

*Improving Engagement and
Retention in Care*

**Engagement of Youth Living
With HIV - The YOUTH ACCORD**

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Disclosures

Presenter: Jason Brophy

- Relationships with commercial interests
None to disclose

Presenter: Adrian Betts

- Relationships with commercial interests
None to disclose

Overview

- Youth Living with HIV and Transition to Adult Care
 - JB
- Existing Supports in Ontario
- The Youth Transition Accord
 - AB

AIDS 2016 - Durban



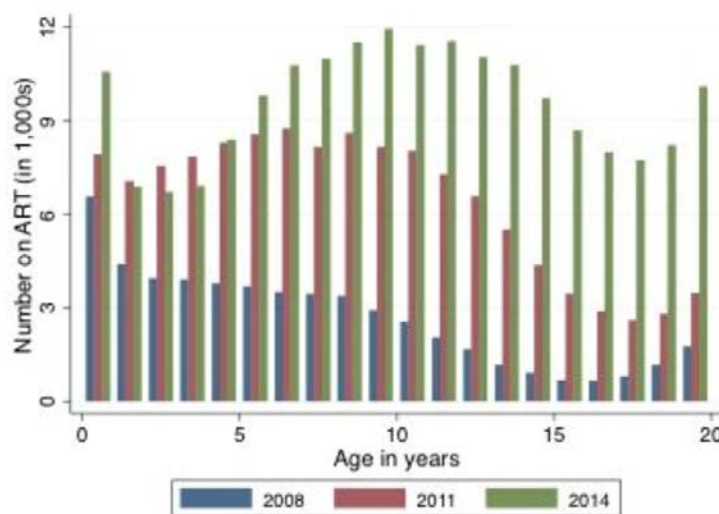
AIDS 2016
 DURBAN, SOUTH AFRICA
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TITLE

The youth treatment bulge in South Africa: increasing numbers, inferior outcomes among adolescents on ART

	0-1 years	1-4 years	5-9 years	10-14 years	15-19 Years
2004-2007	11,593 (15%)	27,157 (35%)	24,921 (32%)	8,854 (11%)	5,904 (8%)
2008-2011	29,983 (9%)	88,391 (26%)	110,737 (33%)	72,774 (22%)	34,981 (10%)
2012-2014	31,299 (6%)	89,530 (17%)	155,163 (30%)	141,945 (28%)	96,042 (19%)

[Table1: Distribution of viral load test results by age category and calendar year]



[Figure 1: Distribution of individual viral load test results by age and period]

Maskew, AIDS 2016

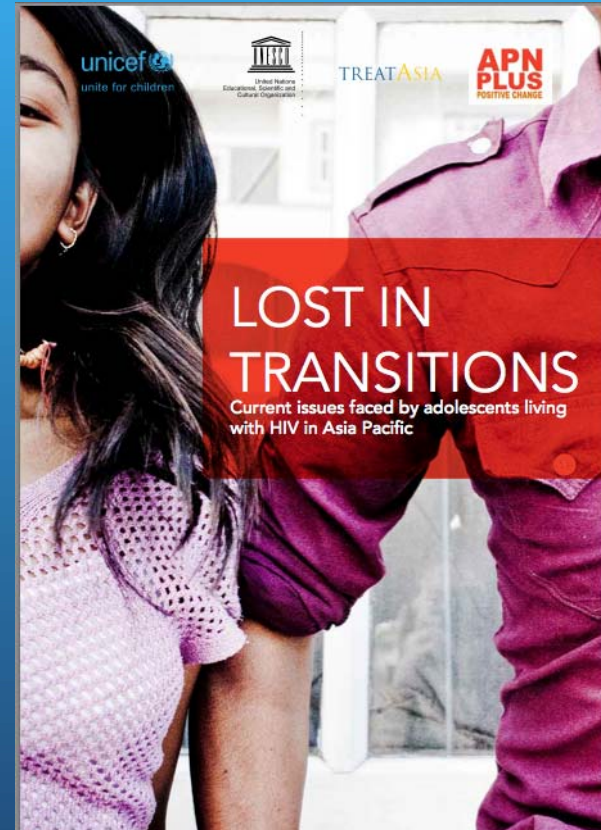
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- With survival of children into adulthood comes a new focus on the process of transition to adult care



POSITION STATEMENT

Transition to adult care for youth with special health care needs

Posted: Nov 1 2007 Reaffirmed: Jan 30 2012



TRANSITION - WHAT IS IT?

