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Risks and Responses: HIV and AIDS and People with Developmental Disabilities

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HIV is one of those topics that we all tend to exclude from our developmental disability discussions. But today, December 1st, World AIDS Day, we need to talk about it. HIV can affect everyone, so everyone needs to know about it, and that includes people with developmental disabilities and the staff who support them.

What do we need to think about for people with developmental disabilities?

“Let’s not talk about HIV because it doesn’t apply to people with developmental disabilities.”

It would be nice if we could say: HIV is something that we don’t have to worry about in the developmental disabilities community. But that’s just not true! For HIV to be irrelevant to people with developmental disabilities, we would have to say with certainty that: 1) they aren’t exposed to sexual partners with HIV (because they only have sex with other HIV negative people, or because they don’t have sex), and 2) they aren’t exposed to HIV through needle sharing because they only use clean needles, or they don’t use injectable drugs.

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Here are the facts about people with developmental disabilities:

People with developmental disabilities have sex. Sometimes their partners have HIV and they don’t use protection. Some of these interactions may be consensual, and some may not. It is even possible that someone with a developmental disability can get HIV from one of their care providers. This happened in a residential program in Israel, where three individuals with severe disabilities were infected.

People with developmental disabilities use drugs. Addiction rates in those with developmental disabilities are as high as, if not higher than, the general population. So, it is possible that some of these individuals use injectable drugs. And that can pose a risk.

This past year, we looked at Ontario-wide rates of HIV for adults with and without developmental disabilities. Rates of HIV were similar in the two groups. However, the group with developmental disabilities



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was younger and also had more women in it than those with HIV without developmental disabilities.

Importantly, people with developmental disabilities and HIV had more health problems and used more health care [services than people with only HIV](#) or only [developmental disabilities](#), meaning they have lots of health care needs we need to address. Our study could not tell us how they came into contact with HIV, or the types of treatments they were getting, but it was an important starting point for getting us to think about how we might encourage more conversations on HIV in the developmental disabilities community.

Precursors to HIV prevention in people with developmental disabilities:

Before we look at prevention, we need to understand two ways that make people with developmental disabilities more vulnerable to HIV which may explain some of the statistics on HIV in the developmental disabilities population. It's important to remember that disability is more than a diagnosis, it has real meaning in the lived experience in the way people with developmental disabilities live their lives.

- 1) [People with developmental disabilities are at increased risk of sexual abuse than other people, and 97 to 99% of abusers are known to them, sometimes in caregiving roles.](#) So clearly people with developmental disabilities need to have training in recognizing and reporting abuse. Further, they need to learn a strong set of boundaries so they can be more alert to the grooming behaviours that they may experience from support workers or others in their familial and social circles. It's impossible to discuss the rate of HIV in the population of people with disabilities without also recognizing that people with disabilities are, without training and without encouragement to use assertion skills, being left vulnerable to unwanted sexual behaviour.
- 2) Loneliness and social isolation are not uncommon amongst people with developmental disabilities. In fact [people](#) with disabilities are much more likely to experience loneliness than those in the typical population. In [studying HIV / AIDS in people with disability in South Africa](#), it was reported that, "Social isolation and increased risk of manipulation ..." was one of the factors that increased risk for people with disabilities to engage in risky sexual behaviour in order to maintain even an exploitative relationship. Staff need to understand how important it is to help the people they support to build relationships with others that are positive and safe.

How do we prevent HIV in people with developmental disabilities?

- (1) We get educated about how it is contracted
- (2) We learn skills to promote safe sex and safe needle use, and
- (3) We get screened if we think we might have been exposed through:
 - a) needle use
 - b) consenting sexual behaviour
 - c) victimization or exploitation

(1) Get educated about how HIV is contracted:

You need education to understand how it is contracted. But so long as we believe that people with developmental disabilities can't get HIV because they don't have sex and they don't use intravenous drugs, we won't see the need to offer that education. So let's start by changing our attitudes and beliefs and making HIV education more available.

