

# Autism & 90 90 90: Reaching for the Goal



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# **Agenda:**

**What is Autism?**

**Autism & HIV Prevention Needs  
Assessment**

- Literature Review**

- Online Survey Data & Quotes**

- Recommendations & Learnings**

**Questions?**

# Introductions: Ryan Lisk & Brandon Wulff

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Please keep applause to a quiet clap or the deaf clap



Do you know an Autistic person?

# Autism & 90 90 90: Reaching for the Goal

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*“How do I have sex? Like how does it happen? I know how the mechanics of sex works, but like, how do I get in that situation in the first place? I don’t understand it. I’m so horny all the time and masturbation isn’t good enough. I just want to have sex with someone but I don’t know how to even begin.”*





# **What is Autism?**

# Autism is:

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## A Non-Verbal Social Communication difference with a narrow focus



- We don't translate non-verbal, social communication
- We don't understand taboo's or social constructs
- We are specialized thinkers
- We have detailed rituals and routines but not OCD

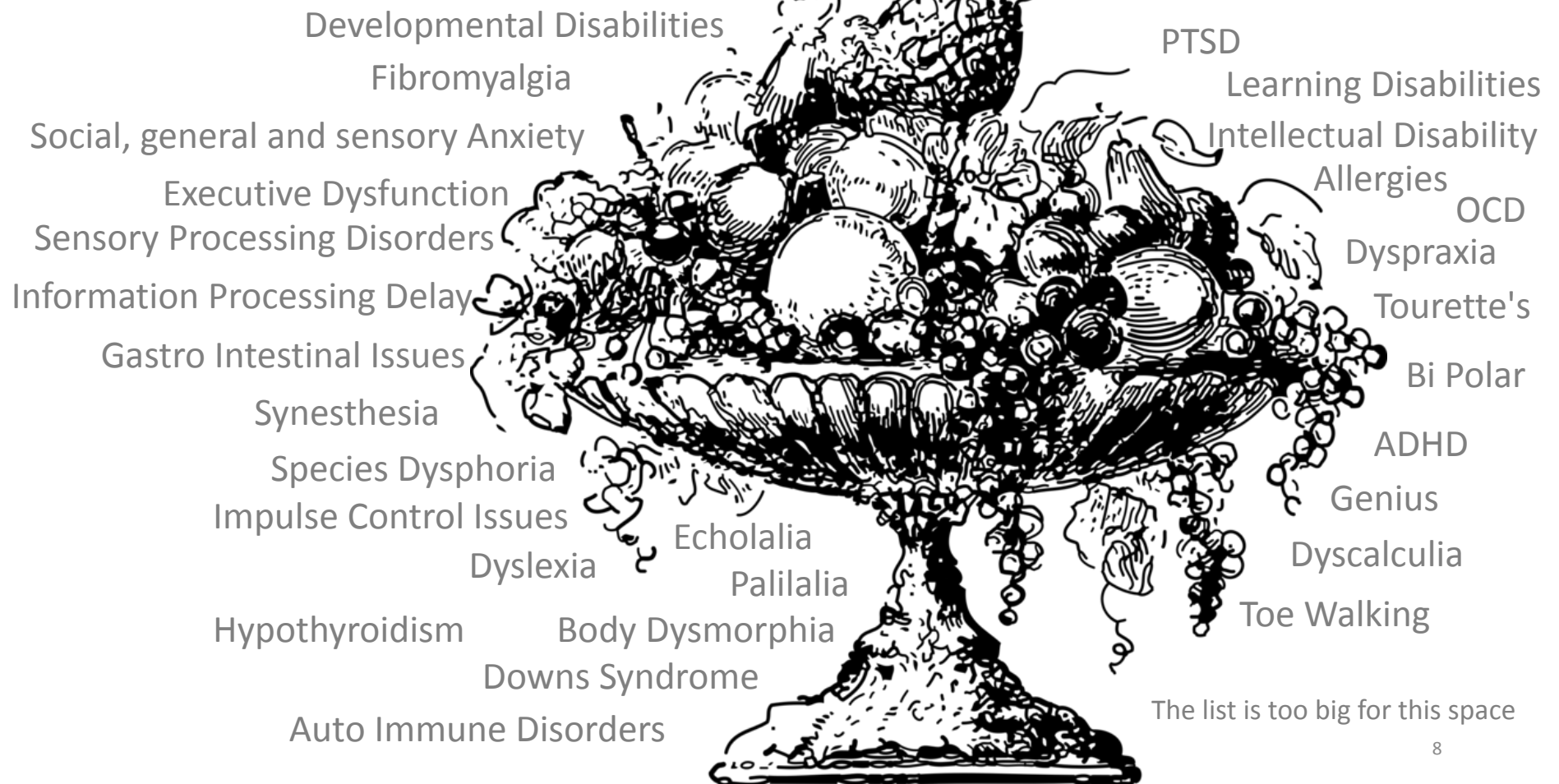
Satoshi Tajiri created Pokemon based on his narrow focus of bug collecting and categorization this is Autistic Narrow focus

# Autism is a Non-Verbal Social Communication difference

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I was in LA, and ah, I was walking around and there was a guy and he wanted me to drive his car home because he was too drunk. I said ok, ya, sure. He offered me \$100 and then I went, and umm, he started asking me questions questions about my penis and things and I said, oh I'm not comfortable with this but then he kept the conversation going and I continued to drive him home. At that point it was uncomfortable because he was asking me to like take off my clothes and things and I said, I was not comfortable, so in that way I kinda felt tricked. It was just awkward and ah, I was standing there awkwardly. The guy said Oh, I have to go I drove him home and took a cab from there. I have never heard of PrEP, is PrEP condoms? - Focus Group

# Autism is a fruit salad of disorders



## Functioning Labels

# Can you cut and boil potatoes?

Do you remember to turn off the stove?



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## Purs(on) First Language

### Person Living with (HIV)

Person first:  
Something outside of  
the person that needs  
to be treated or  
cured.



### (Autistic) Person

Identity first:  
This is who the  
person is. No need  
for a cure does not  
need fixing.

**Autism is not an accessory**

Please note we are in no way saying that Bob the Drag queen is Autistic or HIV+

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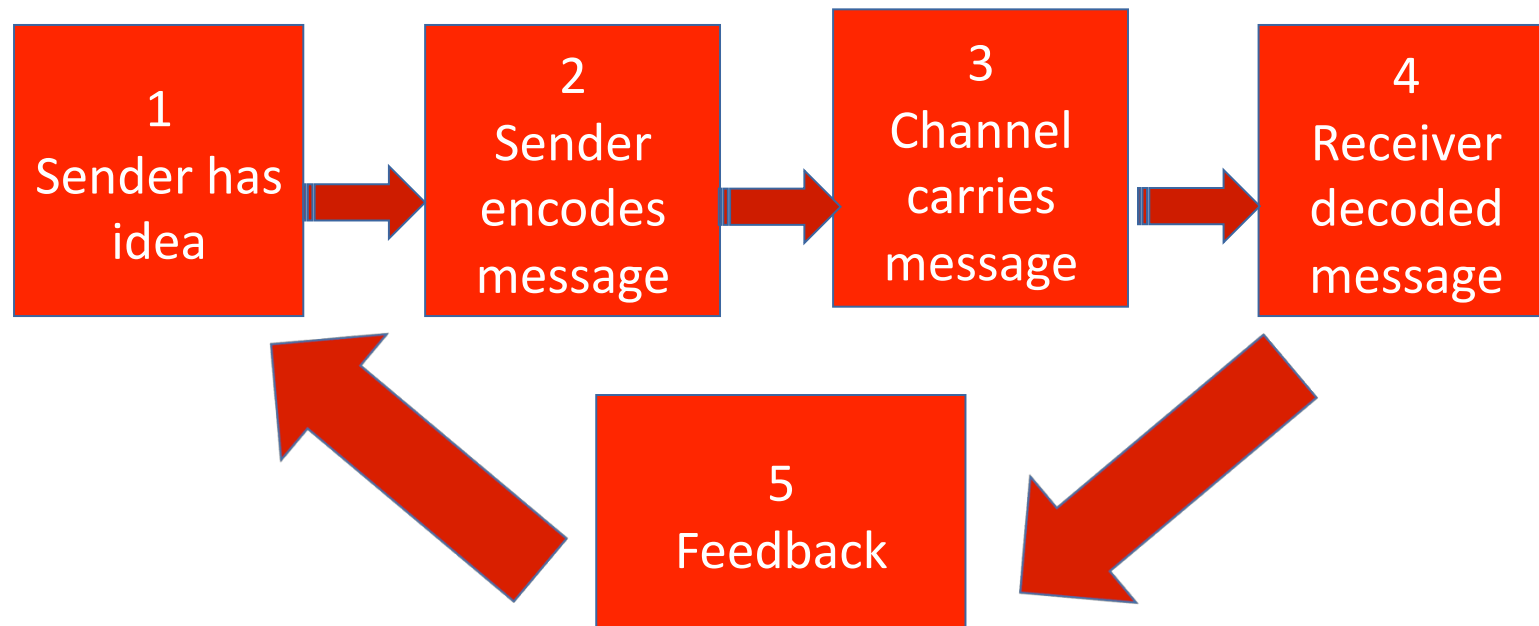
Autism is not a processing error like mental health.  
Autism is a different operating system.



# The Feedback Loop

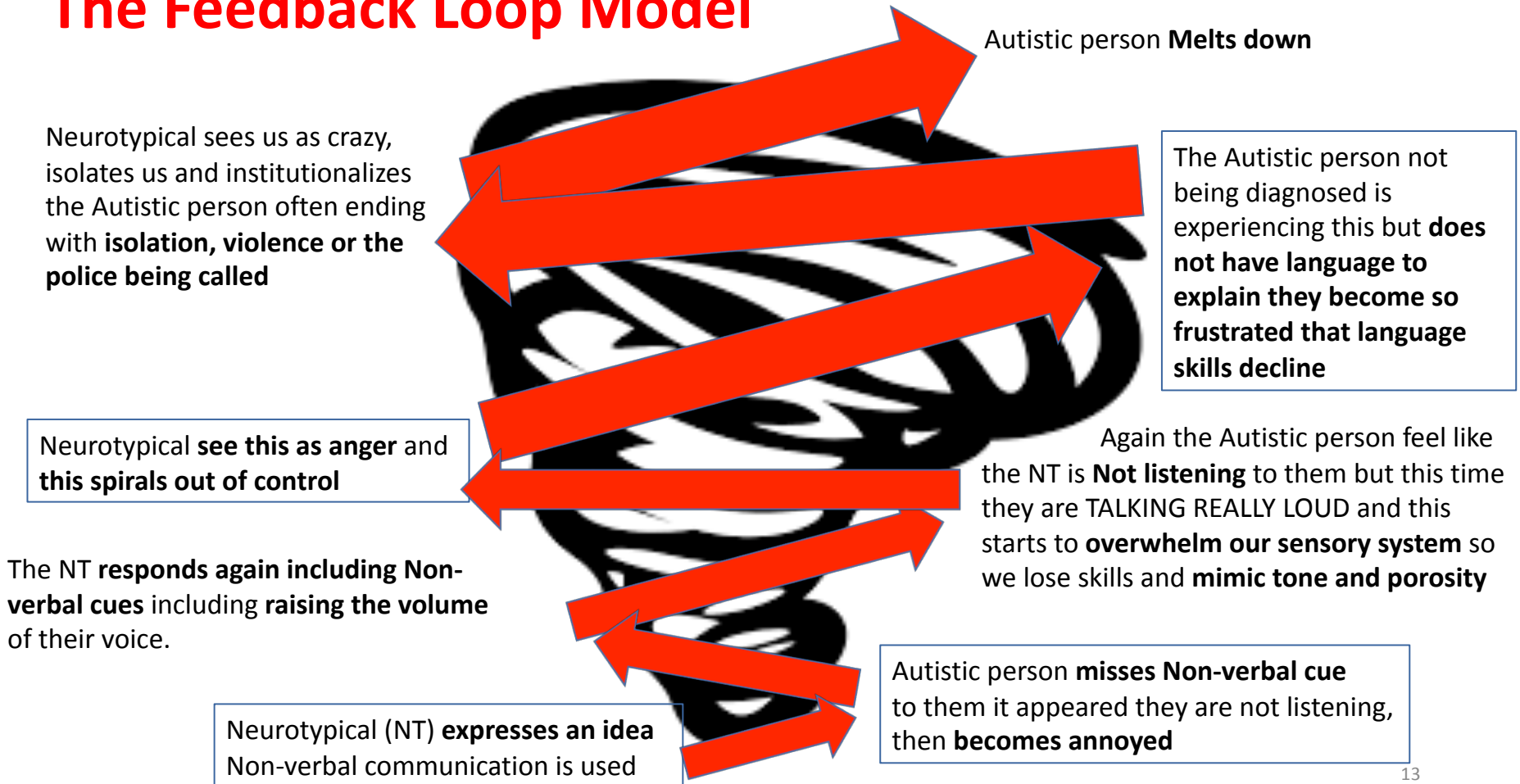
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Basic communication model





