transition Readiness		
Was there an improvement in transition readiness as measured by the JaxHats transition scale?	Teen participants	JaxHATS transition scale
Are participants meeting the core MCHB	Teen participants	Teen/Parent survey of

transition readiness criteria?	Parent participants	transition readiness

Long-term Outcome - Objective 3: By Spring 2010, 100% of TALC program graduates will have graduated high school, 80% of TALC program graduates will either be in post-secondary education or working full-time.

Evaluation question	Participant	Evaluation method
What percent of TALC program graduates since 2005 have graduated high school?	Program coordinator Program graduates	Record review Survey of graduates
What percent of program graduates are working part- or full-time?	Program coordinator Program graduates	Record review Survey of graduates
What percent of program graduates have attended some form of post-secondary education?	Program coordinator Program graduates	Record review Survey of graduates
What percent of program graduates are currently in post-secondary education?	Program coordinator Program graduates	Record review Survey of graduates
What types of jobs and education are program graduates participating in?	Program coordinator Program graduates	Record review Survey of graduates
What types of jobs/education are college mentors who graduated the program participating in?	Program coordinator Mentor graduates	Record review Survey of mentor graduates

Long-term Outcome - Objective 4: In 2 years, Spring 2012, 80% of TALC program graduates will have made a successful transition to an adult medical provider.

Evaluation question	Participant	Evaluation method
Do TALC graduates see at least one adult medical provider?	Program coordinator Program graduates	Record review Survey of graduates
What kind of doctor do TALC graduates see?	Program coordinator Program graduates	Record review Survey of graduates
Do TALC graduates still see any pediatric providers?	Program coordinator Program graduates	Record review Survey of graduates
What barriers are there to seeing an adult provider and how are they addressed?	Program coordinator Program graduates	Survey of graduates
For those who are seeing an adult provider, what helped them transition?	Program coordinator Program graduates	Survey of graduates

Long-term Impact - Objective 5: In 3 years, Spring 2013, 50% of adolescent patients with chronic illness cared for at Hasbro Children's Hospital will meet the MCHB core transition readiness outcomes.

Evaluation question	Participant	Evaluation method
Do patients 13 years and older at Hasbro Children's Hospital meet the MCHB core transition readiness outcomes?	Subspeciality clinics	Survey of patients in subspeciality clinics

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Goal 2: Increase Medical students' and pediatric residents' understanding of adolescents with chronic illness and career choices to work with adolescents with chronic illness.

Short-term outcome – Objective 1: By Spring 2010, 90% of medical students and residents who participated in TALC over past academic year will report a positive attitude towards caring for children with chronic illness on post-survey

Evaluation question	Participant	Evaluation method
What % of medical students and residents who participate in TALC have a positive attitude towards caring for children with chronic illness?	Medical Students Residents	Survey of Medical Students and Residents
What careers are medical students and residents who participate in TALC planning on pursuing?	Medical Students Residents	Survey of Medical Students and Residents
Do medical students and residents recommend participation in TALC to other trainees?	Medical Students Residents	Survey of Medical Students and Residents

Short-term process – Objective 2: By Spring 2010, all pediatric interns who started in 2009 at Hasbro Children's Hospital will have received training from TALC program staff regarding chronic illness in adolescence.

Evaluation question	Participant	Evaluation method
Have pediatric interns who started in 2009 participated in a TALC training?	Program coordinator	Record review
How did pediatric residents view participation in TALC training?	Pediatric residents	Survey of residents- post
What do pediatric residents report learning from participation in TALC training?	Pediatric residents	Survey of residents- post
Do pediatric residents report changing how they talk to adolescent patients about medical transition issues?	Pediatric residents	Survey of residents- post

Long-term outcome – Objective 3: By Fall 2010, 50% of physicians who participated in TALC programming over the past 5 years as medical students or residents will currently be working clinically with children with chronic illness.

Evaluation question	Participant	Evaluation method
What % of physicians are are working with children with chronic illness?	Medical Students Residents	TALC medical student and resident graduate survey
What are the jobs of medical student/residents who participated in TALC?	Medical Students Residents	TALC medical student and resident graduate survey
Do the jobs of medical student/residents who participated in TALC involve care of children with chronic illness?	Medical Students Residents	TALC medical student and resident graduate survey

Long-term sustainability outcome – Outcome 4: By Winter 2011, TALC will have a commitment from Rhode Island Hospital to provide ongoing funding and be providing services to a variety of pediatric divisions.

Evaluation question	Participant	Evaluation method
What level of funding support is Rhode Island Hospital providing to TALC?	Program coordinator Hospital administration	Program coordinator
What funding has TALC received in fiscal year 2010?	Program coordinator	Program coordinator
What programming has TALC conducted in 2010 for specific pediatric departments?	Program coordinator	Program coordinator TALC Records
How do divisional leaders view TALC program and its value?	Subspeciality Pediatricians	Survey of pediatricians at Hasbro Children's Hospital

Long-term dissemination outcome – Outcome 5: By Fall 2011, three programs based on the TALC model will be started at other medical centers by physicians who participated in TALC as medical students or residents.

