Your Questions ANSWERED

a Project HOPEFUL Publication
A Note To Our Readers

This booklet was born out of a successful Project HOPEFUL blog series. The staff invited our blog readers to submit their most burning questions to be featured in a series titled, *Your Questions Answered*. We noticed that many of the emails we received contained threads which related to the same topics. Contained in this booklet are the most successful posts from that series. We hope that you will find answers to your questions. However, if you require further assistance we invite you to write us at projecthopeful@projecthopeful.org. Please note that Project HOPEFUL consists of parents raising and advocating for children with HIV/AIDS. We are not medical professionals. Any advice contained within this booklet should be discussed with medical professionals specializing in the treatment of HIV/AIDS.

Contents:

- Facts About HIV/AIDS  
  Page 1
- Injuries and Clean Up  
  Page 3
- HIV and Reproduction  
  Page 5
- Dealing With Family  
  Page 7
- Building Support Through Education  
  Page 8
- The Disclosure Decision  
  Page 9
- School/Sports Disclosure and Privacy Protections  
  Page 11
- Daily Life  
  Page 13
- Older Orphans Who “Age Out”  
  Page 14

HIV is transmitted in three main ways: sexual contact, IV drug use through the sharing of dirty needles, and mother-to-infant (during pregnancy, birth, or breastfeeding).

HIV has never been transmitted through normal family living conditions. It cannot be transmitted through casual contact.

HIV is not found in sweat, urine, feces, tears, saliva, or snot. It is found in blood, semen and vaginal fluids, and breastmilk.

Today, HIV is considered a chronic but manageable disease much like Type II Diabetes (though diabetes cannot be transmitted).

If a pregnant mother does not receive medical treatment there is approximately a 30% chance she will transmit the virus to her child. By treating mother and infant, doctors can reduce that rate to approximately 1%.

Children who are HIV-positive and receive medical treatment are expected to live a normal lifespan.

Medications called ARVs (Anti-RetroViral) can mean the difference between life and death for individuals living with HIV.

HAART (Highly Active Anti-Retroviral Therapy) is the combination of three or more ARVs in a daily drug regimen designed to treat HIV.

A person’s viral load is the amount of HIV found in their body.

Through the use of HAART treatment it is possible for a patient’s viral load to become undetectable in laboratory tests.

Having an undetectable viral load does not mean a person is cured. It simply means the medications are working to prevent the HIV virus from replicating within the body.

Currently there is no cure for HIV, though medical research has provided exciting advancements and it is believed that a cure is on the horizon.

A person’s HIV+ status is protected medical information. There are US laws in place to protect the privacy of individuals living with the virus. There are also laws to protect citizens from being discriminated against because they have HIV/AIDS should they decide to disclose their HIV+ status.

Social stigma is perhaps the greatest challenge an HIV+ individual will face.

In 2009 the Kaiser Family Foundation conducted a study titled Survey of Americans About HIV/AIDS which found that levels of knowledge about HIV/AIDS had not increased in the US since 1987. We are working to change that statistic.

Project HOPEFUL exists to educate, encourage, and enable families and individuals to advocate for and adopt children with HIV/AIDS.
Injuries and Clean-Up

Question:

As a mom of 5 children, I know I’ve had situations where my children are bleeding and as I rush to help them, I inevitably get their blood on my clothing, skin, etc. As the mom of an HIV-positive child, how do you handle these situations? Do you grab a pair of gloves first? Or do you take some kind of drug to counteract the HIV if you do end up directly handling their blood?

~Rachel

Answer:

Great question Rachel.

Families with HIV+ children practice Universal Precautions whenever there is a blood spill. However, it is a good idea for all families to model responsible handling of blood for their children no matter the HIV status of their family members. Kids need to learn that we never touch anyone’s blood. Teaching them about Universal Precautions enables them to offer assistance to injured persons in a safe and healthy way.