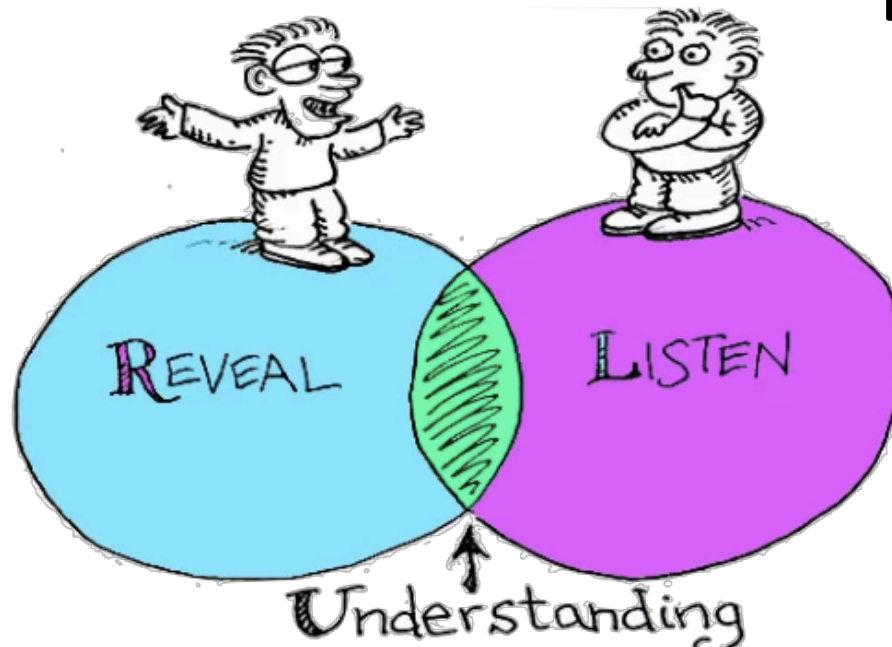
# The Feedback Loop Model



## Listening to Autistic people

Autistic people are “truth tellers”, if you listen with ego you will get hurt, person centered approach always works best.

# Intention VS Perception



14

Don't worry  
about it  
An  
responded

## 90 90 90: THE UNAIDS STRATEGY TO FURTHER CURB THE HIV EPIDEMIC

based on expanded access to treatment and on the “treatment as prevention” concept

**90%**

of all people  
living with HIV  
will know their  
HIV status

2015: 88.3%

**90%**

of all people  
diagnosed with  
HIV will receive  
sustained  
antiretroviral  
therapy.

2015: 81.9%

**90%**

of all people  
receiving  
antiretroviral  
therapy will have  
durable  
suppression.

2015: 80.7%

15

# What participants said about Accessibility

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- My previous family doctor would rush me and talk over me, as well as contradict other specialists - it's difficult enough as is for me to talk to doctors, so the added intimidation made me basically never go there, and when I did I never had my issues addressed.
- When people misinterpret my communication or give greater credence to my non typical body language over my words. People are dismissive when I point out stuff causing sensory problems, or think I am lying about struggles because I am educated and should be able to do something in their opinion.
- Personal stress of the Doctor

# **Autism Spectrum Disorder (ASD) & HIV Prevention Needs Assessment**



- Ryan and Brandon met on a regular basis for about 3 years
- Advisory Team slowly grew
- We applied for and were awarded the **TUHF Toronto Urban Health Fund** for a Needs Assessment



**Dr. Kevin Stoddart**



**Dr. Johnathon Weiss**



**Dr. Yona Lunsky**

**Dr. Gordon Gates**

**St. Michael's**

Inspired Care. Inspiring Science.

**Dr. Sean Rourke**

# **Rationale: What the science says (aka: Literature Review)**

**“Those with [Intellectual Developmental Disabilities (IDDs)] are at greater risk for experiencing sexual abuse than the general population, which predisposes this group to forced unsafe and risky sex.”**

(Aderemi, Pillay & Esterhuizen, 2013; Hanass-Hancock, 2009).



Furthermore, cognitive differences including decreased impulse control and impaired judgment can result in people with IDD engaging in risky sexual and drug-using practices that increases their risk of HIV infection. (Brown & Jemmott, 2002; De Beaudrap, Macseing, & Pasquier, 2014; Hanass-Hancock, 2009).

Another major barrier to protection from HIV is a lack of appropriate resources to educate individuals with IDD about safety.(Cheng & Udry, 2005; Greenwood & Wilkinson, 2013; Groce et al., 2013; Mandell et al., 2008).

A recent collaborative scoping review by researchers from the Centre for Addiction and Mental Health, the University of Toronto, St. Michael's Hospital and the Institute for Clinical Evaluative Sciences, all based in Toronto, analyzed 32 documents pertaining to the intersection between IDD and HIV (Jung, Heifetz, Durbin & Lunsky, 2017). A recurring theme amongst the literature was poor knowledge and attitudes towards people with IDD by service providers, including notions that individuals with IDD are incapable of engaging in intimate relationships, are not at risk for HIV and would not benefit from preventative measures.(Aderemi, 2014; Alford, Aruffo, Thompson, Dobbins, & Gottlieb, 1994; Macdonald, Murray,& Levenson, 1999).

**“Additionally, inconsistent condom use was found to be a common risk factor for HIV in individuals with IDD, which suggests a lack of appropriate education on contraception from providers.”**

al., 2013)

(Aderemi et

Thus, sex education is a critical tool for HIV prevention among young adults and has been demonstrated to be cost effective (Hogan, 2005). Unfortunately, several studies have found that people with IDD tend to have fewer opportunities to access sex and HIV education compared to people without IDD (Aderemi & Pillay, 2013; Aderemi et al., 2013; McGillivray, 1999).

In particular, a recent review by Jung et al. found that individuals with IDD had a significant lack of understanding of HIV and HIV transmission. One of the key barriers to sex education in the IDD population includes the attitude by health service providers that patients with IDD are less likely to form intimate relationships, be at risk for HIV, and/ or benefit from safe sex and HIV education (Jung et al ).

**“Contrary to population belief, numerous studies have reported that IDD individuals engage in high risk sexual behavior that may put them at risk for acquiring HIV.”**

(Aderemi et al. 2013, Brown and Jemmott, 2002).

Specifically, poor condom use was one of the most commonly found high risk behavior among numerous studies. Moreover, work by Durbin et al. recently reported that substance abuse was more common in the IDD population compared to that in non-IDD adults, and that IDD individuals who were HIV positive were more likely to have substance use disorders in comparison to IDD individuals without HIV.

Studies that have explored the effects of sex education on the knowledge and behavior of IDD individuals have obtained reassuring results (Jung et al). Several educational strategies have been investigated, including computer-based interactive lessons (Carr-Nangle et al, 1997), role play based skills training (Scotti, Speaks, Masia, Drabman, & Boggess, 1996),

Studies that have explored the effects of sex education on the knowledge and behavior of IDD individuals have obtained reassuring results (Jung et al). Several educational strategies have been investigated, including computer-based interactive lessons (Carr-Nangle et al, 1997), role play based skills training (Scotti, Speaks, Masia, Drabman, & Boggess, 1996), as well as lecture and discussion based teaching methods. These studies consistently demonstrated an improvement in the knowledge of HIV transmission and HIV prevention among IDD study participants, highlighting the fact that IDD individuals benefit from sex and HIV education programs (Jun et al).

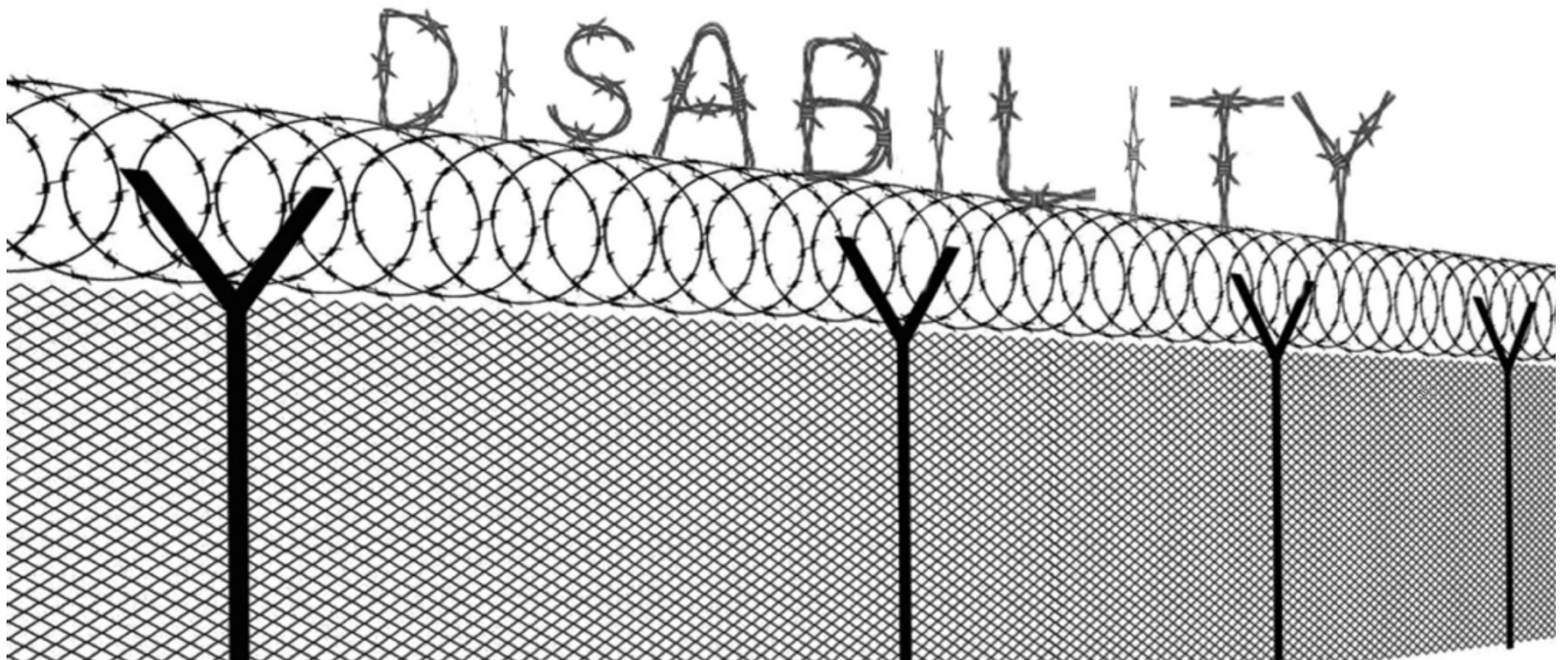
Therefore, it is imperative for the safety and well-being of IDD, and more specifically ASD population, that a needs based assessment be conducted to define specific strategies that can be developed in order to meet the sex educational needs of this population and promote safe sexual practices. As it has been stated by the United Nations Special Rapporteur on the Right to Education, access to education on sexual and reproductive health is a human right (UN Human Rights Council, 2010).



**Several studies have found that school based sex education is an effective strategy for promoting HIV related knowledge and for decreasing high risk sexual behaviors. Sex and HIV education programs have been shown to increase condom use, delay sex, and decrease the number of sex partners.**

(Fonner et al, 2014).

