



Transplants for Children (TFC)

Pediatric to Adult Care Transition (PACT) Support Program

Introduction

Adolescence and emerging adulthood is challenging enough, regardless of physical health, but for those who've received a lifesaving organ transplant, this difficult period could mean a matter of life or death. The mortality rate of all 18–24-year olds is more than twice that of those aged 12–17ⁱ. Significantly, substance/alcohol use and abuse peaks, and the suicide rate is triple that of adolescents (12–17 years)ⁱⁱ.

The burden of a serious health condition creates additional difficulties. Of all the organ transplants, young adult and adolescent renal transplant recipients have the highest rates of acute and chronic rejection leading to organ lossⁱⁱⁱ. Up to a third of all adolescent transplant recipients may be non-compliant^{iv}.

Normal adolescent tendencies of questioning authority often times predisposes them to reject previously accepted medical advice and treatment. Preoccupation with body image and the adverse cosmetic effects of some immunosuppressive drugs too often collide^v. Many other factors may contribute, among them impulsivity and risk taking.

As pediatric transplant recipients reach this vulnerable age, health professionals often struggle to effectively facilitate the transition from pediatric to adult care. It is broadly acknowledged that

- (i) there is a general need to improve the transition process;
- (ii) many youth are ill-equipped to receive care in the adult system;
- (iii) adult providers may lack knowledge and skills to care for young adults with childhood-onset chronic conditions and
- (iv) Inadequate and health insurance and transition services funding negatively impact patient outcome^{vi}.

The pediatric to adult care transition encompasses provider, family and patient communication, education and action. Therapeutic alliance team members include the patient and family unit, transplant nurses, physicians, surgeons, social worker and coordinator, primary care providers and sub-specialists, allied health professionals and community resource/nonprofit organizations^{vii}.

For these reasons and to fulfill the responsibilities of our mission statement, Transplants for Children has designed and will launch its innovative PACT Support program beginning in April 2019. The goal of this critically important program is to implement proven strategies resulting in a positive quantifiable impact on medical regimen compliance and healthy patient outcomes.

Pediatric to Adult Care Transition (PACT) Program

Program Goals:

The goals of the PACT Support program are to coordinate with health care professionals, families and young people who are pre and post-transplant/chronically ill to build the key skills necessary to successfully make the transition to adult based care. While we believe the skill “toolbox” may be adjusted through the process of rigorous evaluation and program review, the initial goals are to build improved self-awareness and reflective thinking skills and to strengthen tools to improve relationships with peer groups, family members and healthcare professionals. Additionally, complex problem solving skills and a desire to be a lifelong learner are fundamental components to the program launch year design.

Program Philosophy

At all times the PACT Support program will teach, role model and incentivize *healthy diet, appropriate exercise, family and friends, service to others, positive mindset and creative expression.*

Program Design:

Through a set of strategically designed events and multi-generational mentoring, TFC will guide young people through the process of building the “toolbox” of skills needed to successfully transition to adult based care. In between events and activities, TFC will connect with young people through the messaging system and a program specific iPhone/Android compatible app currently under development. These support systems offer a means of contact and support between program events and seeks to inspire increased adherence with medical regimens and continued learning, personal growth and skill building. Readiness checklists will be developed for parents and teens to help determine readiness for transition. TFC will provide incentives for youth participation through our STARS Scholarship program. Through active participation and successful completion of the program, participants become eligible for STARS Scholarships to support their continued education beyond high school. A key element of the program will be to use the term “graduation” instead of transition to emphasize the celebration of a milestone achievement.

STARS Scholarships and College Success (Academics – Leadership – Medical Adherence):

STARS College Scholarships serve many purposes within the PACT Support program. These college grants serve as an incentives for young people to be engaged in the program, learn skills to help them organize their school work and maintain their medical adherence. Scholarship applications stress program involvement, academic organization skills, service to others and medical compliance. All PACT program participants that meet the scholarship requirements will be awarded a grant at some level. STARS students will have access to TFC Emergency Assistance Program funds to ensure at no time during their academic career will they need to choose between food, rent, school and medications.

STARS students will be automatically enrolled in the College Success program. Through this program, they will have access to the resources and the support to help them be successful and medically adherent.

STARS students will have access to:

- Emergency Assistance grants – to help with unexpected emergencies that would cause a student to go without medication or drop out of school.
- Signal Vine message – to encourage students, remind them of important due dates and to inspire adherence.
- Annual STARS Scholarship and Alumni Celebration - during National Pediatric Transplant Week to recognize scholarship awardees and celebrate college success.
- STARS alumni events and gatherings – informal visits to constantly connect STARS mentors and leaders with the next generation of students.

Peer Engagement

There is no shortage of academic research that concludes that the presence of peers makes adolescents and youth more likely to take risks and more likely to make risky decisions. Peers can have both a positive and negative impact on post-transplant medical routine adherence. One of the key goals of the PACT Support program is to engage, educate and inspire peers to be supportive of the unique needs of post-transplant young adults. Large PACT Program events are designed to be attractive to both the post-transplant young person and their peer support group.