Because our family practices Universal Precautions we have a couple of kits set up in strategic places should we require them. Our main “Clean Up Kit”, as we call it, is in our kitchen. It contains a box of gloves, some antibiotic ointment, various sized band-aids, and a few other common first-aid type ointments. I also keep baggies filled with some gloves, a few paper towels, and band-aids in my purse, as well as in the glove box of my car.

In Universal Precautions it is suggested that an additional barrier be added between your skin and any body fluid from another person for extra protection. Most people automatically think of plastic gloves because that is what they see medical professionals wear. But, something as simple as a paper towel or a band-aid is just fine for minor cuts and scrapes. Even your clothing is a barrier between spilled blood and your skin.

Most people don’t know that healthy skin is a natural barrier against the HIV virus. So, to address your question, if some blood were to accidentally splash on your clothes or skin there would be no need to panic. Blood to blood contact presents the risk, so if you had an open wound which came into contact with infected blood, there would be a small risk of transmission.
While HIV may live for a short while outside of the body, HIV transmission has not been reported as a result of contact with spillages or small traces of blood, semen or other bodily fluids. This is partly because HIV dies quite quickly once exposed to the air, and also because spilled fluids would have to get into a person’s bloodstream to infect them.

It should also be noted that the amount of risk blood poses correlated to the concentration of HIV virus in it. Obviously, the more virus found in the spilled blood the higher the risk of transmission becomes. In the majority of patients receiving HAART (a combination of three or more anti-HIV drugs referred to as Highly Active Antiretroviral Therapy) the medication works so well the levels of HIV in their body decreases to undetectable levels. That means that in laboratory tests the HIV virus was not able to be detected in their blood. With decreased levels of HIV in their bodies these patients present an even LOWER level risk should a blood spill occur.

You should know that since the development of HAART there has NEVER been a case of HIV being transmitted within a family. And, as you stated in your letter, families with kids tend to have to deal with blood and injuries some time or another.

If you’d like to do further research, www.avert.org has great resources which address FAQs about transmission.

**Universal Precautions**

You should follow some standard or Universal Precautions when cleaning up blood spills, or dealing with other body fluids such as semen, vaginal fluid, and breast milk, as well as tissue from anyone who is infectious. These guidelines don’t apply to other bodily fluids like saliva, urine, sweat, tears, nasal secretions, sputum, and feces unless they contain blood. Professional Universal Precautions include:

- washing hands before and after any medical intervention.
- wearing gloves whenever coming in contact with another’s blood, bodily secretions, or tissues even if the person you are helping is a family member.
- wearing a facemask or body gown whenever there is a possibility of blood splashing.
- dispose of contaminated sharp objects in the appropriate puncture-proof container.
- dispose of all contaminated equipment in an appropriate biohazard container.

**In The Home**

For home care it is not necessary for families to have all the required equipment professionals use but it is good to know the professional guidelines and work from there.

In the home families can use band-aids, gloves, paper towels, and bath towels depending on the severity of the injury and amount of blood they are dealing with. Placing bloody bandages, rags, or towels in a plastic bag for disposal is a good practice. Cleaning up blood spills with a disinfectant and washing soiled linens in hot water and bleach is also recommended as a precaution.
Question:

How does HIV affect an adult who is married (and therefore sexually active) to an HIV-negative spouse? How would the couple go about having a child who is negative without compromising the health of the spouse who is HIV-negative?

~Anonymous

Answer:

A couple with one partner HIV+ and the other negative, is an HIV discordant couple. The good news for discordant couples is that there are options available and child-birthing IS possible for them. To help us answer today’s questions regarding conception and reproduction our good friend, Linda Walsh, NP, Clinical Director of the University of Chicago Adoption Center shares some information:

To answer the question about conception depends on which partner (woman or man) is infected with HIV as to what strategy will be utilized. Being on a stable ARV regimen, having an undetectable viral load, not having other STDs all decrease the risk of transmission, but do not eliminate it entirely.

