Lost in Transition

Challenges and Solutions to Healthy Transition in Care for Young People Living with HIV

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XIX International AIDS Conference

July 22 – 27, 2012 Washington DC, USA A-452-0280-02372







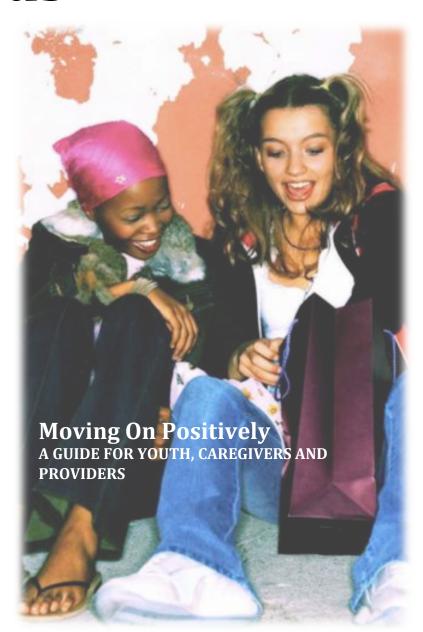


Background

- There are 254 young people (13-24) in Massachusetts that were born with HIV.
- Just over half are male and 77% are Black or Latino.
- These young people have to start transitioning to adult care but they face many challenges in that transition.
- Leaving pediatric providers that have cared for a young person since birth is difficult for the patient, caregivers and health providers.
- Transition is a major issue for young people with all types of chronic diseases but social stigma and transmissibility make HIV unique.
- Many young people "fall through the cracks" during this transition period, putting themselves and others at risk.

Methods

- In order to better understand how to help these young people successfully transition from pediatric to adult health care, we talked to the people who know the most about it.
- We conducted two workshops with young people and caregivers and two workshops with health providers.
- We asked questions about the challenges to transition.
- We also asked for simple solutions that youth, caregivers and health providers can start to put in place in advance of transition.
- We created a **guidebook** that shares all that we learned.



Results - The Guidebook

- Moving On Positively A Guide for Youth, Caregivers and Providers is a vibrant, user-friendly guide that speaks to all three audiences about how to prepare for transitioning young people living with HIV from pediatric to adult health care.
- The book was peer-reviewed by young people, caregivers and providers.
- The guide provides information in the form of short narratives, checklists, useful resources and quotes.
- Some sections are supported by information and transition guides found in related literature.
- Symbols are used to direct readers toward sections specifically written for them (youth, caregiver or provider).
- While written for a Massachusetts audience, the majority of information is general and adaptable for audiences anywhere in the U.S.

Challenges to Transition

Ten Reasons Why Transition is So Hard

- **1.** Everyone is scared to let go.
- 2. The "what" and "why" of transition is not clearly defined.
- **3.** Institutions lack common language and standardized protocols for transition.
- **4.** Youth sometimes lack the skills and confidence to take responsibility for their care.
- **5.** Often, adult care is in a different building or institution and is confusing to navigate.
- **6.** Adherence is hard and youth do not always understand the importance of adherence.
- **7.** Sometimes, the parent or caregiver is too involved in the young person's care.
- **8.** Young people do not have access to the psychosocial support they need.
- **9.** Caregivers lack the support to cope with transition and possibly their own HIV.
- **10.** In adult care there is less access to job placement, peer and transportation support.



Solutions at a glance

- Start transition conversations early and include everyone involved in the patient's care.
- Learn about HIV and how to stay healthy.
- Know who to call in case of an emergency.
- Research changes in health insurance and benefits.
- Take a tour of the new facility.
- Create a "medical passport" with the patient to consolidate health history.
- Slowly shift responsibility ensure youth can call in prescriptions, attend appointments independently, understands medication.
- Allocate extra time for initial visits.
- Communicate with one another.



"He knows a lot more than he lets on...He knows about taking care of himself and others, sexual partners... at 14, he is starting to be concerned about these things." - FATHER

Solutions at a glance

- Build on past successes with other life transitions (e.g. school).
- Build a support network of people that can help you through.
- Meet privately with health care providers.
- Ask questions!
- Keep medical information in a safe place.
- Focus on adherence.
- Discuss and prepare for disclosure.
- Find peer support opportunities.
- Know what medications you take.
- Talk to your providers about "other stuff" (e.g. relationships).
- Love yourself; embrace transition!



"Maybe his support group would have more impact on him than mom can right now. He needs to be able to talk with people in the same boat he's in" - MOTHER

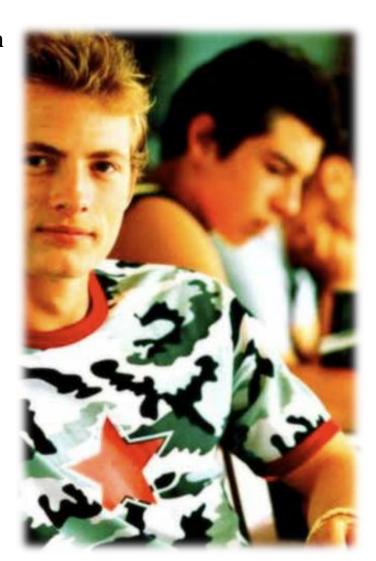
More Solutions

• **Hold a transition day** at your institution for patients, caregivers, pediatric and adult providers. This is a place for networking and getting information about transition.

• Establish a coordinator that can:

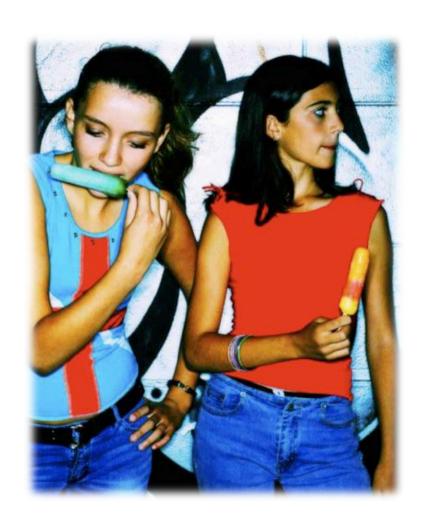
- Help patients practice new skills
- Help providers prepare health histories
- Accompany youth to the adult clinic
- Assist with communication
- Assist with health insurance
- Help patients access peer support

A lot of the kids who transitioned really early on, they had a lot of anger at us because we were setting them up...putting them out into this adult world without any tools, and they were right" – PEDIATRIC PROVIDER



Conclusion

- Transition is a process, not an end result. Its definition will constantly evolve as young people do.
- Communication and collaboration, between everyone involved in transition, leads to good ideas and successful outcomes.
- We hope this guidebook will help young people, parents/caregivers and health providers take the small steps necessary to plan for a seamless and successful transition to adult care.



"I liked how they (my pediatric care team) asked me if I felt comfortable and if I had anyone in mind... I felt like I had my own opinion on it." – AGE 18

Thank You

For more information or to order copies of the guidebook, please contact us!

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