**Our work aims to address the barriers that currently exist to sexual education in our ASD community and to create strategies that will improve sexual safety.**



# **What Needs Assessment Participants Told Us (Online Survey \*Data & Quotes)**

\*The data presented here is **preliminary**, and is still being analysed by our research team.

# Our Toronto Participants: N=47

We had 2 million impressions of Advertising



8941 Visits

Survey length

Mean 1:45:29

Median 00:29:54



176 Internationally

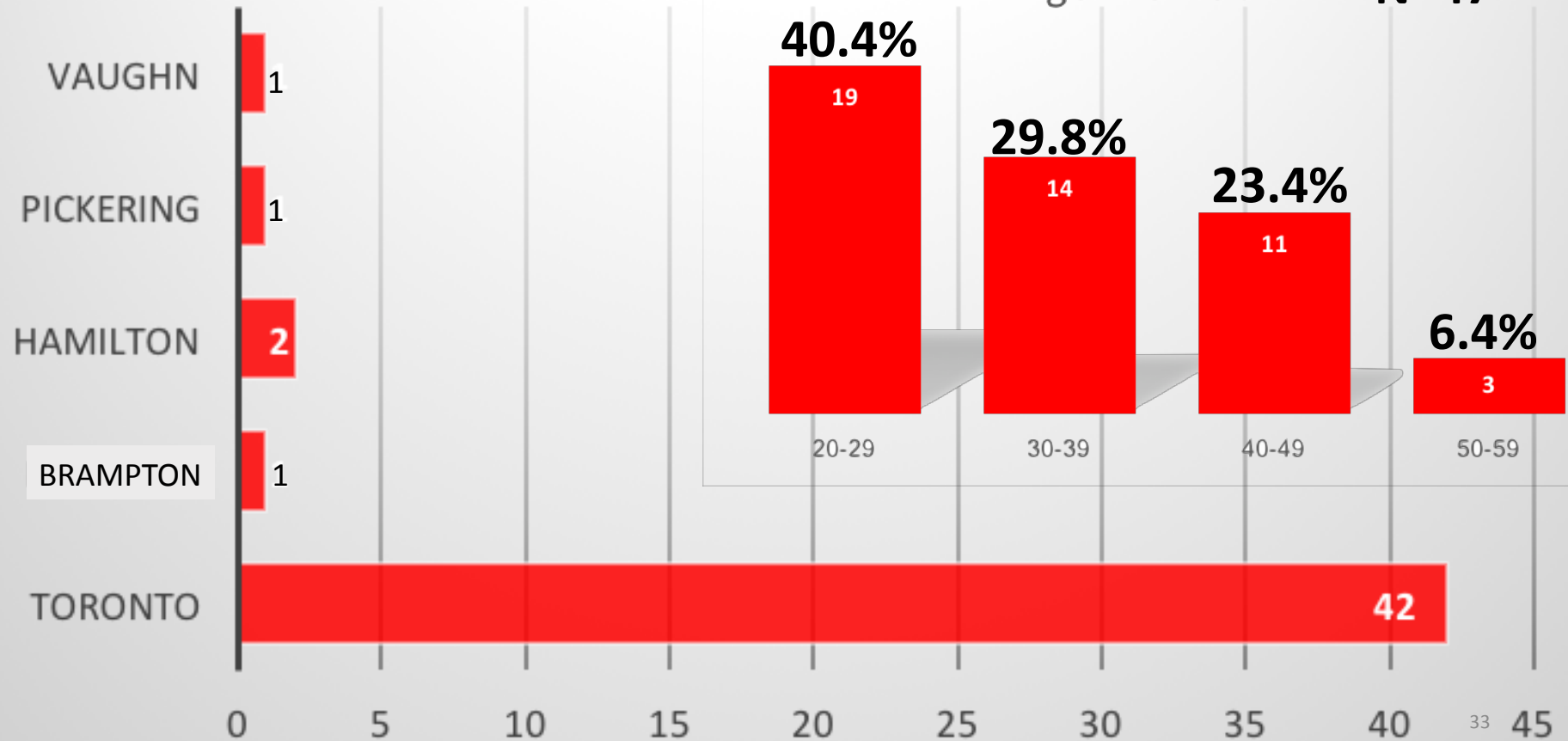


91 Canadian

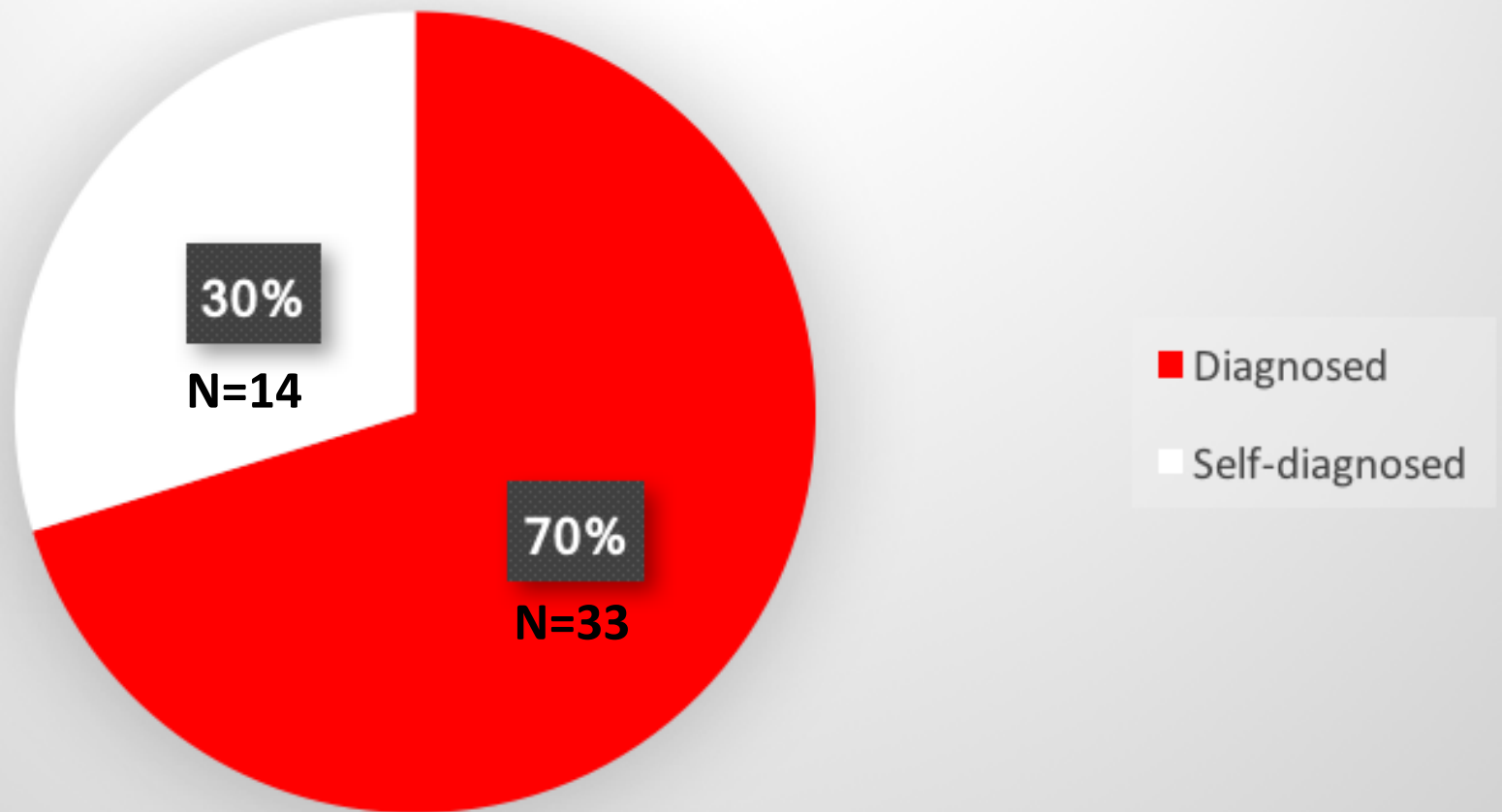


72 Ontarians

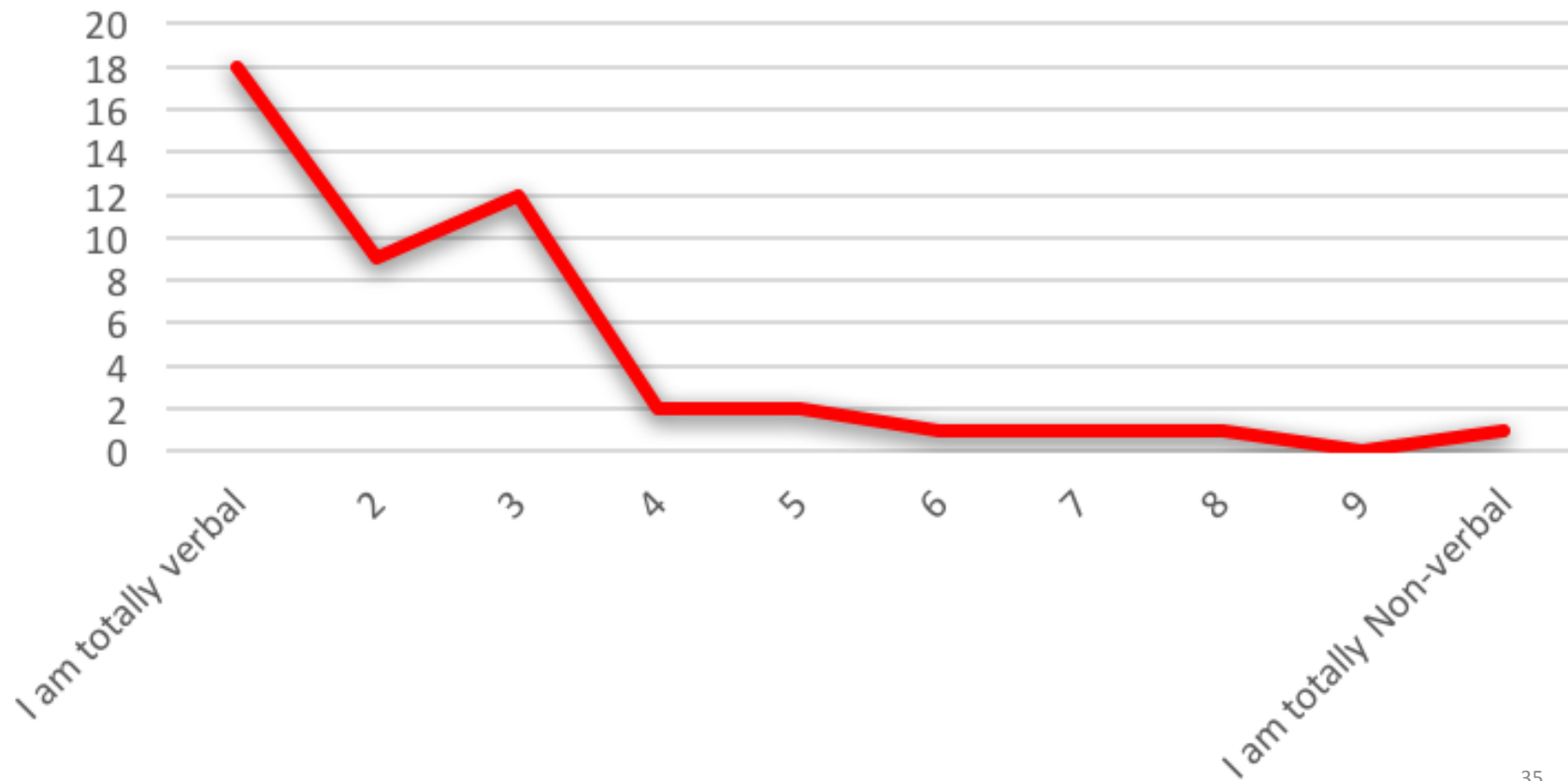
# Location



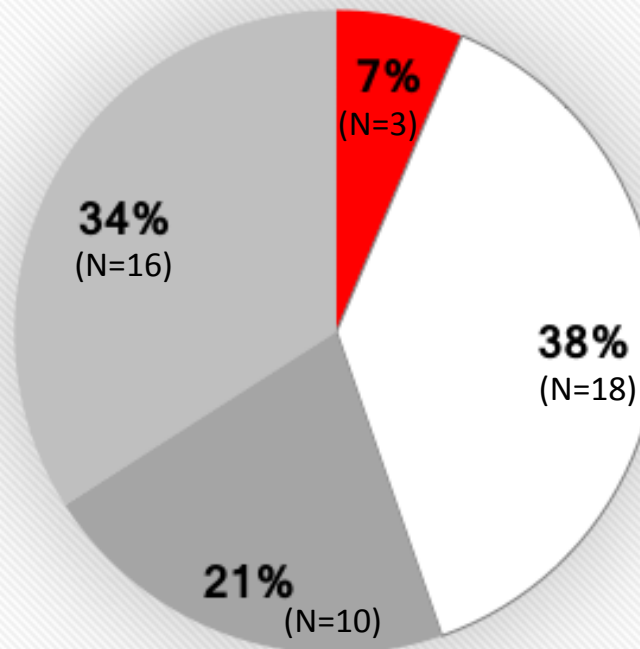
# Are you Diagnosed Autistic?