There is a technique called sperm washing [for positive men], also artificial insemination is an option [for protection for either a negative man or a negative woman.] And there is some data on doing it the old fashioned way with an undetectable viral load, etc.

Most of my patients, who are young adults/adolescents, have not used the sperm washing technique. All have been young women who’ve had children that are thus far HIV negative. I have no knowledge of any of their partners becoming positive.

www.avert.org tells us more about sperm washing:

This involves separating sperm cells from seminal fluid, and then testing these for HIV before artificial insemination or in-vitro fertilization. Sperm washing is a very effective way to protect both the mother and her baby, but it is only available at a few clinics and can be difficult to access, even in well resourced countries.
Sperm washing is a technique that was first developed in Milan. The concept of sperm washing rests on the premise that HIV resides mainly in the seminal fluid of an HIV positive male. Sperm washing concentrates and separates the fertilizing sperm from the infectious seminal fluid. During ovulation, the woman is then artificially inseminated with the concentrated sperm. Without the infectious seminal fluid, the theory is that the risk of the woman being infected with HIV is greatly reduced, thereby reducing the risk of vertical transmission (transmission from mother to child) as well. In July, 2010 the World Health Organization (WHO) issued new HIV and AIDS guidelines on PMTCT (preventing mother to child transmission) and on HIV and breastfeeding.

According to the 2010 guidelines, all HIV positive mothers, identified during pregnancy, should receive a course of antiretroviral drugs (ARVs) to prevent mother to child transmission. All infants born to HIV positive mothers should also receive a course of ARV drugs and should be exclusively breastfed for 6 months and complementary-fed for up to a year.

The risk of transmission from mother to infant without medications is approximately 30%. With PMTCT medical care that number plummets to approximately 1%.

A great resource for learning about comprehensive care is: HIV/AIDS Care and Counseling by Alta van Dyk. You can read the book online by going to Google Books and searching for the title. Project HOPEFUL has also created a webcast which discusses the topic of HIV and reproduction. To watch those videos visit:

www.projecthopeful.org/media
Dealing With Family

Question: How do you suggest I go about sharing news with family and close friends about our decision to adopt a child with HIV? I shared with my sister (who has 2 children) and she seemed very anxious about the idea.

~Anonymous

Answer:
People commonly wonder which approach is best for sharing the news that they plan to adopt a child with HIV/AIDS or other special needs. There is no formula to follow for guaranteed success. But there are some helpful things to consider.

In Person Is Best
This may seem like a given, but, believe me, some people have chosen to share their big news via email, or even had family members stumble upon their announcement by visiting their blog. This definitely is not the way to go if you want to ensure feelings do not get hurt. If you plan on disclosing your child’s status you’ll want to make sure the people closest to you know first. Just like you might for any big occasion in your life, plan to share with your inner circle first, and in person. Setting down for a talk will give you a sense of people’s initial reaction to your news and help guide you in determining who might require a little more reassurance about your decision.

Adjust Your Expectations
Though it can be a real bummer, my best advice for parents adopting a child who is HIV+ is not to expect anyone to cheer them on in a big celebration when they first reveal their plans. Experience tells me that most extended family and friends experience an initial bit of shock upon hearing the news. Remember, most people haven’t learned anything new about HIV/AIDS since the late 80’s. Given the major lack of education it’s common for people to have some serious misconceptions. If you enter the scenario confident of your own decision making and determine to leave some space for your loved ones to digest the facts, and do not require immediate acceptance from them chances are you won’t experience great disappointment in people’s initial reactions. Tempering your expectations can help you to stay calm when people express their fears and concerns. It’s vital to remember that it took you time to come to the decision to pursue your adoption. It is only fair to give your family the time they need to come around as well.

Ask Questions
It may seem strange, but, sometimes our family members feel insecure about their role in our adoptions. It’s a well known fact most people don’t like change. When members of our family realize that decisions we are making will bring change to the family structure they sometimes experience “interesting” emotions. Not that your family will have the final say in what you decide, but it is important to remember that your family members have to deal with their own thoughts and feelings on adoption, HIV/AIDS, and disclosure. They will need to consider stigma and what that might look like for them personally if you do decide to disclose your child’s status.

