AIDS Committee of Durham Region's

HIV+ Youth Peer Engagement Program

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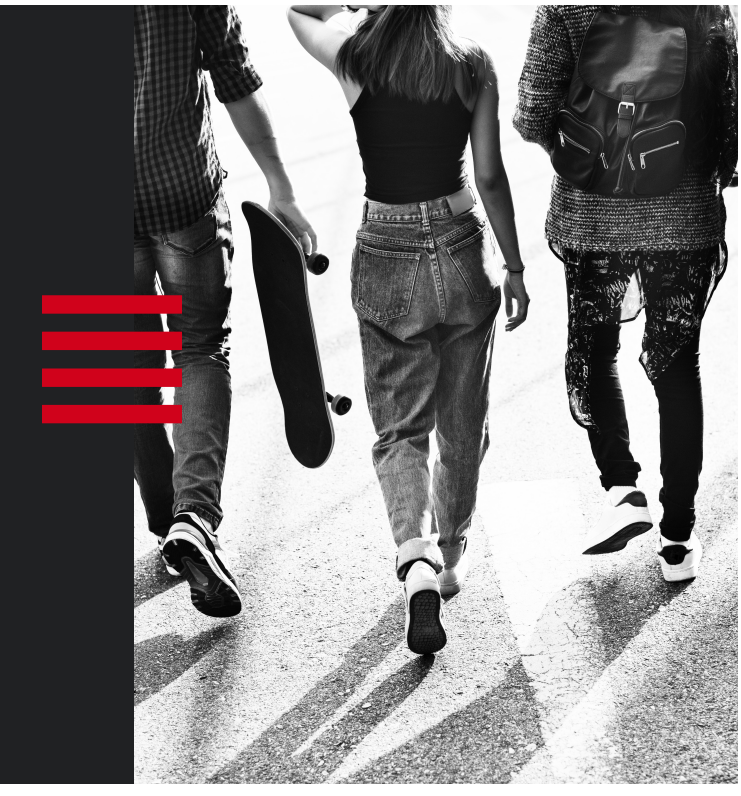

BACKGROUND

One population in particular is often underrepresented in conversation about HIV - namely those children born to a HIV positive parents who were themselves infected with the virus.

Many of these children, born at the height of the epidemic were not expected to live to adulthood, and indeed, many lost one or more of their parents to AIDS related illnesses during the late 1980s and 1990s. However, with the successful roll-out of ART (anti-retroviral treatment) in pediatric populations, more children are surviving into adolescence and are emerging into adulthood.

With this, comes a new focus on the process of transition, which poses particular challenges for young people living with HIV as they age.

WHAT IS TRANSITION?

The concept of transition, within the field of chronic illness, is a process that relates specifically to the "purposeful, planned mocement of adolescents with chronic medical conditions from child-centered, pediatric care to adult-oriented care.

Transitioning from pediatric or adolescent HIV care to adult HIV care involves many challenges. Many children and youth growing up with HIV are used to family-centered, child-friendly, multidisciplinary primary care teams that might involve pediatricians, pediatric nurse practitioners, nurses, social work case managers, child life therapists, psychologists, nutritionists, chaplains, and other dedicated caregivers. Long-term bonds often exist between these care providers, patients, and families.

In contrast, the adult care model is more fragmented – with medical care, mental health care, and social services being offered separately – and requires more independent navigation of the healthcare system. Youth in transition must also confront the possibility of discrimination and stigma when disclosing their HIV status to new providers and other patients.

Youth often receive little or no preparation for this transition, which occurs at time in their life where they are already undergoing tremendous changes such as beginning post-secondary education, moving out their own, and/or entering the workforce.

PROBLEM STATEMENT

It is clear that the current system does not meet the needs of young people living with HIV. Research has found that many young people living with HIV feel that 18 is too young to transfer to adult care. Moreover, this transition occurs at a crucial developmental stage, when inadequate care and support may negatively affect health outcomes:

- Youth who have acquired HIV perinatally may be especially vulnerable, as they often have more advanced disease than patients that have acquired the illness later in life. For example, they are more likely to be treatment resistant and require more complex medication regiments.
- The youth cohort also have more complex mental and emotional needs such as dealing with the loss of parents who may have died from AIDS related complications, social isolation within their peer groups, social rejection following disclosure, loneliness, hopelessness, and treatment fatigue and fears concerning their long-term health.
- More generally, youth facing transition are often already undergoing enormous change in their lives such as graduating from high school and moving on to post-secondary education, moving out on their own, becoming sexually active, and entering the workforce. Handling these other life events may cause young people de-prioritize their health.

All of these factors have an impact on the health of young HIV-positive people. Until recently, little attention was paid to process of transition, and youth were often given little or no preparation for this shift. In the absence of programming designed to assist with the transition process, youth face serious negative health outcomes: adolescents are the only population with increasing rates of mortality among HIV positive people. Transitioned teens are more likely to stop taking their medications, and thus develop resistance to medications, they more likely to miss or stop attending doctor's appointments, and are more likely to become seriously ill, or die, than other group of people living with HIV.