## How verbal are you



## Mutism during sex

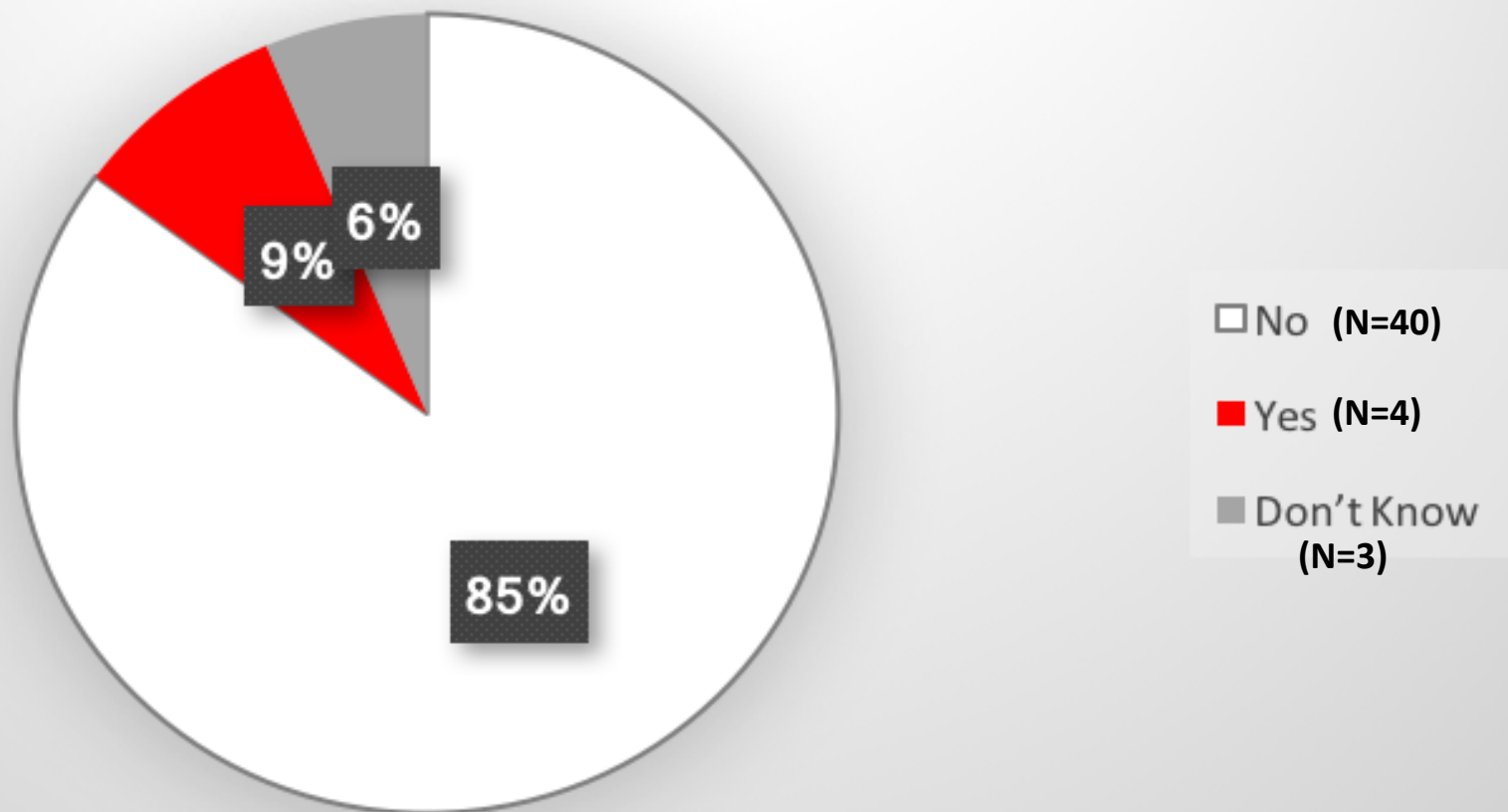


■ Yes □ Frequently ■ Rarely ■ No

36  
(N=47)