- The purposeful, **planned** movement of adolescents with chronic medical conditions from child-centred to adult-oriented health care

**Pediatric
Care**



**Adult
Care**

Transition is not an **EVENT** that occurs at age 18 years but rather a **PROCESS** that takes place over many years

DIFFERENCES BETWEEN PEDIATRIC AND ADULT CARE

- **Pediatric care**

- Family focused
- Parental involvement in decision-making
- Care provided by a multidisciplinary team
- Developmentally appropriate care
- Legal & ethical obligation of care

- **Adult care**

- Patient focused
- Requires patient autonomy
- Same size team, but far more patients
- Support is often a different type and level (eg. crisis oriented)

WHAT ARE THE OUTCOMES FOR TRANSITIONED HIV+ YOUTH?

- Transitioned youth have increased rates of
 - ARV discontinuation & resistance
 - Loss to follow up
 - Death

The Young and the Resistant: HIV-Infected Adolescents at the Time of Transfer to Adult Care

**At the time of transition,
2/3 were failing treatment and
1/3 had triple class resistance virus
(Montreal cohort)**

WHAT ARE THE OUTCOMES FOR TRANSITIONED HIV+ YOUTH?

*Data from ICES on
pre- and post-transition
health care utilization in
Ontario... coming soon*

Health outcomes and the transition experience of HIV-infected adolescents after transfer to adult care in Québec, Canada

Fatima Kakkar^{1,2,4*}, Dimitri Van der Linden³, Silvie Valois⁴, Francois Maurice⁴, Marion Onnorouille⁴,
Normand Lapointe^{2,4}, Hugo Soudeyns^{4,5,6} and Valerie Lamarre^{1,2,4}

45 youth transitioned 1999-2012
4 (9%) died, 8 (18%) LTFU, 8 refused to be interviewed
Of 25 interviewed – 76% engaged in care,
>50% had difficulties with adherence
(Montreal cohort)

WHAT ARE THE OUTCOMES FOR TRANSITIONED HIV+ YOUTH?

- Transitioned youth have increased rates of
 - ARV discontinuation & resistance
 - Loss to follow up
 - Death

Aging and Loss to Follow-up Among Youth Living With Human Immunodeficiency Virus in the HIV Research Network

**20% loss to follow-up
after transition to adult care
(US cohort)**

WHAT ARE THE OUTCOMES FOR TRANSITIONED HIV+ YOUTH?

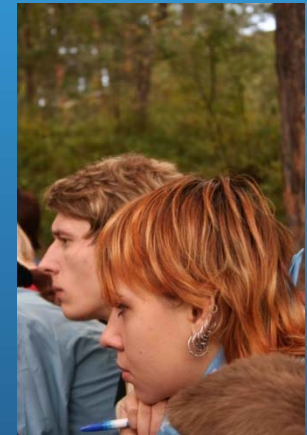
- Transitioned youth have increased rates of
 - ARV discontinuation & resistance
 - Loss to follow up
 - Death

Mortality in perinatally HIV-infected young people in England following transition to adult care: an HIV Young Persons Network (HYPNet) audit

5-fold higher mortality in PHIV >20y in adult care compared to 13-15 yo in pediatric care (UK cohort)

It's not their fault - they're just not ready yet!!