Evaluation question	Participant	Evaluation method
Have physicians who participated in TALC during training established similar programs at other medical centers?	Medical student and resident graduates	Program coordinator Survey of medical student/resident graduates.
What are similarities and differences between the implementation of the program at different sites?	Program directors from sites	Program coordinator Program directors from other sites

Gary Maslow

Appendix B. TALC grant support from June 2005 through January 2010 (total $212,297)

Funding Source	Purpose	Amount	Date
The American Academy of Pediatrics CATCH grant	Start TALC council	$3,000.00	June 2005
Rhode Island Department of Health	General program costs	$10,000.00	April 2006
Rhode Island Department of Health	General program costs	$5,750.00	April 2007
Private Donations and non-grant funding	General program costs	$500.00	2007
The Arnold P. Gold Foundation	Outreach Programs	$5,500.00	July/August 2007
Neighborhood Health Plan	TALC Jr. Programming	$1,750.00	February 2008
The Northern RI Area Healthcare (AHEC)	TALC Camp 2008	$3,460.00	May 2008
The Rhode Island Foundation Strategy Grant	Program Coordinator Salary	$55,250.00	October 2008
Ocean State Charities	TALC Camp 2008	$1,700.00	December 2008
Ida Ballou Littlefield Jones	General program costs	$7,500.00	December 2008
Private Donations and non-grant funding	General program costs	$1,742.00	2008
The Rhode Island Foundation Strategy Grant	Program Coordinator Salary	$57,780.00	January 2008
The Northern RI Area Healthcare (AHEC)	TALC Camp 2009	$1,090.00	February 2009
The TJX Companies	Transition Programming	$2,500.00	March 2009
The Department of Child Psychiatry	General program costs	$1,000.00	May 2009
Brown PACC	Medical student costs	$235.00	June/December 2009
The Rhode Island AAP Golf Tournament	General program costs	$4,000.00	July 2009
The Picker Institute Challenge Grant	Program Coordinator Salary	$3,840.00	October 2009
The Picker Institute Challenge Grant	Transition Programming	$1,200.00	October 2009
The Rhode Island Foundation Strategy Grant	Program Coordinator Salary	$28,000.00	November 2009
Private Donations and non-grant funding	General program costs	$1,500.00	2009
The Department of Pediatrics Research Fund	Transition intervention	$15,000.00	January 2010

Gary Maslow

Appendix C.
Chronicling Chronic Illness
01:00 AM EDT on Tuesday, March 20, 2007
By John Castellucci

Journal Staff Writer

PAWTUCKET
People suffering from long-term sicknesses don't often make works of art depicting their condition. The trouble, pain and distress that the disease causes usually stays in the hospital, hidden from view.

On Friday, a mural displaying aspects of chronic illness went on display in an art gallery on Main Street.

The untitled artwork was produced by participants in The Adolescent Leadership Council, the program at Hasbro Children's Hospital that pairs chronically ill teenagers with mentors from Brown University, who are also chronically ill.

It is a brightly colored work that seems inappropriately festive, until you hear Dr. Gary Maslow explain that the goal of the leadership council is to enable teenagers suffering from such long-term illnesses as diabetes, lupus, cancer and sickle cell anemia to learn to live with their disease.

"A condition or illness is a part of you," Maslow said. "The degree to which you accept that and are able to work with your illness, as opposed to constantly fighting it, can really be important in learning to live your life, not the life that the illness is making you live." None of the teenagers responsible for the mural was at Friday night's opening. Undaunted, John Jacobson, the artist who supervised the mural, and Keith Souza and Lauren Holt, the gallery owners providing the display space, rescheduled.

A second opening will take place from 5 to 9 p.m. Friday at Machines with Magnets, the combination art gallery and recording studio that Souza and Holt operate at 400 Main St.

Gary Maslow

Three other artworks, created by students in the New Urban Artists program, where Jacobson is a mentor, are in the show, too.

The mural is a collage of things significant to the 15 teenagers and dozen Brown students in The Adolescent Leadership Council. Some of the things are obvious: A syringe used by diabetics to inject themselves with insulin. Bottles containing prescription drugs.

Other things in the mural are obscure, like the decrepit barn that the teenage girl suffering from Crohn's disease, a chronic inflammation of the gastrointestinal tract, included, comparing it to her bowels. Or the fanciful ménagerie that other teenagers in the program created: Lupus the Lobster; the Epileptic Elephant, Asthmatic Armadillo and the Takayasu Turtle.

"They made a whole zoo," Jacobson said, using modeling clay taken from a recreation room at the hospital. Armed with disposable cameras, the teenagers photographed the animals, and everything else that went into the mural.

Altogether, 250 photos were taken, fed into an Apple computer, and transferred from Adobe Photoshop to Adobe Illustrator, Jacobson said. The software made it possible to transform the photographs into vector-based drawings that were layered, printed using an ink-jet printer, and applied to a big mirror panels, to make up the mural, Jacobson said. "It's almost like a visual portrait of TALC," Jacobson said, using the acronym for The Adolescent Leadership Council. "All these personalities, computers, all connecting together…. This is a portrait of things that are significant to them and say a lot about TALC."

TALC was founded last year by Maslow and Dr. Wendy Froehlich, both triple board residents in pediatrics, psychiatry and child psychiatry at Hasbro; and by Kim Alexander, a photographer.

Maslow said the teenagers meet once a month, discuss issues related to their illnesses and offer feedback to the medical community.

The feedback is important, Maslow said, because doctors are trained to fix acute problems, not help the chronically ill live with their disease.

"When we do encounter human sickle cell [for example], it's usually because they're in crisis, they're in the hospital and they're really sick," Maslow said.

"They can't tell you anything about their life. All you know is that they're in a lot of pain," Maslow said. "You see them as ill, as helpless and needing medications, as all these kind of very dependent things."

TALC provides doctors with another view of the chronically ill, one that doesn't emphasize their helplessness. "You meet these kids, and they're doing this art project. They are so impressive," Maslow said. "They are so talented and they are so strong."