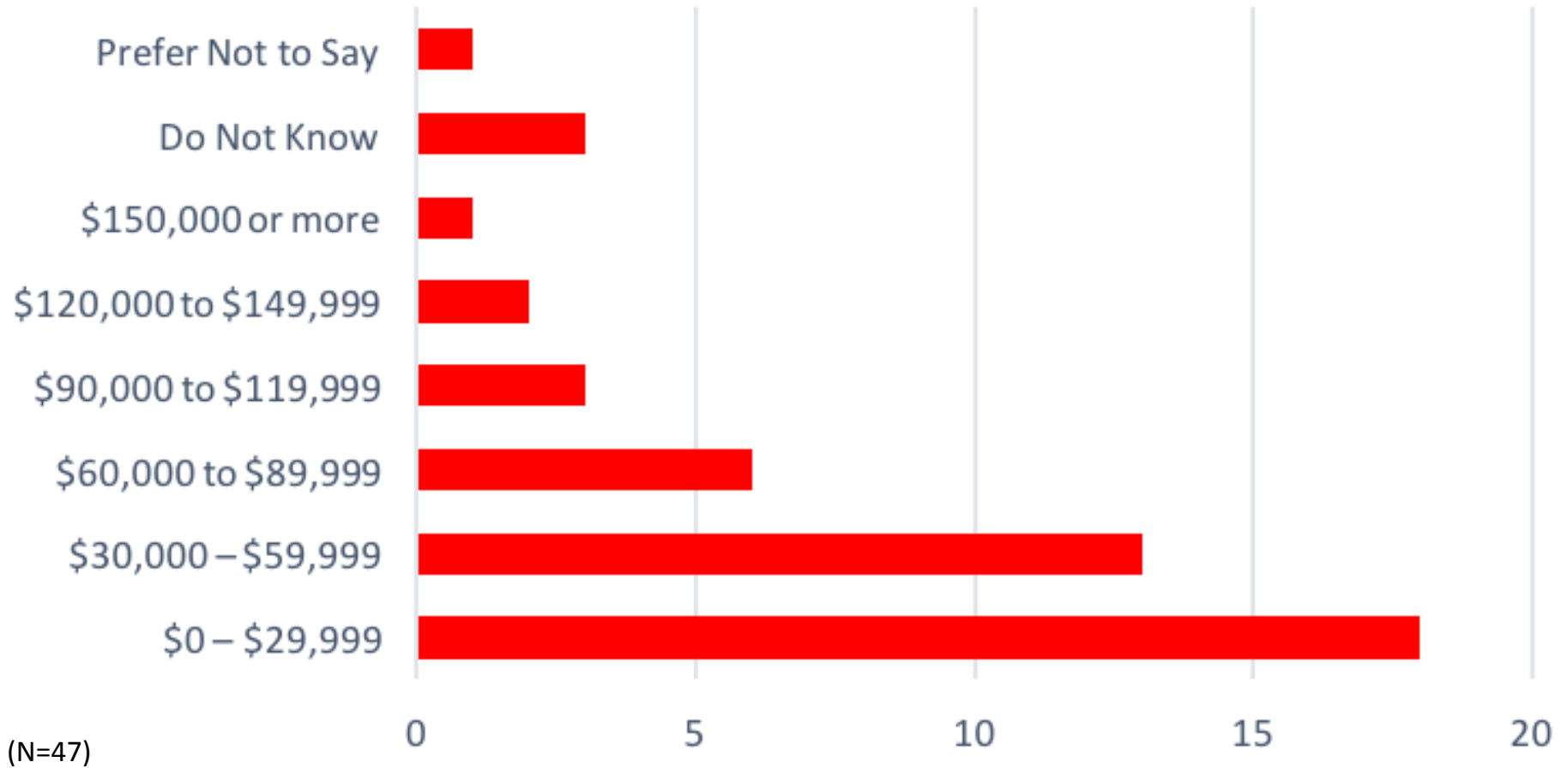


## Are you Living with HIV/AIDS

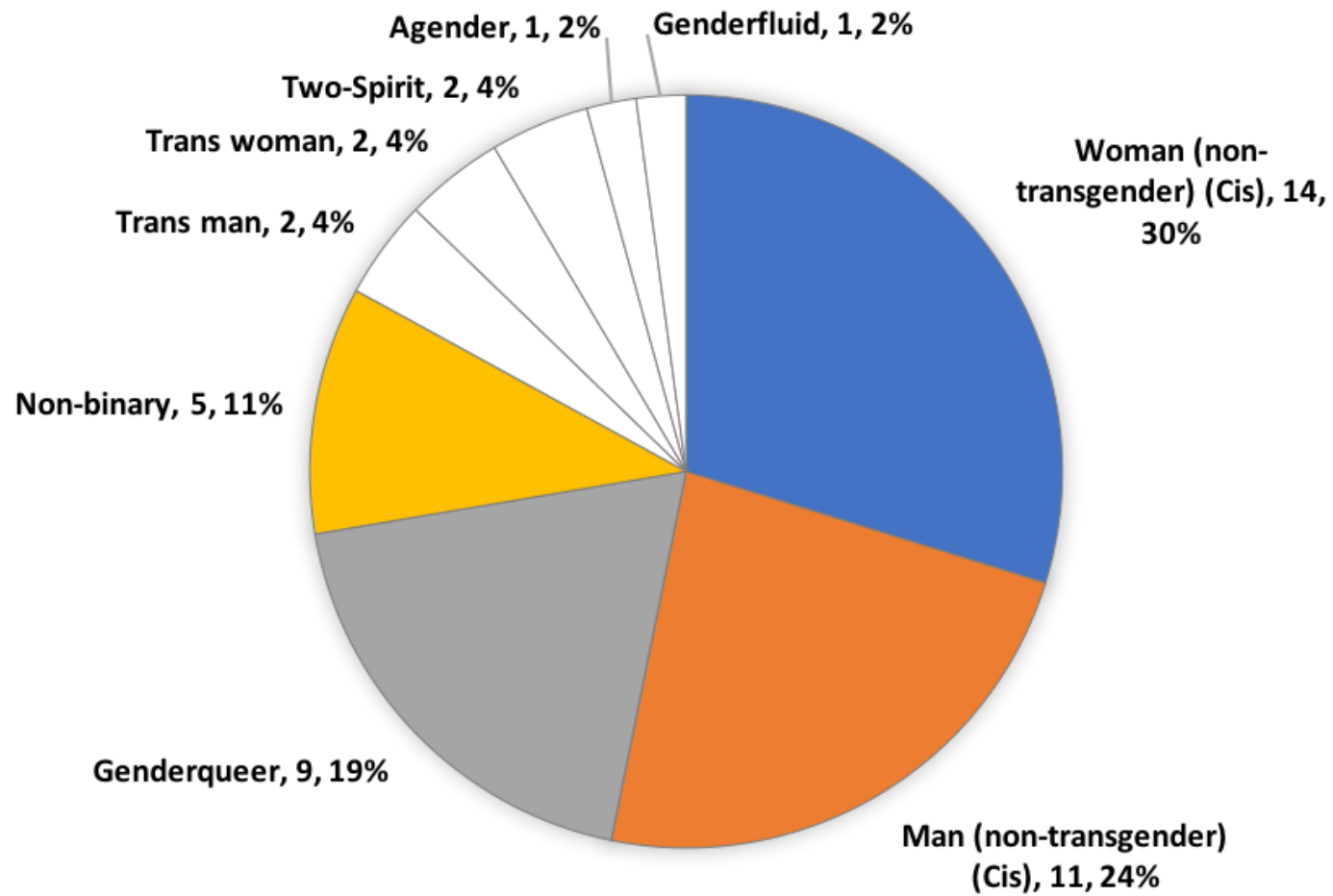


**N=47**

## Household Income

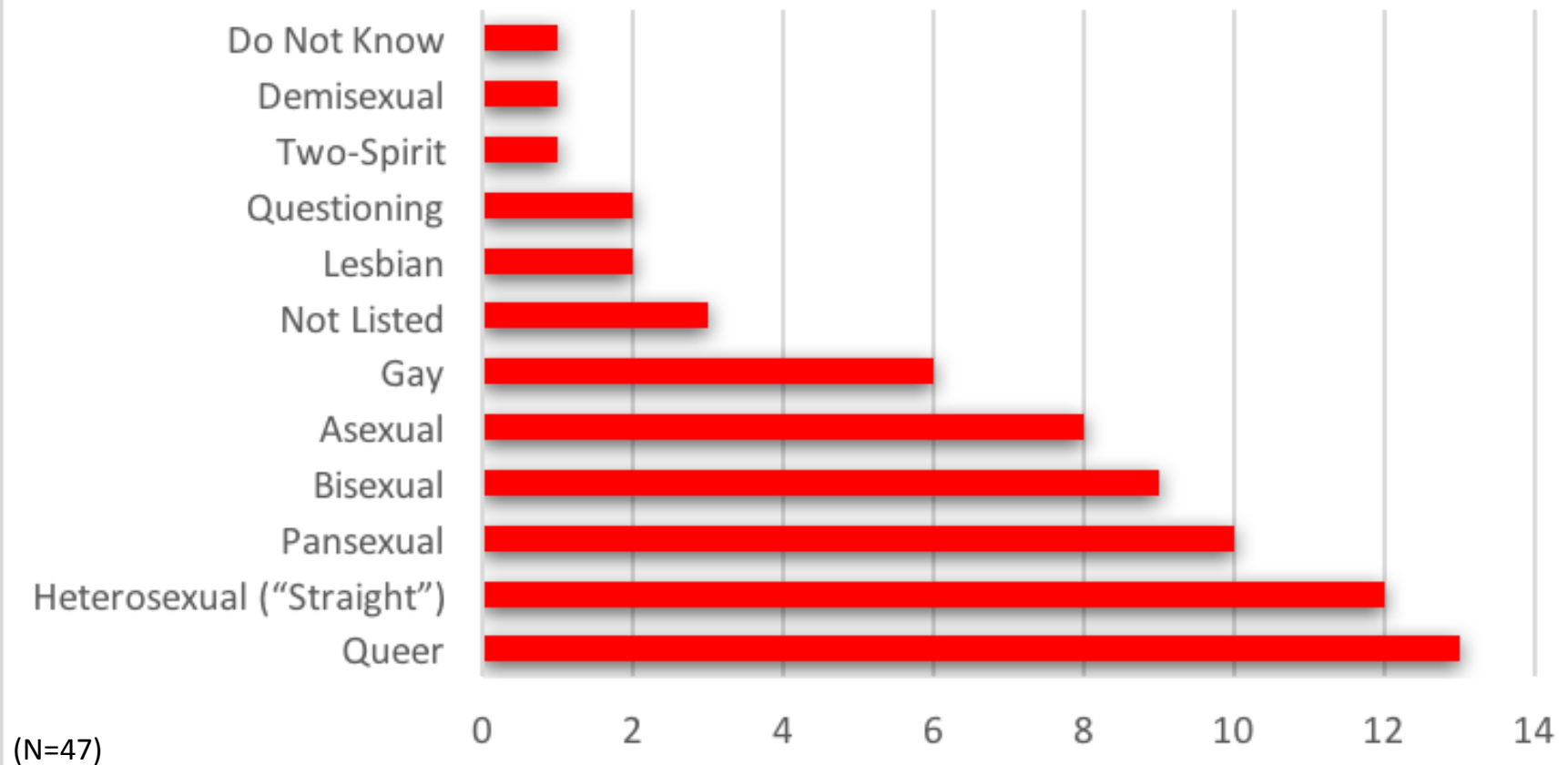


## GENDER



(N=47)

## Sexual Orientation



Cis Gender Heterosexual men  
and women each made up only  
13% of the sample.

**N=6 men & 6 women**

# How do you know if someone is interested in you?



## How do you know if someone is interested in you?

“I don't. Or I only realise it in retrospect, after whatever has passed.”

“I used to know when people were interested by recognizing flirting and such, but I had to train myself into it. It's been a really long time and I'm not sure I've retained the skill and, to my knowledge, no one has expressed such interest in years.”

# Netflix and Chill?

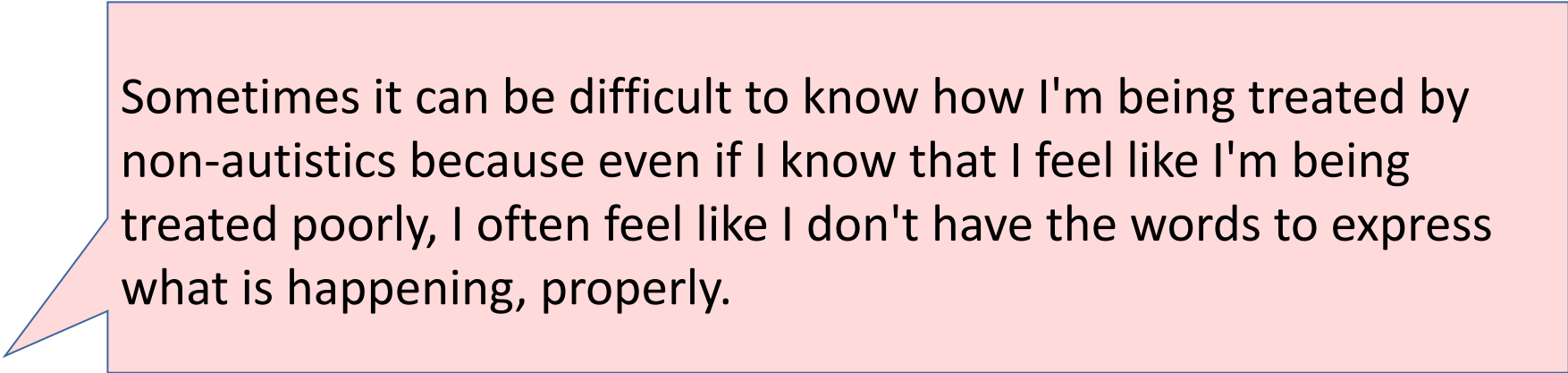
Sure I Love any of the science shows!



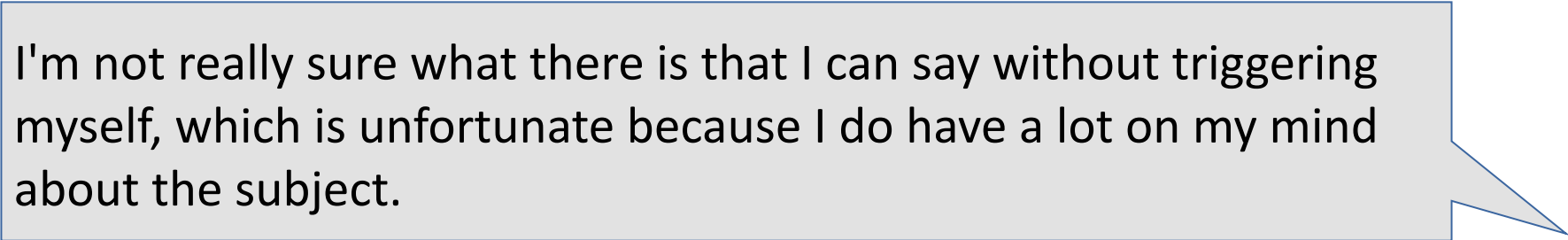


I know, for me, that I had problems around consent and saying 'no' in my early sexual experiences because I had no real understanding of the social norms around these things. As with many things, autistic people have trouble intuitively picking up the normative rules and guidelines around social activities, but this can have particularly awful consequences when it comes to sex.

I frequently don't know if I'm qualified to assess abusive behaviour because I tend to take shit and put up with shit accept the shit that's handed me for as long as I need whatever else I'm there for, like it's the cost of doing business. And then I leave, and I brush the dust off my boots, and generally, I don't go back, ever!

A pink speech bubble with a blue outline and a tail pointing towards the bottom-left corner.

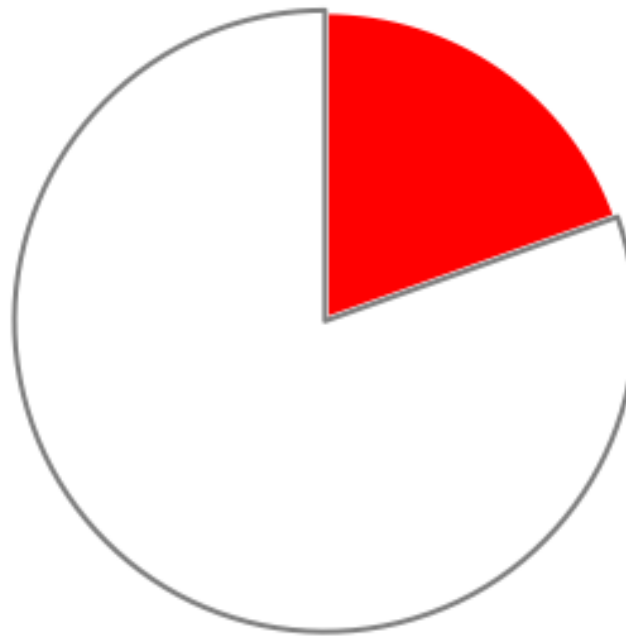
Sometimes it can be difficult to know how I'm being treated by non-autistics because even if I know that I feel like I'm being treated poorly, I often feel like I don't have the words to express what is happening, properly.

A grey speech bubble with a blue outline and a tail pointing towards the bottom-right corner.

I'm not really sure what there is that I can say without triggering myself, which is unfortunate because I do have a lot on my mind about the subject.

There are three men I'd provided services for in the past with whom I've managed somehow to maintain relations. One maintains the exchange of funds as a symbol of power and control, one likes to believe he's providing me with a benefit because the alternative would be to accept that he's aged, infirm, and short of outlets, and the third, money acts as a gate, because Love is too thorny a bramble. And then there's D&G, the couple who aren't a couple, who don't pay, but provide little care packages of party favours. I had a thing for one of them and so put up with the other. Then I realized how shitty an asshole the one I liked was. The other looked better by comparison. Fortunately, I've since realized that I don't need to compare them; they're a limp dick and a gaping hole, and I don't need to be bothered.