- Adolescence is a time of ongoing development of the brain



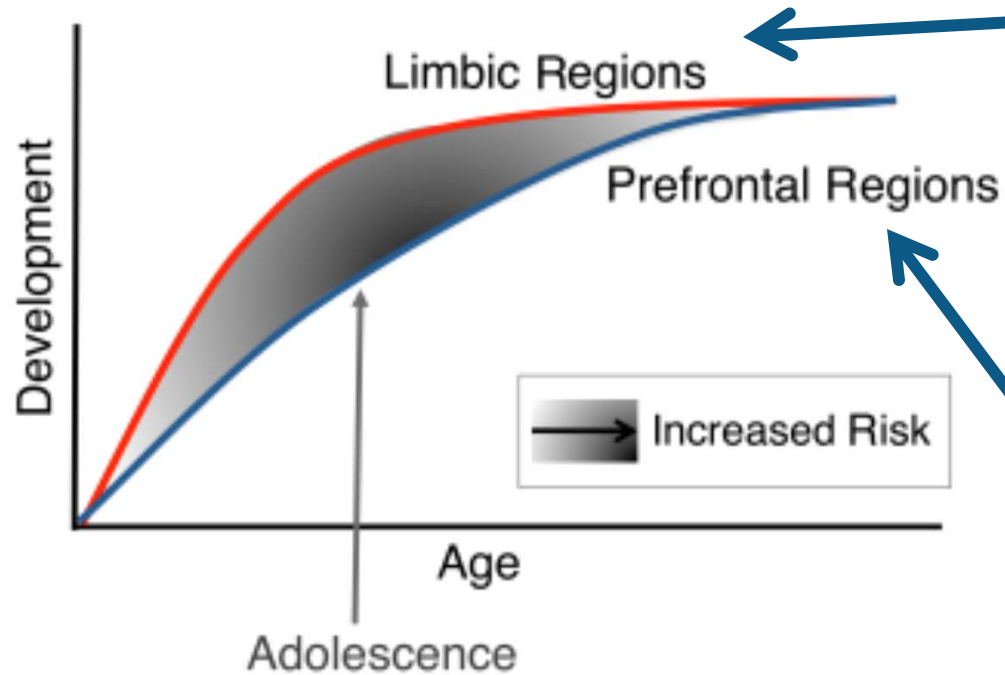
Pre-adolescence
10-13 years

Middle Adolescence
14-16 years

Late Adolescence
17-20 years

Emerging Adulthood
21-25 years

Cognitive Development in Teens... Blame it on the brain!



Limbic System:
Social-Emotional -
Matures earlier - leads
to risk-taking, impulsivity,
sensation-seeking
*Important for learning and
formation of identity*

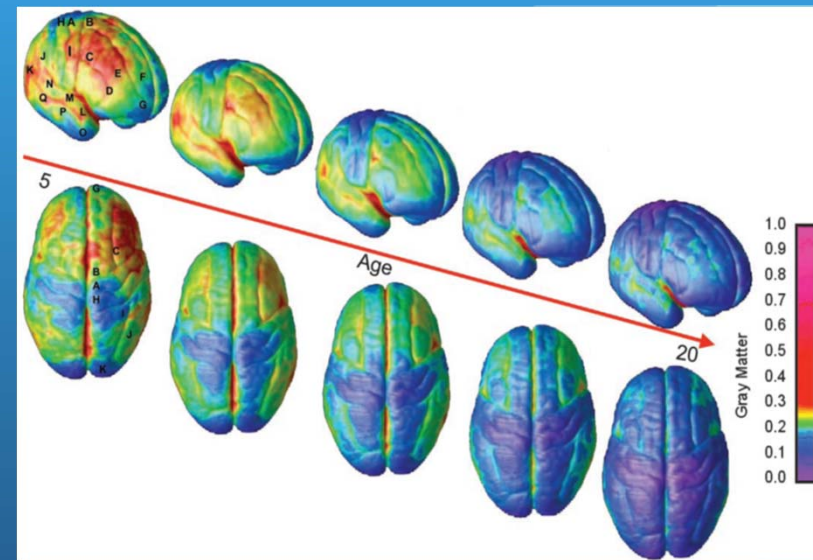
Prefrontal Cortex:
Cognitive control -
decision-making,
rational thought,
organization
Matures later

FIGURE 1 Neurobiological model depicting later development of top-down prefrontal regions relative to subcortical regions involved in desire and fear. This imbalance in development of these systems is proposed to be at the core of risky choice behavior in adolescents in contrast to the popular view of adolescent behavior being due to the protracted development of the prefrontal cortex alone (From Somerville, Jones, & Casey, 2010).

Cognitive Development in Teens

○ Frontal Lobe

- Last to fully develop – sometimes 3rd decade of life
- Give rise to “executive functions”
 - Organization
 - Planning
 - Self-regulation
 - Selective attention
 - Inhibition



The Teen Brain and Implications for Clinical Practice

- Adolescent with a chronic condition is expected to take on tasks of self management
 - Plan ahead for appointments
 - Arranging to be away from school or work
 - Focusing on dialogue in clinic
 - Management of medications and symptoms
 - Problem solving

Difficult to do while executive functioning is developing!