You can help jump start your family’s consideration of these things by asking them questions. Do your family members have fears/concerns about the reactions of people around them? How about how others might treat your child? Do they fear for your child being made fun of? Do they feel insecure about their ability to keep stigma at bay? Are they concerned they won’t have answers to people’s questions? Do they resent the idea of people being curious about your family and the idea of having to defend your choices to others?

Advocacy Begins Here
I’ve written before that once you decide to disclose you basically sign up to instantly become an advocate. I guarantee you your family will have questions. By offering them your assistance in finding answers to those questions you have an opportunity to build up your relationship with them. Making an effort to provide your family with as much up-front information as possible not only allows you to be proactive but also lets family members know how much you care about their needs. Family members appreciate knowing they can come any time for more information and that they won’t be resented for it. You don’t have to have all the answers; simply showing a willingness to help will speak volumes to your loved ones.

After You’ve Done All You Can Do
When we made the decision to adopt a child with HIV, and it was met with some resistance, I made sure I offered my extended family members as much education information as they needed. None of them had an excuse to be uneducated or remain ignorant. If they wanted the facts I knew I had done everything within my power to make sure they were readily available to my family; that I’d even made it easy for them. It paid off dividends. In the end, everyone came around to being supportive.

Unfortunately, it isn’t always the case that everyone comes around. It has been the experience of some Project HOPEFUL families that a few in their family refuse to accept their adoption because of illogical fears and pure stigma. Flat out, these members of the family would rather hold on to their fears and ignorance than embrace the child who will be coming home. These are heart-breaking scenarios where the facts are rejected and adoptive parents’ efforts to educate and inform are shunned. It isn’t common, but if this should happen to you the best advice is to take comfort in the fact that you did all you could. The rest lies in the hands of another. In the end anyone who ignores these wonderful children is the one who misses out on the joy they bring into the lives of all they touch.

I hope these simple tips will help point you in the right direction. Project HOPEFUL is here to support and encourage families throughout their ENTIRE adoption process and beyond. Feel free to write us anytime at projecthopeful@projecthopeful.org
Building Support Through Education

Question: How can local church families prepare to welcome HIV+ children? How should they be preparing their congregations?

Answer: Hi Jennifer. Thanks for sharing your questions.

These days it is fairly common for churches to have the proper safeguards in place when operating programs for children, though some smaller congregations may not. As I’ve written before, any school, day-care, or church operating programs with children should be practicing Universal Precautions. PERIOD. If your church or group isn’t following Universal Precautions protocols then you should request that they implement them immediately for the safety of everyone involved.

As far as educating a church fellowship (or any other group for that matter) goes, it all depends on the willingness of the leadership to join you in this endeavor. Some leaders are resistant to the idea. Some haven’t confronted their own fears and biases related to HIV and therefore are unable to lead their flock in doing the same.

However, there are many, many church leaders who are supportive and willing to promote education within their church… they simply may lack the time. My suggestion is always be willing to dig in and do any work you want to see happen. Don’t bring ideas before your leadership if you aren’t willing to invest the time and effort to bring them to fruition. Sit down and come up with a written proposal for what you hope to see accomplished. Keep it brief but make sure there is enough specific detail in there to prove you have a method to your madness. Ask your pastor for just 30 minutes to share your goals. (Who doesn’t have 30 minutes to spare?) A well thought out proposal will show your leadership you are both passionate and committed, which will likely help to stoke the fires within them.

Sometimes it is best to start small. If you don’t have experience teaching or leading groups you may want to propose that a small group of interested members begin to meet in your home for a few weeks. You’re going to need help. Develop a team of advocates who are well-educated about HIV, the needs of positive orphans, and the families who will adopt them. Pray about and consider your church’s unique personality and the ways God might use those traits to serve in the field of HIV/AIDS orphan care and adoption ministry. Perhaps most importantly, share your excitement about the things God has in store for your church.