But we cannot just use the same HIV education we provide to others. A lot of what is already written, and the videos that were made were not designed with this group in mind. We have to stop to think about HOW to do the educating. How do we make sure people with developmental disabilities understand what we are teaching them? This might include writing information in simpler language, using concrete examples, putting information into video and not just print formats.

(2) Learn skills to practice safe sex and needle use:

These skills might include knowing how to use a condom, and how to use clean needles. But they also include assertiveness and negotiating skills. How do you have a conversation with someone who wants to have sex with you but doesn't want to use a condom? So not only do we need to teach information, we need to teach skills. Presently, those skills are lacking for many people with developmental disabilities. Sadly, sometimes HIV can be contracted through sex with someone when you don't consent. So people need skills and support to make sure that they are not taken advantage of by others so, if they are in a situation they don't want to be in, they can get help.

(3) Get screened:

Getting screened for HIV takes skills to know: Where do you go to get screened? How do you do it independently? If you ask for help, will you be judged for making a poor choice? What if you want to keep this information private?

So we need to teach about HIV screening and the importance of doing it quickly, why, how, and who you can safely ask for help from, without feeling judged.

PEP – this stands for post-exposure prophylaxis. It involves taking a combination of pills for four weeks. It needs to start right after you think you might have been exposed to HIV (within 72 hours). This could be from having sex without a condom, or a condom breaking, or using a needle from someone who has HIV.

PrEP – this stands for pre-exposure prophylaxis. It involves taking a pill every day to reduce the risk of getting HIV. It is prescribed by a doctor, and anyone taking PrEP needs to be monitored regularly by their doctor. It is something to talk about with the doctor if you don't have HIV but think you are at risk of getting it.

That is a whole lot of education.

What if someone you support has HIV?

Staff might have questions about what that means for their own risk of exposure. This is not something that we have focused on in the community sector. Here are some facts to answer concerns of staff...

HIV cannot be spread through touching someone with HIV, or through the air. You cannot get it from doorknobs, mosquito bites or sharing eating utensils with someone with HIV. It is transmitted through contact with an HIV-positive person's infected body fluids, such as semen, pre-ejaculate fluid, vaginal fluids, blood, or breast milk. It can also be transmitted through needles contaminated with HIV-infected blood, including needles used for injecting drugs, tattooing or body piercing.

Staff can also be educators to the people they support with HIV about what it means to have HIV, how to protect others from getting it, and how to take care of your health if you do contract HIV.

Topics to educate on include:

- HIV medication compliance, HIV medication side effect management
- symptoms of HIV
- physical health problems associated with HIV
- mental health problems associated with HIV
- how to talk about HIV with health care providers, and how to talk about it with friends and family

These are very important conversations. In our research on HIV and developmental disabilities, we learned that people with developmental disabilities had more physical and mental health problems than people who had HIV only, and people who had developmental disabilities only. It is not surprising, therefore, that people with HIV and developmental disabilities also used more health services. Staff can really help with this. It might mean more complex profiles in the first place, but it can also mean that better care might prevent all the care that ends up being used, especially emergency care and hospitalizations.

This article has focused on HIV in people with developmental disabilities. But keep in mind that HIV also impacts staff who support people with developmental disabilities, families and friends. Awareness and education can reduce the stigma for everyone. So this year on World AIDS Day, get educated because it impacts all of us.

Helpful Resources

<http://www.easyhealth.org.uk/listing/hiv-and-aids> (leaflets) – this link gives information about HIV written for people with developmental disabilities but it is from the UK so some of the information about where to go to get help would not be useful for people who live in other places.

Resources on HIV (but not for developmental disabilities specifically)

<http://www.catie.ca/sites/default/files/hiv-basics-en.pdf> for basic information about HIV

<http://www.catie.ca/en/practical-guides> (other useful practice guides)

<http://www.actoronto.org/> (health information tab)

<https://www.cdc.gov/hiv/library/factsheets/index.html> - click on consumer information sheets

<https://www.hiv.gov/blog/let-s-try-keep-it-simple>

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