→ means that adolescence is likely a bad time for transition to adult care

Existing Supports & The YOUTH TRANSITION ACCORD

ADRIAN BETTS

AIDS COMMITTEE OF DURHAM

Existing Resources Province Wide

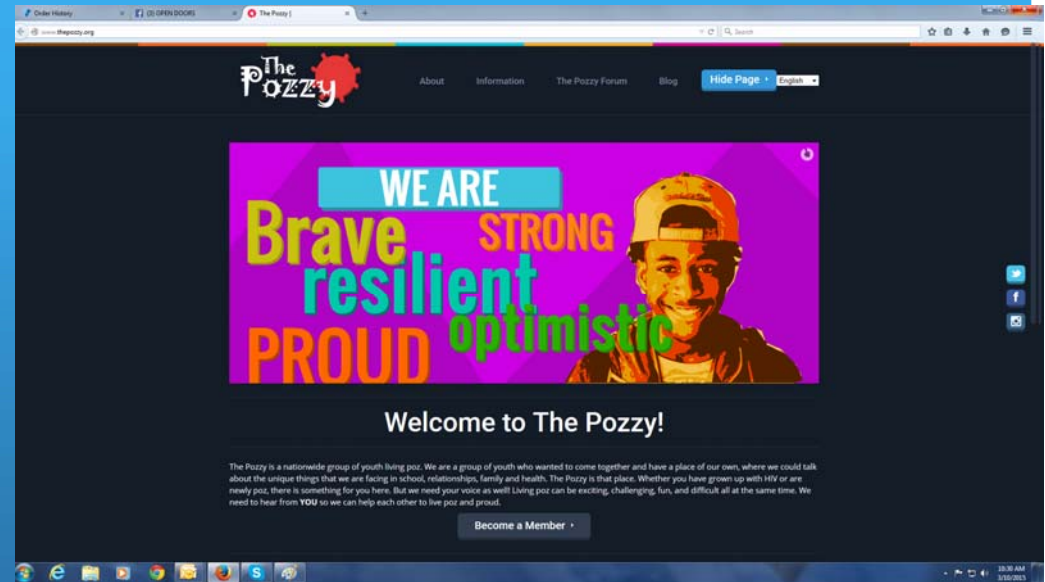
- OASPY - Ontario Agencies Serving Positive Youth (OASPY)
- Individual Counseling, referrals and advocacy through clinic and ASO Support Services
- Transitioning programs at some clinics
- Summer/Youth Camps through some ASOs
- Youth Specific Support Groups
- Online Resources
- Leadership opportunities
- Youth Forums for service providers & youth
- Social Events
- Life skills training
- Peer-to-peer programs

... ACDR PHAC application



National Resources & Initiatives

- thePozy.org - sponsored by ACDR; discussion with CAS and PHAC about making it a national resource



- CIHR-funded Research Planning Meeting held in June 2015 - Medical Needs of Positive Youth, spearheaded by HIV+ youth & clinician-researchers; CIHR grant application submitted for "Adult Camp" intervention
- CAS organized a National HIV+ youth forum June 2015; YouthCo organized another forum July 2016