WHAT CAN WE DO?

There are a number of factors that can facilitate a successful transition to adult HIV care. These factors include:

- *Adequate preparation*: Transition discussions should begin early, and attention should be paid to skills-building training so that young people can acquire the independence, organizational, and communication skills they will need in adult care. Youth living with HIV also need to develop the skills to manage the transition – including making appointments, communicating directly with clinicians, and filling medication prescription.

- *Communication across the HIV care systems*: It is very important for pediatric and adult clinicians to communicate well when exchanging medical and psychosocial information. Some youth living with HIV may have concerns about disclosing information again to a new, so collaboration between clinicians is essential. Further, discussion between the systems allows youth focused care clinics to communicate the specific needs of youth, and allows adult care clinics to adopt some of these practices.

- *Social and psychological support*: Youth living with HIV could benefit from meeting peers who are experiencing the same challenges as them. This helps to reduce social isolation that contributes to youth falling out of care. Additionally, building networks between youth who have already transitioned and are doing well in care, and those who are struggling, allows peers to share techniques, and best practices that can make the process of transitioning easier. Research has show that transitioning teens do better in care when they tour adult clinics, attend appointments and even take their medications at the same time as a peer. Building on the strengths of other youth who already know the system, helps to de-mystify the process for transiting youth, and keeps them accountable to another person.

ENTER THE HYPE PROGRAM

The HYPE program was created to address the negative health outcomes facing young HIV positive people by:

- Building capacity among young people living with HIV in order to better prepare them for the adult care system

- Reducing Social Isolation by building a network of peers to provide support, and share tools for successful navigation of the system, and by creating opportunities for youth with similar experiences to have fun together

- Facilitating communication and cooperation between the adult and pediatric care systems

CAPACITY BUILDING

Create opportunities for youth to participate in educational workshops on: importance of remaining in care and treatment, strategies for adhering to medication and attending care appointment, navigating the disclosure of their status to partners, friends and loved ones, transmission prevention aimed at keep their negative partners healthy, self care, and ways to decrease isolation. This will include ongoing assessments on changes in knowledge level, and behaviour.

REDUCING SOCIAL ISOLATION

Establish a network of peer leaders across Ontario where long term survivors who are doing well in care can mentor the newly infected or younger positive youth. These leaders will:

- Lead educational and social “Pozzy Meet-Ups” in their communities.
- The Peer Leaders will also create and manage online tools to facilitate ongoing communication and sharing of resources and best practices.
- Coordinate a province wide meet-up, where youth can interact with their peers from across Ontario.
- Create a matching program that finds youth who are doing well in care, and matches them with those who are struggling or new to transition. The goal of the matching program is to link youth a person within their community who can provide support which may include attending clinic visits with them, taking medication at the same time (in-person, or over video chat), or simply answer questions that may have.

FACILITATING COOPERATION

Working closely with pediatric clinics, the AIDS Service Organizations that support positive youth and the youth who are navigating the transition process, a document was created to inform adult clinics about the needs youth as they transition. The Transition Accord is a guide developed in the spring of 2016 that aims to ensure a successful transition from pediatric care to adult care. The HYPE Program will deliver presentations to adult clinic and service provider staff to inform issues unique to positive youth, and aims to get adult care clinics to change practices by adopting and implementing the recommendations in the Transition Accord. The key goal of this strategy is to open up communication between pediatric and adult care providers, and to share best practices across these systems.

DELIVERABLE 1

Recruit 5 peer leaders across Ontario to provide support and deliver education workshops in their communities.

Youth Peer Leaders will each deliver 5 educational workshops to HIV positive youth with a focus on importance of remaining in care and treatment, strategies for adhering to medication and attending care appointment, navigating the disclosure of their status to partners, friends and loved ones, transmission prevention aimed at keep their negative partners healthy, self care, and ways to decrease isolation. This will include ongoing assessments on changes in knowledge level, and behaviour.

DELIVERABLE 2

Build The Pozzy Information & Interaction Group - a peer led network of positive youth who provide social and emotional support to each other to decrease social isolation associated with living with HIV/AIDS.

The Pozzy will maintain a facebook page, and website equipped with a message board to allow for communication, and to share resources and best practices among group members.

DELIVERABLE 3

Coordinate Annual Poz Youth Symposium 30 positive youth for a three day symposium which will include two days for youth only focused on skills building workshops, and creating policy and best practice documents affecting poitive youth in their care. Share best practice documents with service providers and clinicians (20 will be invited to attend symposium on Day 3).

DELIVERABLE 4

Facilitate 12 presentations to clinic and service provider staff about issues unique to positive youth. Share and get clinics to adopt The Transition Accord (The Transition Accord is a document created by Poz Youth informing Pediatric and Adult clinics and ASO's what a good transition to adult care should look like).

DELIVERABLE 4

Working with youth who are at a high-risk of being lost to care, identify and match them with youth who have successfully transitioned in their communities.

Facilitate 50 matches.

LET'S GET IN TOUCH

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