If you can gain enough momentum with your core group of advocates and get a solid grip on where you hope to lead the efforts, the next step might be to host an educational event. In preparing a community to support the needs of individuals with HIV/AIDS three issues need to be addressed. Those are the spiritual, emotional, and educational needs of the people you wish to mentor into becoming advocates/supporters. Consider planning some kind of class or seminar aimed at helping teach the truth about HIV/AIDS and deal with the three aspects of education.

Dealing with the emotions of people as they begin to wrap their hearts around HIV/AIDS can be challenging. It is important to remember in all your educational efforts that you once had questions too. Try to recall what it was like when you first discovered about HIV/AIDS and all the questions you had. Don’t lose sight of how powerful fear can be and how often people can feel ashamed for not having the answers. Expect some weird and emotional reactions from people as their fear-based preconceived notions are shattered.

The point is not to berate people for being ignorant of the facts but rather, the goal is to equip them with truth so they can be in the know. This can sometimes be a painstaking experience that might threaten to suck every drop of patience you possess.

Since you’ve written specifically about how to reach out to your church members, I’d also like to address dealing with the spiritual mandates for reaching out in love to HIV+ individuals. Surprisingly people can be very choosy with who they think God has called them, specifically, to love. Sometimes the general attitude is, it’s all well and fine for that organization over there to love orphans with HIV/AIDS… but that’s not for me, it’s not my “calling”. When another member of their church embraces HIV it can sometimes cause members to feel threatened and produce emotional responses. It’s important to speak the truth in LOVE to these resistors. By all means never back down to stigma or give way to lies, but know that often times the underlying issue at the core of a person’s dissent is usually motivated by fear or guilt. Either they can’t get over their unsubstantiated fears about HIV/AIDS or they feel guilty for not wanting to.

The way to overcome these attitudes is by being compassionate. Praying for that person doesn’t hurt either! By being compassionate ourselves we are able to model what it ought to look like in those we seek to inspire. People can only teach what they know. If we want to arm the next wave of advocates in the fight against stigma and complacency it is up to you and I to teach them first. Let’s make sure we are teaching well.

People will always have the choice of whether or not they want to follow in the footsteps of compassion and love, but at least we can leave a well-worn path for them to follow, should they choose.
The Disclosure Decision

Question:

How do you decide whether or not to disclose your child’s HIV+ status. Who should I tell; who shouldn’t I tell? What is it like to be a disclosing family?

~Anonymous

Answer:

Disclosure is a very personal thing. Many families choose to disclose or not to disclose based on various factors such as the type of community they live in, the strength of the support system of friends and family around them, their personality type, and many other things.

Of course, Project HOPEFUL is an organization which is filled with advocates, who have overwhelmingly decided to disclose our children’s status. If you asked our disclosing staff members I think they’d tell you that a main impetus for disclosing is the desire to flush out stigma. HIV/AIDS is no one’s dirty little secret. The issue of whether or not a family should hide their child’s leukemia, or diabetes, or down syndrome is a NON issue. I’ve never heard anyone talk about it being that child’s story which only they should share. Kids are born with many diseases, yet it seems that HIV/AIDS is the singular chronic disease everyone wants to shame kids for having, or discourage from openly communicating their story. No one bats an eye when a mother blogs about her child’s congenital heart defect. No one condemns her for sharing such personal information about her child without her child’s consent…. See my point?

Those of us who have disclosed did so knowing there were risks. We realized it might cause our children pain. There is an ugly side to disclosure and that’s stigma. Though I can say our family has only faced blatant sigma once. And that was by a medical provider who should have known better!

Families that disclose will naturally take on a bit of an advocacy role. Because, with disclosure comes questions. One has to weigh how willing they are to answer those questions, because – WOW! – do they ever come.