Transition Accord: Think Tank

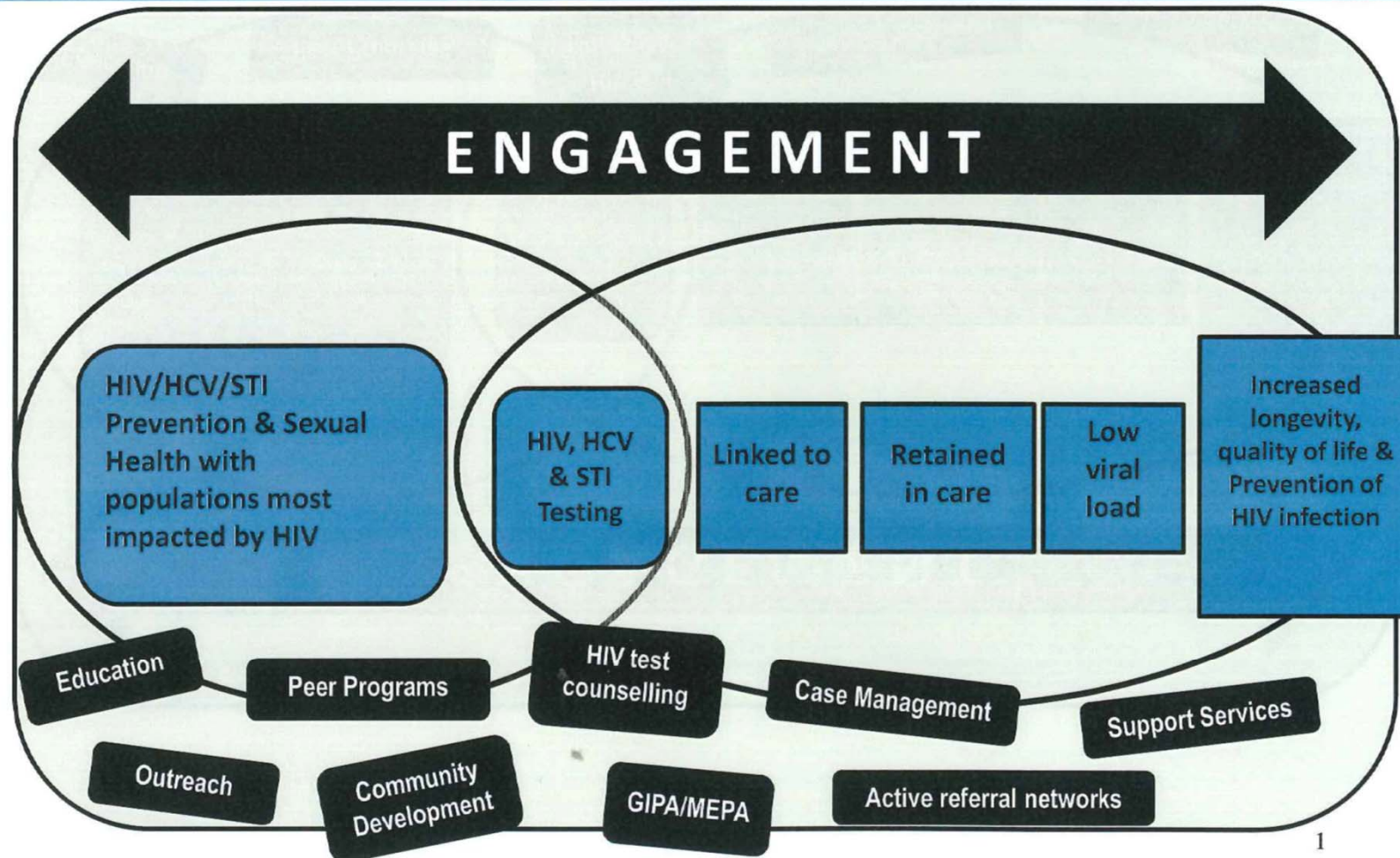


AIDS Strategy - Prevention Cascade

- The Transition Accord was created as a **response to the AIDS Strategy**, more specifically, the **HIV Prevention/Treatment Cascade** which is the model that outlines the sequential steps of HIV medical care from the moment a person is diagnosed with HIV to when they achieve the goal of viral suppression. The Cascade also seeks to keep people living with HIV engaged in care.



Strategic Approach #2: Develop an Ontario model; a... 'Prevention, Engagement and Care Cascade'



In the beginning...



AIDS Committee Of Durham Region + OHTN invited 12 youth living with HIV from across Ontario to participate in the creation of the “**Transition Accord**”. This is a document to **inform pediatric and adult clinics** what the ***ideal transition experience*** for young positive youth moving from pediatric care to adult care should be.





The Process

- Dionne Falconer (Ontario Organizational Development Program) opened by setting the context of the two-day Think Tank.
- This created a **safe place** for youth to share their experiences living with HIV and their experiences in pediatric and adult care.
- Their stories provided insight into their life and how much they all had in common.
- Using flip chart paper, the youth had an opportunity to write down **what they appreciated** and **what needs improvement** in both stages of care, including their expectations for themselves as autonomous youth