## Been forced or felt pressured, to trade money, drugs, gifts, or services in exchange for sex



Yes	N=9	19.6%
No	N=37	80.4%

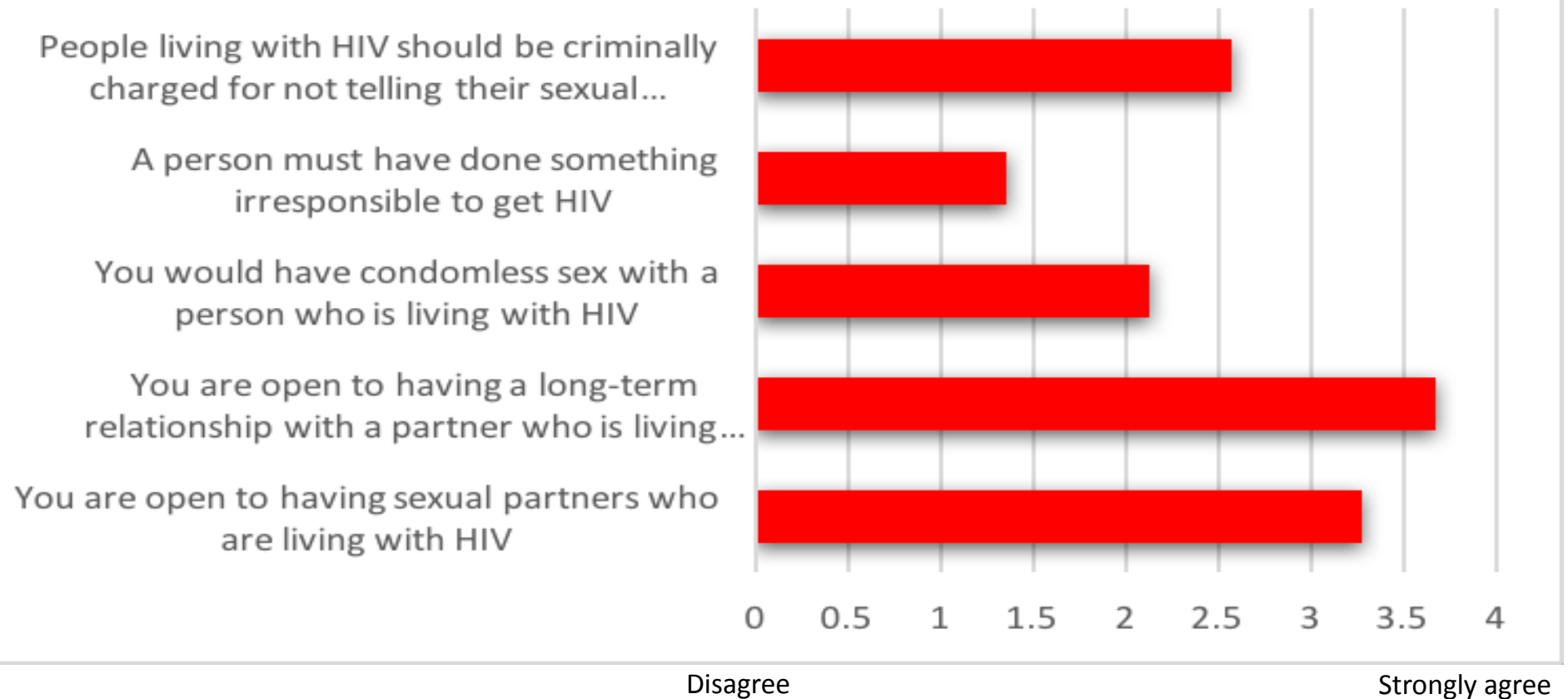
■ Yes □ No

N=46

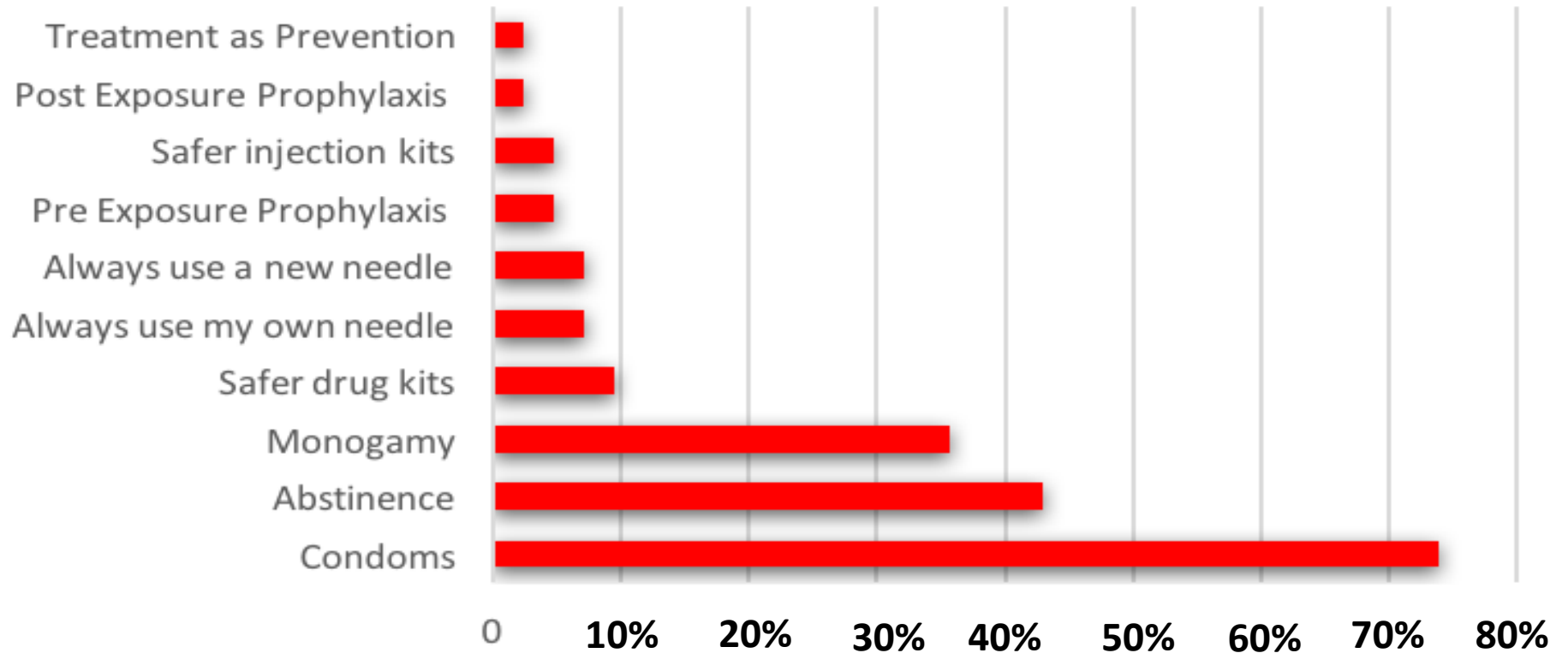
I think I interpreted the question wrong. I've felt forced to trade sex for things but not things to get sex. I don't like sex with other people enough to give things for it, but I have engaged in sex work and traded sex for money, food or a place to sleep.

I hooked up with a guy who took me to an ATM and threatened he was going to beat the shit out of me if I didn't give him cash. I met up with a guy online once who went all psycho and also threatened he was going to hurt me in my home if I didn't give him drugs or money fortunately I was twice his size and got rid of them. I also hooked up with a guy once who demand cash afterwards saying that this was a pay transaction when it absolutely wasn't

## HIV Attitudes



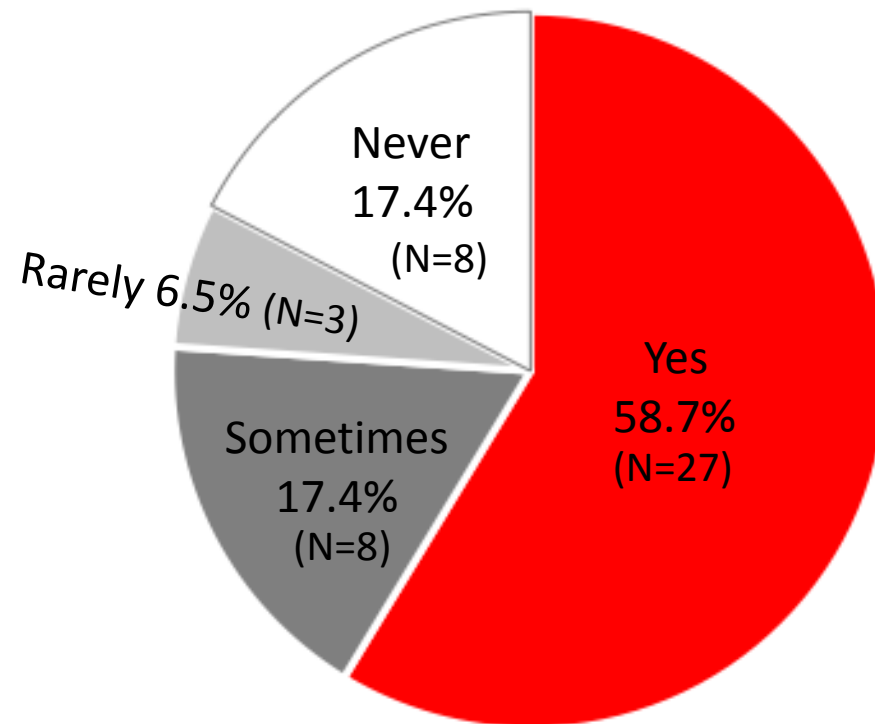
## Harm Reduction



N=42



## Do you use Condoms?



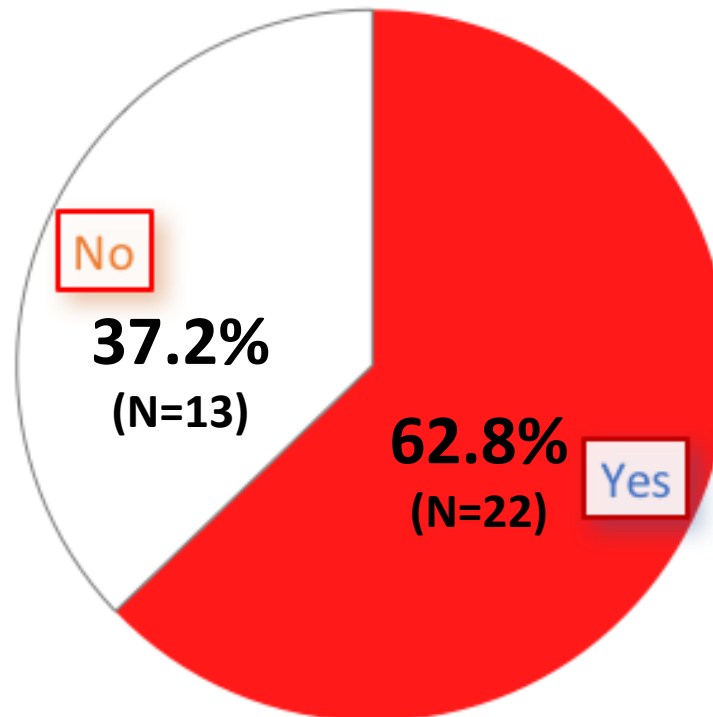
N=46

■ Yes ■ Sometimes ■ Rarely □ Never

# Do you have any sensory issues with condoms?



## DO YOU HAVE SENSORY ISSUES TO CONDOMS?



N=35

lube is fine, it's just the way that condoms feel that puts me off, not in a "oh it feels better raw" way, more in a 'this is physically uncomfortable holy shit' way-- that said, they're important, so i usually just deal with it

I find the touch of condoms difficult. Lube, it depends on the lube, but usually a good lube works well for me.

I hate when it touches my hands. Condoms feel like they will stick to my skin. Lube is too slippery and I can't let my fingers touch each other if there is any lube on.

# Recommendations & Learnings

Institutionalization ended in the 1980s but still exists today in the notion that society believes Autistic people IDD, LD, and Mental health belong in institutions.