PACT Mental Health Navigators

Chronic illnesses in young people are often accompanied by emotional, cognitive, and social changes requiring considerable coping skills. Additionally, families stressed by financial, emotional and social pressures face additional challenges that often combine to lead to adherence issues post-transplantation. For that reason, TFC will launch a new program providing access to licensed counselors and mental health support to families and youth active in the PACT Support program. To address financial issue families may face during this process, TFC's Family Emergency Assistance Program will provide vouchers for families engaged with contracted TFC mental healthcare navigators.

PACT Program Event Calendar

Q2 National Pediatric Transplant Week – Kickoff Event Featuring Chloe Temchine (April 25); propelled to fame as an award-winning singer and songwriter, Chloe Temchine performs with supplemental oxygen due to a 2013 pulmonary hypertension diagnosis. Chloe is a highly sought after speaker and performer. Her message of five key principles to maintaining health and happiness while facing a chronic illness along with her pop music following provides the perfect mix to fill the room with young people and open the doors to their participation in the PACT Support and STARS programs.

STARS Skill-Building Workshops these events focus on life-skills, organizing and prioritizing school-work and medical compliance. Workshops are led by former STARS scholarship awardees, academic and healthcare professionals

Q4 20th Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-based Care; Sponsored by Baylor College of Medicine and Texas Children’s Hospital. The Houston-based conference will be live-streamed at the Santikos Palladium in San Antonio. This symposium will bring together not only youth and young adults who have a chronic illness or disability and their parents or guardians but even more critically, physicians and health care providers of all disciplines who play an important role in the medical care regimen. TFC will sponsor and coordinate this event in October, 2019.

Q4 T-Camp a weekend “retreat” event that facilitates learning, relationship building and reflective thinking. This event brings together participants with mentors and health care professionals to tackle difficult topics such as Surviving High School, Alcohol Use and Risky Behaviors Post-Transplant, Navigating Health Insurance, Post-Transplant and in College, I’d Like to be a Mom One Day and more. This critically important event is the centerpiece of the effort to meet the program’s skill building goals.

2020 STARS Reunion and Scholarship Banquet In 2020 this event will bring all the STARS Scholarship awardees together with current STARS program participants and alumni in a ceremony celebration. This event will also present an opportunity to reengage relationships and build program leadership depth. Young people seeking STARS Scholarship will be encouraged to attend and be a part of the event as well as set personal goals for lifelong learning and skill building that will allow them to be Scholarship awardees at some point in the future.

Leaders of the PACT

In preparation for the program launch, TFC has been cultivating a group of parents and young adults experienced in the organ transplant/chronic illness pediatric to adult care transition to serve as mentors, volunteers and program champions. The “Leaders of the PACT” group will ultimately be a focal point of leadership training for STARS Scholarship Alumni providing yet another incentive for young people participating in the PACT Support program to strive to be a part of once they have made the transition and had success in the adult care environment.

Testing Impact

Written evaluations and Focus Group testing will be done to test the effectiveness of the efforts throughout the year. Findings from these evaluation tools will be made available to funding sources as well as health care professionals in an effort to improve and adjust program design to have the greatest positive impact on patient compliance and outcomes.

Funding

TFC believes this program will become a national model for how community based nonprofits partner with local transplant/chronic illness clinics to improve outcomes during the difficult and complex pediatric to adult care transition. Additionally, we believe it will require a 24 month window of evaluation to fully prove its impact. For that reason, TFC has chosen a select group of philanthropic leaders in our community to request seed funding necessary to launch this important program in 2019. Once proven as successful we believe a broad pool of funding to support the program long term will become amiable from cultivated sources.

Conclusion

Clearly, 2019 will be a transformative year in the 30 year history of Transplants for Children. At the center of that organizational transformation will be this one-of-a-kind transition support program designed to uplift, inspire and educate post-transplant and/or chronically ill young people during what is often the most difficult part of their healthcare journey. Investment in this program is an investment in the success of the transplant and healthcare process as well as an investment in the growth and personal development of children, their quality of life and success as individuals in the adult world that is often challenging enough without the weight and stress of lifelong healthcare challenges.