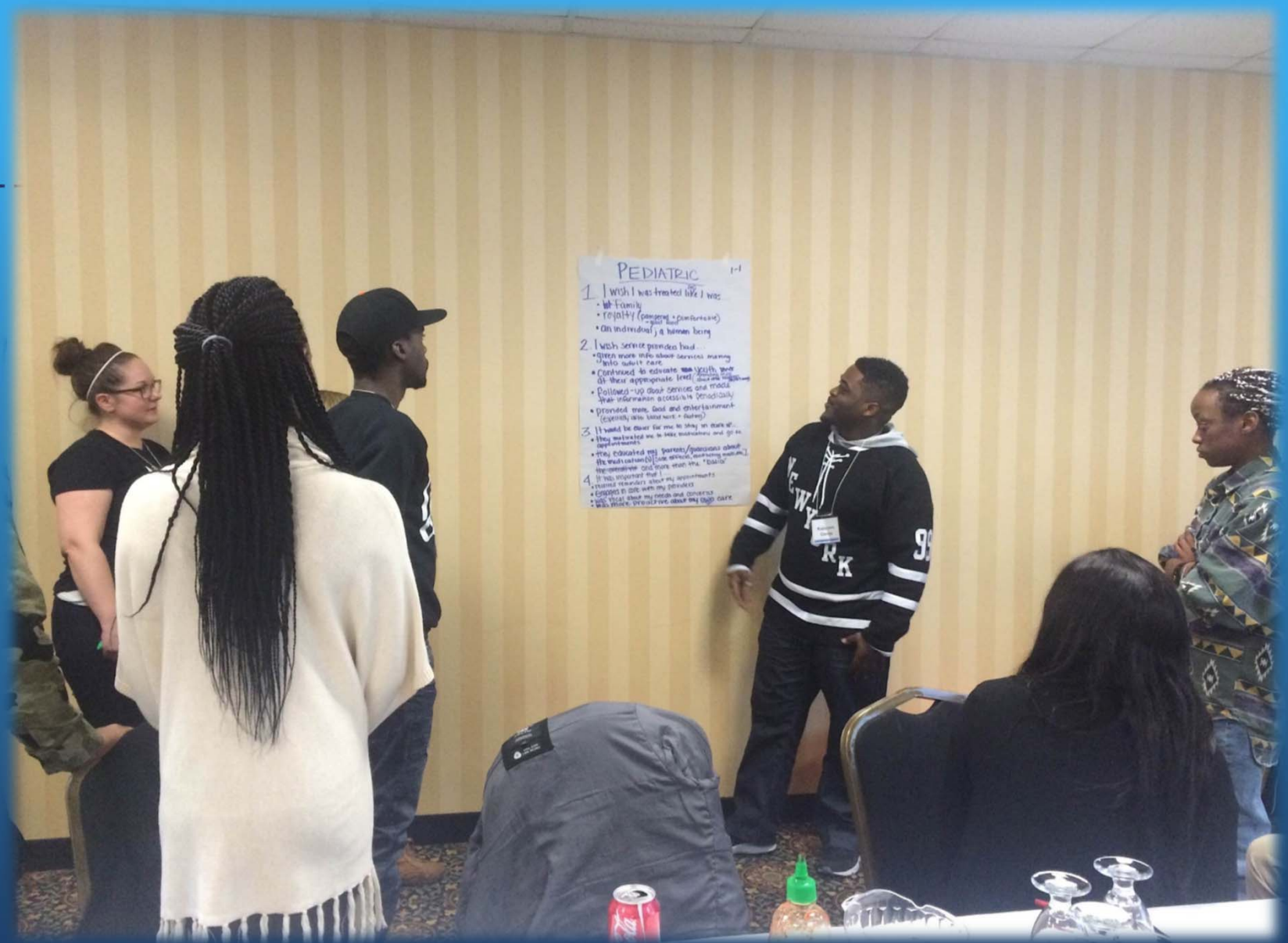


Dianne Falconer



PEDIATRIC 1-1

1. I wish I was treated like I was:
 - My family
 - Myself (patient + person)
 - An individual & human being
2. I wish service providers had:
 - Given more info about services, making "info" suit it care
 - Continued to educate me (with) me at their appropriate level
 - Followed-up about services and medical info/information as needed
 - Provided more food and other entertainment (snacks, etc. food, water, etc.)
3. I would be over for me to stay in more of:
 - They motivated me to see specialists and go to appointments
 - They educated my parents/guardians about the situation (and other, including nutrition, requirements and more about the "basic")
4. If you reported that:
 - I would research about my appointments
 - I would be over with my providers
 - I would share my medical concerns
 - I would be over for me to stay in more of



Overarching Themes

don't feel like a number

- don't make me feel like a number

• An individual; a human being

Do not want to be treated like a number...