I will say that some friends of mine (he’s a pastor of a small rural church) have chosen not to disclose because they do not feel their community is educated or mature enough to handle that information responsibly. I would NEVER fault them for their decision. Only they know what is best for their family and child. And, in their case I truly believe they are right. I believe they would be placing their daughter in the line of fire in their small town. For that family non disclosure is the best kind of advocacy they can do for their daughter.

For our family the idea of not disclosing seemed ludicrous. We’re an extroverted family anyway. Plus, we had 4 other kids. We couldn’t imagine educating our kids all about HIV/AIDS, telling them we would be adopting a brother who had the virus, and then trying to keep them from sharing that news with anyone.
In our family the surest way to make our kids want to squeal is to tell them they can’t talk about something. (haha) Honestly, we thought the secrecy would create an atmosphere of shame.

And we didn’t want our HIV negative children feeling sorry for our positive son as if he were a pity case. Nor did we want them to feel like their brother’s differences were bad; so bad that they had to be kept secret.

We ended up telling our kids that they could share the news with people they trusted. We told them that it was like any other personal issue for our family. We just don’t need to broadcast private information to any old person we meet. And while I’m a very vocal advocate for HIV/AIDS, it’s not like I run around my community with a megaphone telling every Jane and Joe we meet my son’s status. I am careful to create stricter boundaries with real-life people, simply because people in our neighborhood have more access to my family.

Being that we are a disclosing family I will say the issue of privacy and what is or is not socially acceptable has come up. I’m not going to say it is always easy being a disclosing family. It can be difficult sometimes to navigate people’s curiosity in real life with my son standing right there. Sometimes people, (or their children) don’t always know that some questions don’t need to be asked, some are appropriate, and some are intrusive.

I’ve had some tough lessons in my new role as mom/advocate. I’ve had to redraw some boundary lines in close relationships. And that hasn’t been easy to do. It’s hard to explain to people – and even harder to navigate through – this concept of being open to discussing HIV and adoption while NOT being open to discussing my son’s PERSONAL health. People around me haven’t always understood that the topic isn’t open for conversation all the time, any time they’d like. (Especially while my son is present).

When in person, any conversation about my son needs to happen under my terms. Some people don’t love that.

The line can get blurry sometimes even for myself. While I always want to be an advocate, I am a mom first. I have to consider how my son may feel about disclosure.

As my son ages and develops his own preferences and level of comfort with disclosure I have to consider that he might want to go private. My husband and I have discussed this and both agree we’d be willing to do whatever it took to give our son anonymity should he desire it when he’s older. If that means selling our home and moving far away, so be it. We feel that is only fair. But, for now, while he’s young, we do the best we can. We disclose because we believe it makes the world a better place for our HIV+ son. We believe the more people we can reach with the truth about transmission, etc., the more likely they are NOT to discriminate against our son as he grows.

Carolyn’s daughter Selah is a great example of a child who is totally comfortable in her skin and absolutely willing to talk to anyone, anytime about HIV. She’s her own advocate at this point. I believe this is because their family has always been open about her status. But, again. I could see some children with different personalities wanting their privacy no matter what.

In the end there are great arguments for and against disclosing. It’s such a personal decision.

When it comes to disclosure there is no wrong decision, only the decision a family comes to after much thought and discussion – and, for our family, MUCH prayer.
Question:
We feature related questions from two of our readers:

QUESTION 1: What are the legal implications of sending your children affected by HIV to school? Do you have to offer this information publicly?
~ Andie

QUESTION 2: How do you handle negative and/or hysterical reactions [at school]?
~ Valerie

Answer:
I’ll Address Andie’s question first because the answer takes a little more time.

Andie, According to a 1993 CDC article¹, “no cases of HIV transmission in school have been reported, and current epidemiologic data do not justify excluding children with HIV infection from school or isolating them in school to protect others. Children with HIV infection should be able to participate in all school activities with the same considerations as other children, to the extent that their health permits.”