# Education



# Ontario Human Rights Commission on Education

- The Ontario Human Rights Commission (OHRC) has recognized for some time that, despite a highly regulated and complex education framework designed to address the “special needs” of students, students with disabilities continue to face obstacles in their attempts to access educational services in Ontario. “Disability” continues to be the most often cited ground of discrimination under the Code in human rights claims made to the Human Rights Tribunal of Ontario (HRTO),



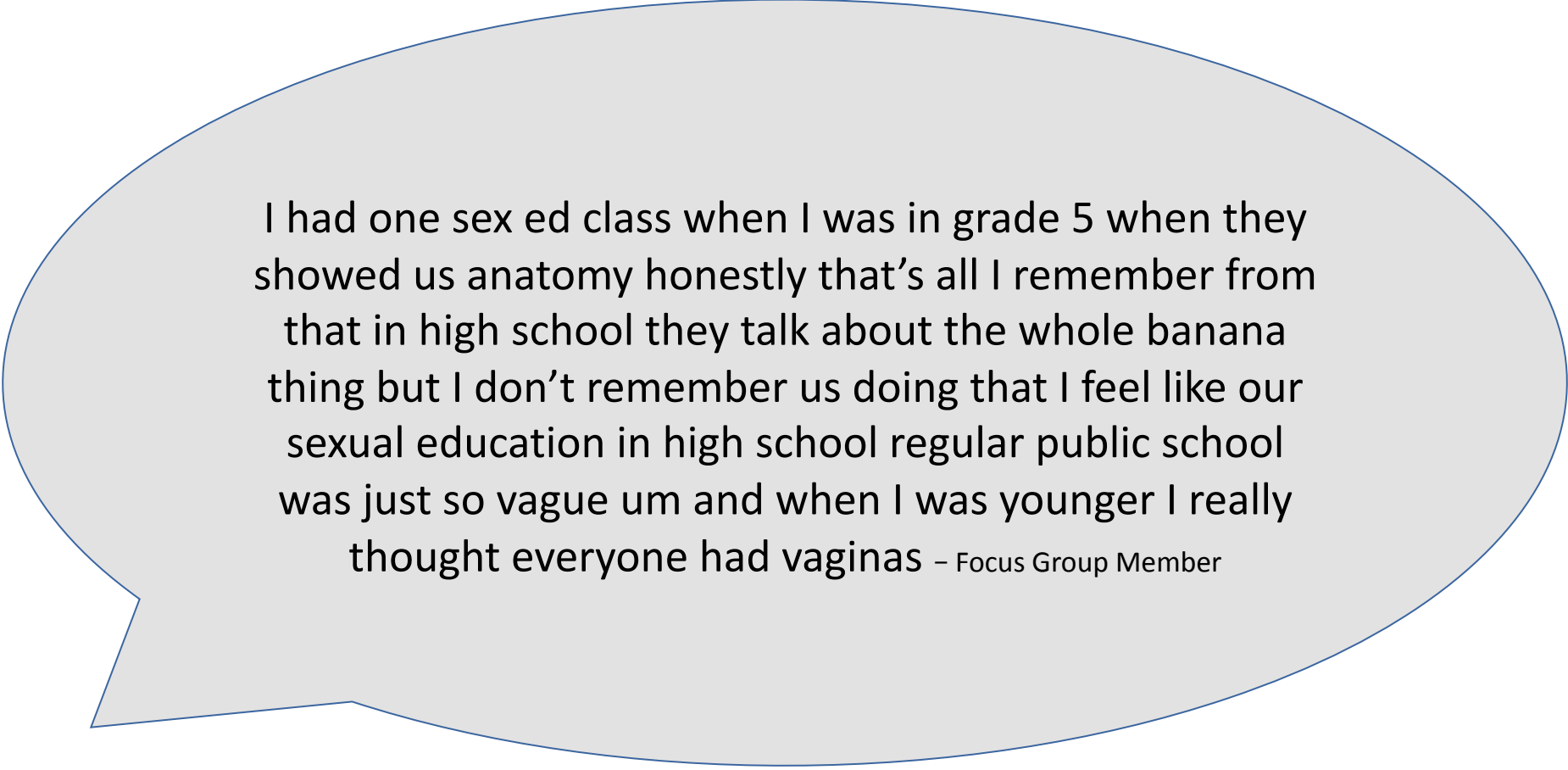
Ontario  
Human Rights Commission  

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Commission ontarienne des  
droits de la personne 60



I felt as though someone put me in a locker they could forget about me I could die and that was my concerns and trust issues with the adults at the time. the people taking care of us at school. they seemed preoccupied with their own relationships and drama their own lives and then in high school there was some bullying like I noticed a clear hierarchy of social order which I found interesting and I like to play with that because as someone who is different I can transcend the social order – Focus Group Member



I had one sex ed class when I was in grade 5 when they showed us anatomy honestly that's all I remember from that in high school they talk about the whole banana thing but I don't remember us doing that I feel like our sexual education in high school regular public school was just so vague um and when I was younger I really thought everyone had vaginas – Focus Group Member

# Housing



I was kicked out of the house when I came out as a teenager, and couch surfed for a few years.

- Survey Respondent

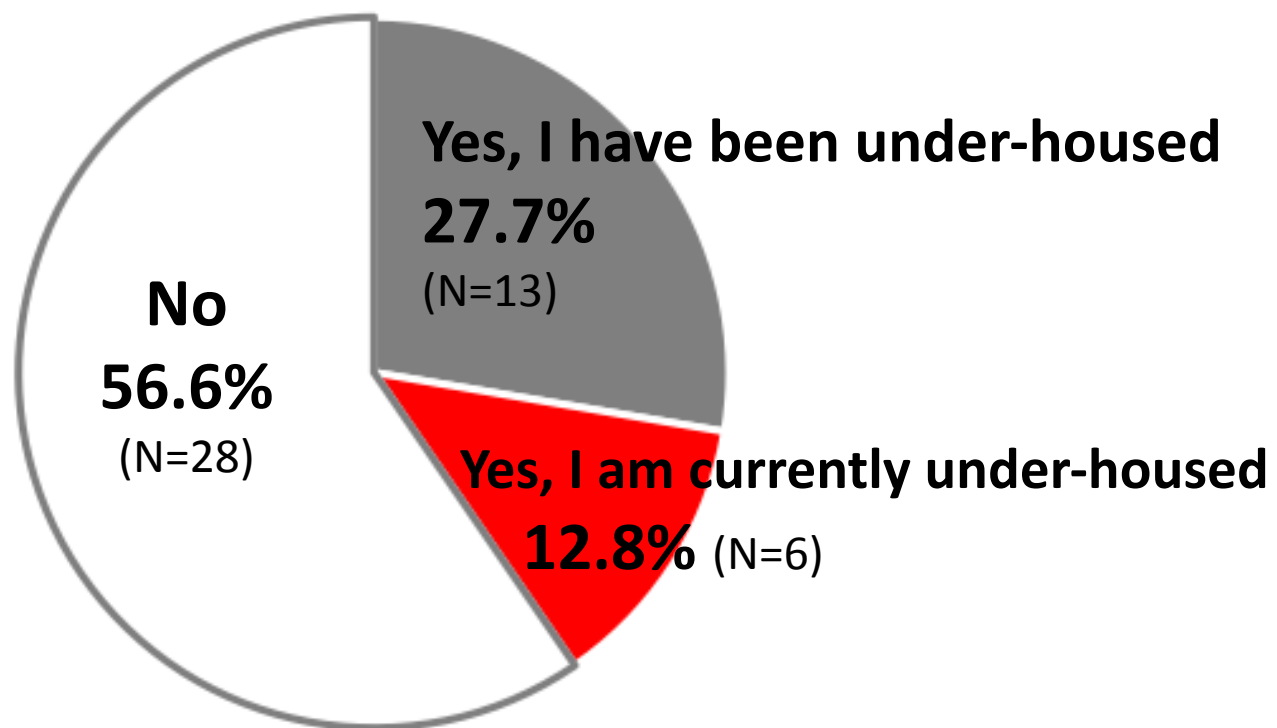
It was after I was first diagnosed with HIV after becoming sick. My partner was also very ill and he was about to die, but he started having delusions about me, so I left the apartment and lived at friends places, shelters and bathhouse for a 6 month period

- Survey Respondent

I lived in my car for two years because shelters were too overwhelming and nobody understood my needs, also it was not accessible physically.

- Survey Respondent

## Under Housed



N=47

■ Yes, I have been under-housed

■ Yes, I am currently under-housed

□ No

# Health/Medicine



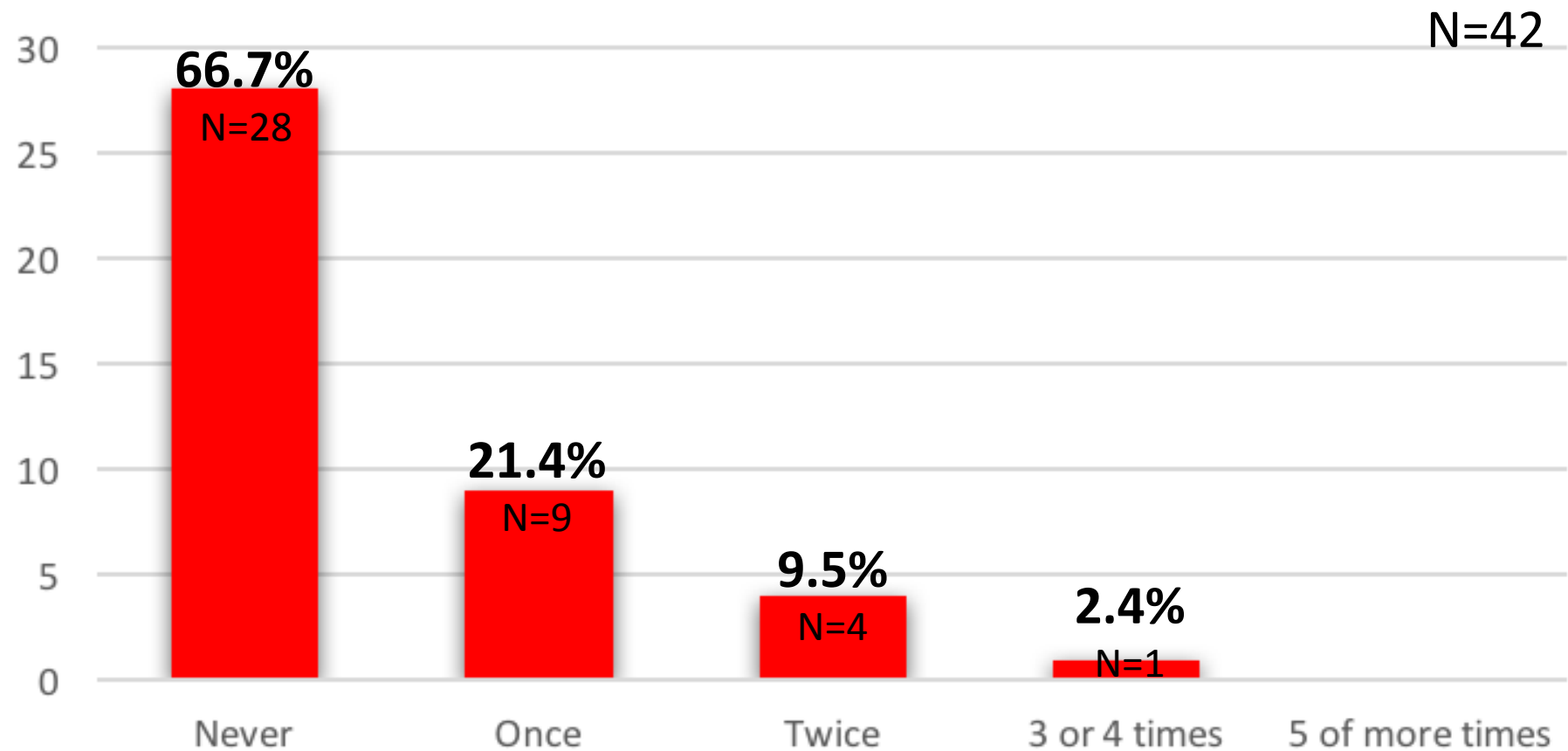
There are too many examples to give examples. I'm Black, Queer, fiscally unsound, and I have a poor relationship with things like Time and regulations. I feel "unwelcome" just about everywhere. Tolerance and a begrudging acceptance are so much the norm for me, I'm actually leery of warmer welcomes. Familiarity. Having a video tour helps a lot. Quieting features like carpet so there aren't a lot of echoes, natural light, easy-to-avoid air conditioning vents.

-Survey Respondent

commitment to understanding trans, lgbt and ethnic/cultural issues as well as commitments to informed consent & personal autonomy. anything that can reflect that a place is professional & non-judgmental. must not inherently gender a person by 'anatomy'.