Overarching Themes

ADULT CARE

I want to be treated...
like a long-term survivor

- trust me I know my own body
so listen to me. I am a long term
survivor.

- I AM AN EXPERT
- THAT I AM A SURVIVOR &
SEEN THAT WAY

Being treated like a long-term survivor...



Overarching Themes

- schedule me w youth I know I am used to community
- create a young adult support group. (clinic/Assoc)

- MEETINGS & OTHER YOUTH.

- A group for people in adult care.

SEE PEOPLE MORE
SEE SAME PEOPLE
CLOSER WITH EVERYBODY
OUTSIDE THE CLINIC BUILDS
BONDS THAT CARRY THROUGH

- LINK YOU W COMMUNITY

↳ LEARN
↳ ENCOURAGE
↳ SUPPORT

3. It would be easier for me to stay in care if...
• I was connected with other HIV youth
• I was connected about my appointments and

A need for community...



Overarching Themes

Understand us as patients. To
check in and make sure I
completely understand

- TOGETHER.
- CONFIRM UNDERSTAND.
 - GIVEN YOU A CHOICE (INFORMATION)
 - NOT JUST A CHECK UP, BUT LEARNING OPPORTUNITY
- WANT THAT

Y - like an 18 year old not a
35 year old.

- MORE EDUCATION AS YOU PREPARE FOR INDEPENDENCE
- MEETINGS & OTHER YOUTH.

Talk to me in a way that I understand...

Overarching Themes

- Reminders, a calendar. Appointments too far in advance.

4. It was important that I...
• received reminders about my appointments
• my providers

Want to have reminders of appointments...

PEDIATRIC 3-1
~~THE~~ LIKE SOMEBODY STILL THERE FOR YOU
- LIKE A COMPLEX TEENAGER
- CONFLICTING EMOTIONS & IDEAS & NEEDS
- I NEED INDEPENDENCE BUT SIMULTANEOUSLY NEED SUPPORT
- YOU ARE MY FAMILY, TREAT ME THAT WAY!
- ~~WISHING~~ WISHING IN CARE, SOMEONE ON THE RECEIVING END THAT I KNOW (SIBLING)
- PROPER ORIENTATION
- FACILITY
- PEOPLE (MEETING BEFORE HAND)
- SERVICES
- WHAT AM I GETTING INTO?
- MORE EDUCATION AS YOU PREPARE FOR INDEPENDENCE
- MEETING & OTHER YOUTH

PEDIATRIC 3-2
- EASING INTO IT
- PEER NAVIGATOR/EXPERIENCE YOUTH
SERVICE PROVIDERS
- KEEP THINGS BRIEF/CLEAR DEVELOPMENTAL APP.
- STAY IN CONTACT !!!
- THEY ARE FAMILY
- LINK YOU TO COMMUNITY
- MADE A TRANSITION PLAN TOGETHER
- CONFIRM UNDERSTAND
- GIVEN YOU A CHOICE (INFORMATION)
- NOT JUST A CHECK UP, BUT LEARNING OPPORTUNITY
IMPORTANT THING
- I HAVE AN OPPORTUNITY TO BE EDUCATED! / WAS MORE EDUCATED
- I EDUCATE THE OTHER LGS/YOUTH
- I MAKE THE EFFORT TO DEVELOP A RELATIONSHIP

PEDIATRIC 3-3
- I ASK QUESTIONS
- I KEEP FOCUSED/CONCENTRATE
- I AM AN EXPERT
- THAT I AM A SURVIVOR & SEEN THAT WAY
GENERAL
SEE PEOPLE MORE
SEE SAME PEOPLE
CLOSER WITH EVERYBODY
OUTSIDE THE CLINIC BUILDS BONDS THAT CARRY THROUGH
↳ LEARN
↳ ENCOURAGE
↳ SUPPORT



The Transition Accord:

- **Opening Statement**
- The nature of care in the pediatric system is fundamentally different from that of the adult system. For HIV positive youth, the transition from pediatric to adult care is a unique experience.
- In order to make this transition healthy and successful, we, youth living with HIV, pediatric HIV clinics, and adult HIV clinics,

commit to the following...