According to the same CDC article, “despite the large number of persons participating in contact sports, only one case of HIV transmission attributed to sports had been reported worldwide.”

That was in 1993. I hunted all over for any updated numbers but couldn’t find any.

Do you wanna know why I think that was? Because there AREN’T ANY.

Today, the ability for patients to receive HAART makes it extremely likely that those numbers haven’t changed since 1993. So, if there was only ONE sport related case of transmission WORLDWIDE in 1993, and NO cases of transmission in school, it is safe to say there is no reason for parents to be concerned about transmission in school or during sports activities these days.

As Dr. Steven J. Anderson, Chair of the Academy of Pediatrics Committee on Sports Medicine, and team doctor for the U.S. Olympic Diving Team puts it:

“‘There is clearly no basis for excluding any student from sports if they are infected. — I personally feel parents have no obligation to disclose the infectious status of their children to anyone.’”

The US Government feels the same way too.

An HIV+ person’s health information, whether they be a man, woman, or child, is protected information under United States law. There are also laws in place to protect citizens with HIV/AIDS from discrimination.
I’ll explain these laws briefly:

Section 504 the Rehabilitation Act of 1973
Section 504 prohibits discrimination against persons with handicaps in federally assisted programs such as elementary and secondary schools. It provides that: No otherwise qualified individual with handicaps in the United States … shall, solely by reason of his or her handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

The law of which Section 504 is a part of defines a handicapped person as one who has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is perceived as having such an impairment.

Persons with HIV/AIDS are substantially limited in a major life activity due to the reaction of others to their perceived contagiousness. The fear of HIV/AIDS includes a perception that a person with the disease is substantially impaired in his/her ability to interact with others, for example, to attend school. Persons, such as those with HIV/AIDS, who are “regarded” as impaired, are just as “handicapped” under the law as those who possess the physical limitations that arise from actual impairment. Discrimination based solely on the fear of contagion is discrimination based on handicap when the impairment has that effect on others.

Title II of the American With Disabilities Act (ADA)
The Title II of the ADA prohibits discrimination by state and local government entities, even if they don’t get Federal funding. Examples of entities that may be covered by Section 504 and the ADA include hospitals, clinics, social services agencies, drug treatment centers, and nursing homes. Again, under these laws, discrimination means that you are not allowed to participate in a service that is offered to others, or you are denied a benefit, because of your HIV disease.

In the first Supreme Court case involving HIV/AIDS discrimination (Bragdon v. Abbot), the Court ruled that Congress intended HIV infection to be included as a disability under the ADA. HIV infection has been found to meet the definition of disability under Federal and state laws protecting the disabled from all forms of discrimination.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA)
HIPAA is designed to protect the privacy of patients’ medical records and other health information. It also provides patients with access to their medical records and with significant control over how their personal health information is used and disclosed. HIPAA has proven to be very effective in preventing discrimination against people living with HIV/AIDS by preventing others from knowing their HIV status.

Together these laws provide strong protections for children with HIV. Families are under no obligation to disclose their child’s HIV+ status to schools, coaches, or anyone. The exceptions would be medical providers and potential sexual partners should they choose to engage in a sexual relationship.

Now to answer your question, Valerie:

Any one who shares personal medical information about an individual without being authorized to do so is subject to punishment according to US law.

Local county health departments will notify a school if a student in their population is HIV+ but they will not disclose the identity of that student. That’s because there is no need. Law abiding schools practice Universal Precautions FOR EVERYONE in attendance. A school’s operations should not be affected one way or another by the presence of an HIV+ individual in their student population.

Some types of negative reactions toward a child who discloses their HIV+ status by school staff, students, or their parents could be considered a form of harassment and/or discrimination, which is against the law.

People with HIV/AIDS who believe that their health information privacy rights have been violated may be eligible to file a complaint. For information about your privacy protections, see the US Department of Health and Human Services website for more information.

Daily Life

Question:

I’m curious what daily life is like for parents raising children with HIV/AIDS. Can you share what it is like?  