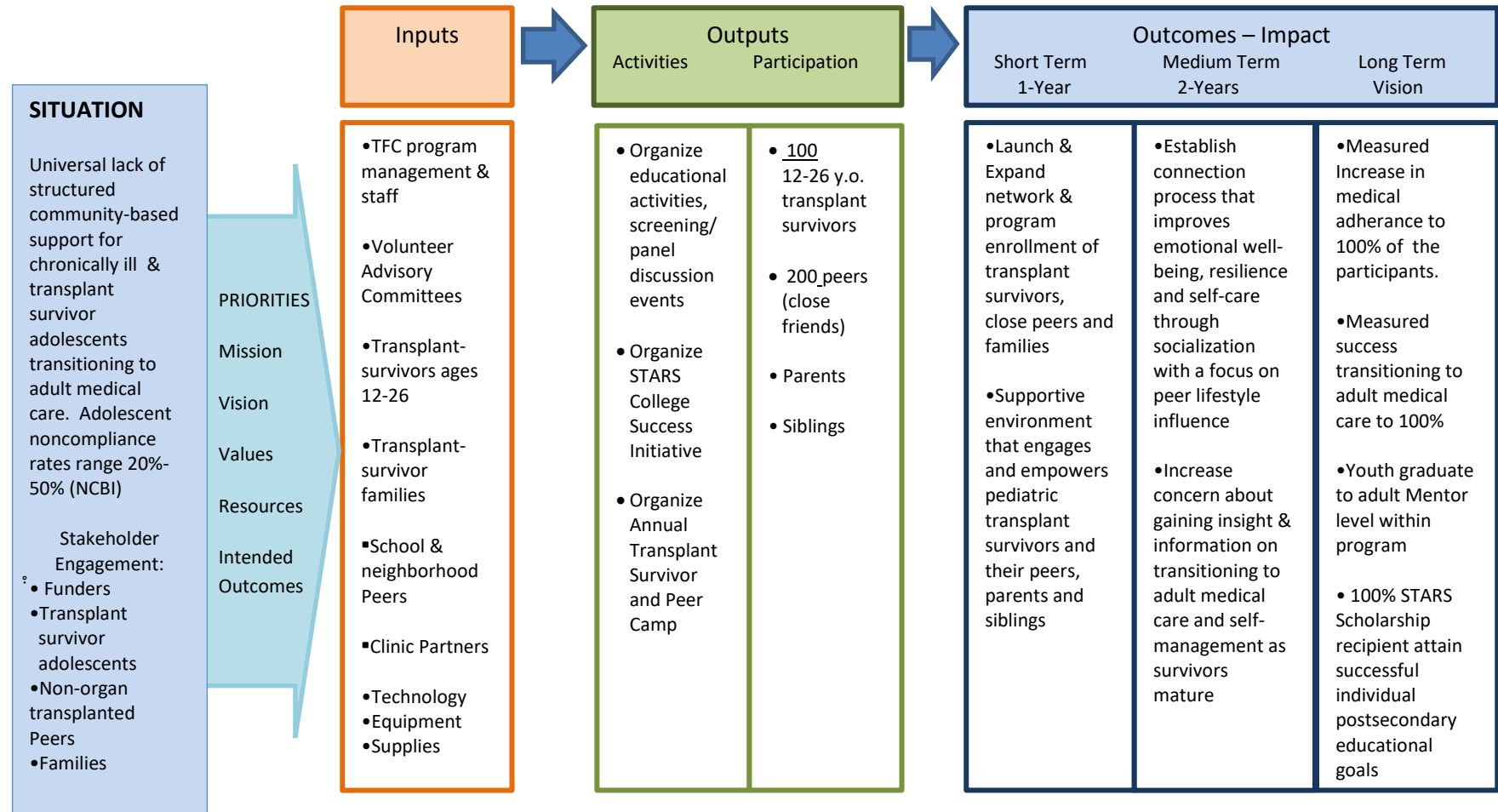
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Pediatric to Adult Care Transition Program – PACT 2019

Planning – Implementation – Evaluation

Program Action – Theory of Change Logic Model



Evaluation

Collect Data - Analyze and Interpret - Report

The goal of the evaluation is to help improve the efficiency and effectiveness of PACT's activities design and implementation, and steadily improve outcomes and participation.

Skills to be measured: 1) Academic Organization-STARs 2) Medical Adherence 3) Leadership skills

These skills are designed to Support building self-management skills, the ability to manage their daily regimen and develop responsibility for their health management in an adult care setting.

Notes:

The disparity between surviving pediatric transplant surgery and later mortality due to non-compliance reveals three pivotal factors:

- Need for assessment of transition readiness to adult medical care
 - providers often treat pediatric post-transplant transition to adult medical care as a transactional event and not as a process that takes into account the developmental and physical needs of the adolescent, his/her psychosocial needs, and those of the family. Transition readiness is unique to the individual, and not age-driven.
- Changes in the roles between providers, parents and transplant recipients post-transplant and pediatric to adult medical care
- The absence of “other than the clinical team” support that fosters independent living and self-care management. Opportunity for an effective community-based support system in tandem with the clinical team to further increase a positive and significant impact on successful transition to adult medical care.
- Augment the programmatic psychosocial supports with effective technology; mobile apps and programs which “involves one or more of the following activities: education, mentorship, peer support, medicine compliance, and resiliency (self-identity). Each has an embedded entertainment factor that continually engages adolescent participation via new challenges or rewards, particularly those designed as e-health games. Qualitative and quantitative outcome studies have supported anecdotal reports of effectiveness.”

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5447825/>