HIV Positive Youth

- **Engage with service providers.**
 - Express our own needs and concerns.
 - Make an effort to develop a relationship with service providers.
 - Ask questions.
- **Be proactive about our own care.**
 - Seek information and become more educated about the medications we take and our own health.
 - Go to appointments and take our medications.
 - Inform service providers when and why we miss medication doses or do not take our medications.
- **Nurture relationships with other HIV positive youth outside the clinic.**
 - Develop ways to encourage, educate and support each other.
 - Find ways to ensure we adhere to treatment, e.g. develop buddy system for taking medications at the same time.



Pediatric HIV Clinic

- **Value HIV positive youth as long-term survivors with expertise in living with HIV.**
- Trust the youth to make their own choices.
 - Better prepare HIV positive youth for the adult system.
- Use age-appropriate language to educate the youth about their medications.
- Introduce the youth to an adult clinic social worker and an ASO support worker on-site before the transition to adult care, regardless of location.
- Inform the youth of services available to them following transition to adult care.
- Equip the youth with information and strategies to address issues such as HIV stigma, abandonment and multiple loss.
- Provide greater autonomy to the youth as they age.
- Make a written transition plan together with the youth before the change.
- **Better prepare the adult system to receive HIV positive youth.**
- Provide the youth's entire medical history/file to the adult clinic.



Pediatric HIV Clinic

- **Motivate HIV positive youth to stay in care.**
 - Provide incentives for the youth to take their medications and go to appointments.
 - Provide appointment reminders.
 - Stay in contact with the youth after their transition to adult care based on the agreement in the written transition plan.
 - Allow for the youth to overlap with an adult clinic during the transition.
- **Involve parents/guardians in the care of HIV positive youth.**
 - Educate parents/guardians about HIV issues and medications beyond the basics.



Pediatric HIV Clinic

Be mindful of the issues HIV positive youth face as they age, including stigma, shame, conflict with family, and the increased stress of the medication as a reminder of their HIV status.

- Acknowledge that disclosure is difficult and compounded by race and gender.
- Remember teenagers are complex with conflicting emotions, ideas and needs.
- **Foster community for HIV positive youth.**
 - Partner up youth going to the same adult clinic.
 - Link youth about to transition from pediatric to adult care with youth who have made the shift.
 - Provide a welcoming, comfortable and supportive environment that includes food and entertainment.



Adult HIV Clinic

- **Value HIV positive youth as long-term survivors with expertise in living with HIV.**
- Trust the youth to make their own choices.
- **Engage with HIV positive youth as teenagers/young adults.**
- Use age-appropriate language.
- Treat the youth as individuals and not numbers.
- Provide information on how to communicate with us as service providers.
- **Invest in building a relationship with HIV positive youth.**
- Provide introductions and have a session dedicated to getting to know the doctor.
- Visit the pediatric clinic.
- Express warmth and appreciation for the youth.
- Be passionate and conversational with the youth.
- Treat the youth with respect.



Adult HIV Clinic

- **Support HIV positive youth to stay in care.**
- Provide **appointment and follow-up reminders** and use relevant technology, such as texting.
- Be knowledgeable about the reasons for poor/lack of treatment adherence among the youth.
- Be firm with the youth who stop taking their medications, as appropriate.
- Ensure the youth understand information that is provided to them.
- Provide all clinic appointments in one day (e.g. doctor and social worker) when possible.
- **Work with community partners** to reduce barriers to accessing the clinic services, e.g. transit costs, parking and food.



Adult HIV Clinic

- **Foster community for HIV positive youth.**
 - Schedule appointments for the youth together.
 - Work with ASOs to create a young adult support group at the clinic.
 - Provide a welcoming, comfortable and supportive environment that includes food.
 - Link the youth to resources, opportunities and services for HIV positive youth, e.g. The Pozzy.
- **Support the whole person.**
 - Provide relationship and marriage counselling.
 - Talk about the youth's whole health story and not just their viral load.
 - Recognize each youth has a different reaction to the transition to adult care.
 - Communicate with other service providers about the youth's care e.g. coordinated and cooperative case management



Role of the AIDS Service Organization

- **Support youth to navigate**
- Bridge between old and new services - medical and community services
- Advocacy role with Adult Clinic to:
 - Ensure appointment reminders/supports
 - Grouped youth appointments to allow youth to come together
 - Allow youth groups to take place in coordination with Adult Clinic - eg. "Youth Day" or "Breakfast Club"
- Follow beyond the transition period to adult care to ensure youth successfully navigates other transitions (eg. education, entry into work force, relationships...)