~Rebecca

Answer:

Rebecca, truth is that daily life for families with HIV-positive children is much the same as any other family. Of course our kids need to take medications, usually twice a day. It is vital for the effectiveness of the medications that they be taken on a regular schedule and that no doses are skipped. Our physician said we are allowed to “fudge” the schedule two times a year. This is because the effectiveness of ARVs depends on them being taken regularly. If they are not, the HIV virus could develop resistance and render the medication useless. So, I would say that the main difference in our family’s daily life is planning our schedule around making sure our son always takes his meds on time.

The actual administration of my son’s meds literally lasts only a few seconds. I keep alarms set in my home and on my cell phone to ensure that I never forget. I carry our son’s medications in a travel case if I know we will be away from home during the time he takes his medications.

Aside from following universal precautions if there is a blood spill in our home (though, every family should do this as well) the medications are really the only difference.

Our HIV+ son does go to a few extra doctor appointments per year. He sees a specialist called a PID (pediatric infectious disease) doctor who monitors and treats his HIV. Those appointments are every three months, or four times per year. At every appointment blood is drawn to monitor my son’s viral load. His CD4 count is also measured to indicate how his immune system is functioning. The doctor also checks his liver to determine if any negative effects from his medications are being experienced.

People often imagine that parents with HIV+ kids are constantly nursing their sickly children. Because my son’s viral load is undetectable and his immune system is functioning normally, he isn’t sick any more than my HIV-negative kids. Our son is healthy and strong and growing.

So, that is it. Not much to report, honestly. As I said before, life is pretty much the same for us as it ever was before we adopted our HIV-positive son, but it is richer and fuller because he is in our family. His virus really doesn’t play into our daily life. What I mean is, it isn’t in the forefront of our minds daily. My son is a kid just like any other. He simply has a chronic but manageable disease which he is learning to thrive with.
Older Kids Who “Age Out”

Question:
I recently heard about orphans aging out of the system in Ukraine. Can you tell me what life is like for young-adult orphans around the world?

~Jennie

Answer:
Jennie, yours is an important question. I’m afraid the answer is a difficult one to hear.

Whether a teen ages out of the US foster system or is released from an institution onto the mean streets of a developing country, it is a heart-breaking scenario. That any young adult should be launched into life without the support of a loving family to cheer them on is a travesty. But, for young orphaned adults in other nations fate can be even more tragic:

Each year 14,505,000 children worldwide grow up as orphans and age out of the system by age sixteen.

Every day 38,493 orphans age out.

That means that every 2.2 seconds another orphan ages out.

In Russia and the Ukraine, studies have shown that 10% – 15% of these children commit suicide before they reach age eighteen.

These studies also show that 60% of the girls become prostitutes and 70% of the boys become hardened criminals.

A different Russian study reported that of the 15,000 orphans that age out of state-run institutions every year, 10% committed suicide, 5,000 were unemployed, 6,000 were homeless, 3,000 were in prison within three years of aging out.

While the crime statistics above are specific to Russia and Ukraine they should give you a pretty good idea of what orphans around the globe can look forward to when they age out.

Some nations simply don’t track their orphans beyond release from institutions so there is no way to know for sure, but it is safe to assume the experience is similar for older orphans worldwide. With no job-skills training and no social safety net in place, these young adults don’t have much to look forward to. Add to that the fact that in many nations orphans will never lose their social stigma (some of them literally carry papers around for life designating them as orphans) you can see that the obstacles these young people face are enormous.

For the young HIV-positive adult the burden of caring for their health looms even larger. How can a person afford medications and treatment with no job skills or education? The statistics I referenced above show just how the cycle plays out over and again. Having had their emotional, physical, and spiritual needs ignored, most orphaned adults live a life of crime, drugs, and prostitution, and in turn produce more orphans. Nothing will change, unless someone is willing to break through and pull teens out before it is too late. Until space is created for these young people within a loving family I’m not sure any real change can be accomplished.