- Survey Respondent

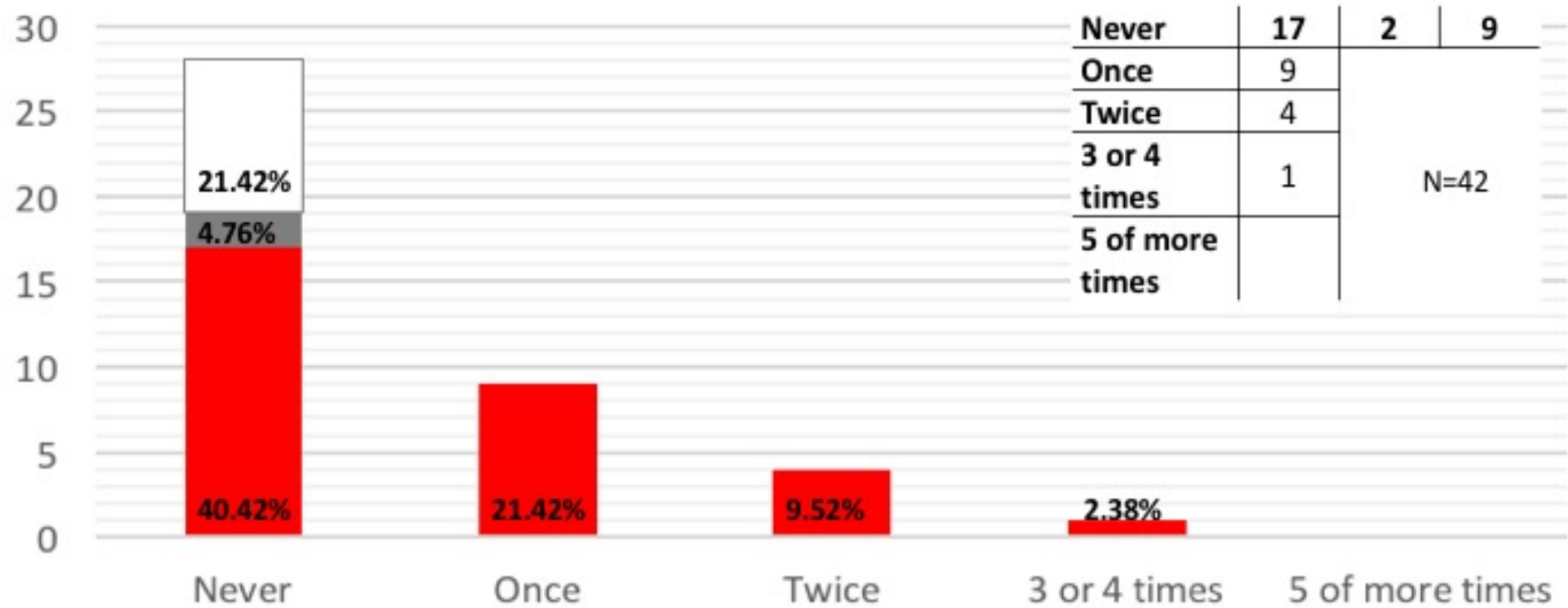
## HIV test in the past year





# HIV Testing in the past year

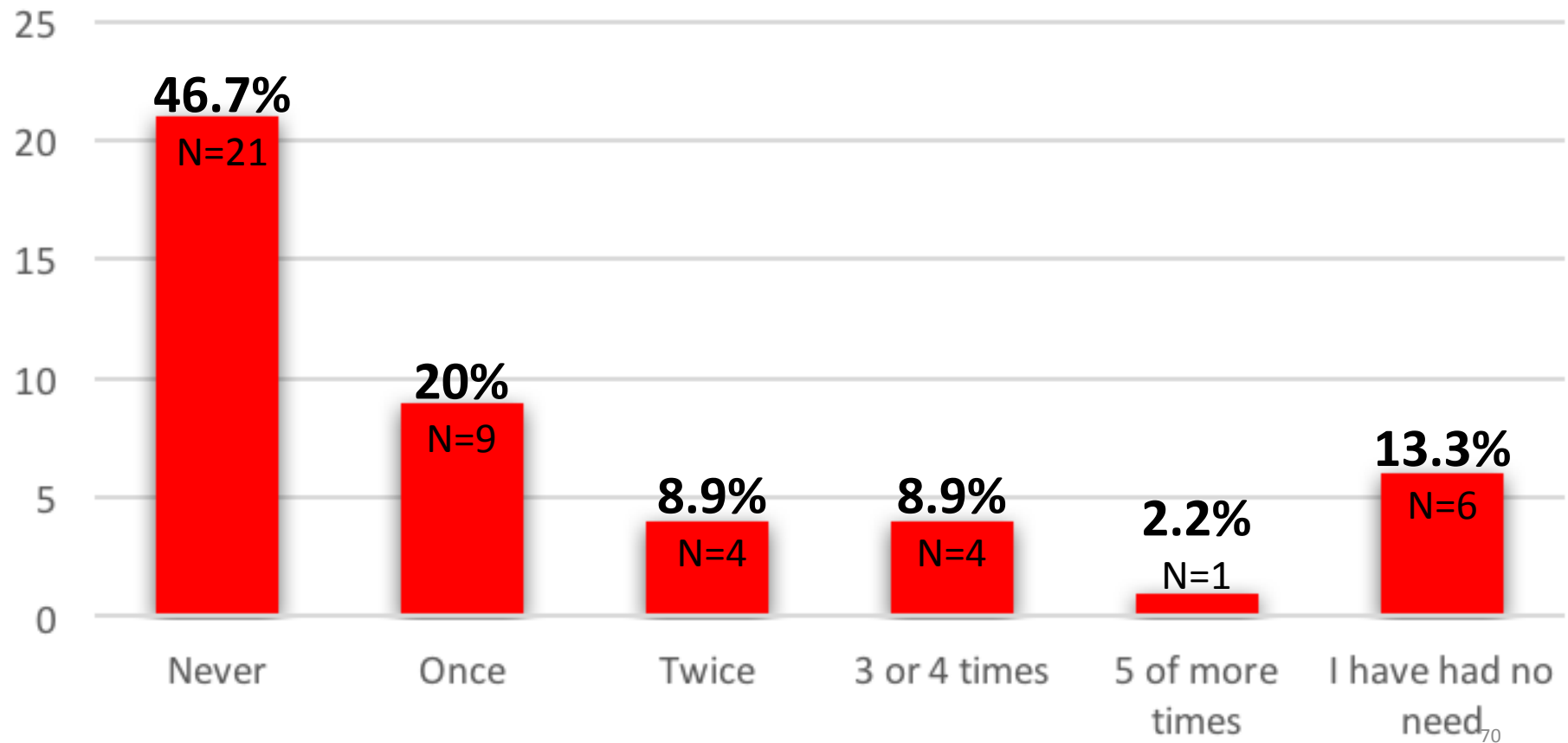
■ Asexual □ Partnered momogomous



Never	17	2	9
Once	9	N=42	
Twice	4		
3 or 4 times	1		
5 of more times			

## STI test in past year

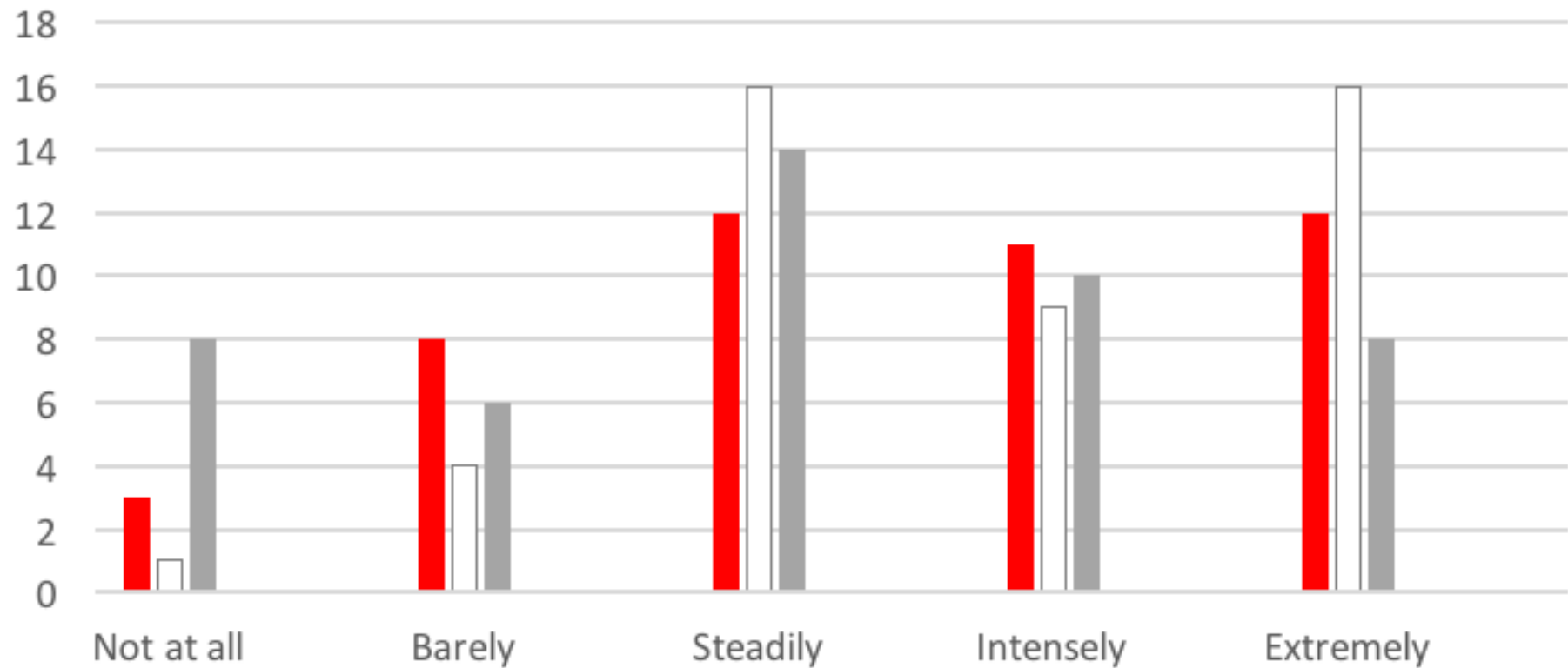
N=45



I am quite the eccentric person as I have a rather high IQ. A mentor taught me this past decade that means I have the ability to see perceive understanding patterns that 95% of the population can't. So unfortunately most people don't see or understanding what I do so I often feel not listened to and misunderstood. But my doctor once recently told me in the two decades that I have seen him regardless of my own understanding or perception about things I've always been right when it comes to what's going on inside my body. - Survey Respondent

I was unable to get my doctor to agree to have me tested for autism. I'm too old, and have had too much 'lived experience'. By that standard, I'd had too much lived experience by age four, but whatever. I think that the greatest impediment is me. If I feel offended, or slighted, or unwelcome in any way or for any reason, I refrain from attending. If I feel guilty of even the smallest offence, I'll hide. All that it takes is for me to miss an appointment, I believe that I've done more harm to myself than the virus has, and it's difficult for me to ask for, to accept, and to adhere to assistance feeling that way about myself. - Survey Respondent

## Felt in past 6 months



N=46

■ Depressed   □ Anxious   ■ Lonely



It took 7 years for me to qualify for ODSP, in part because the first caseworkers at OW didn't take me seriously. In autism organizations, I am often seen as too "high-functioning", so unworthy of support, or support available is for others, with very different needs.

- Survey Respondent

As someone who's on the asexual spectrum, the hyper-sexualisation of many queer spaces often makes me feel a bit out of place. Similarly, I often find queer spaces and events to be quite inaccessible to me because of sensory overload. I've been living in a rural area since coming out as asexual and genderqueer so I don't really have many services or programs to access, to be honest. I don't feel comfortable being open about my identities with my doctors or therapist.

- Survey Respondent

As an adult autistic person seeking supports pretty much every organization that purports to support autistics has made me feel unwelcome. All of the supports seem to be for young people. Further, other programs and supports all seem to focus on cognitive-behavioural therapy which is not what I need. In queer and trans spaces, LTBTTQIA+ spaces being autistic is almost never spoken about. Further, the policies and practices of many organizations, and LGBTTQIA+ health centers, usually discriminate against trans woman. This is particularly true in hiring practices, who is in management and decision making, etc. In Toronto there are a lot of trans women who do not use or go to The 519 or Sherbourne Health Centre because of this. I have had that confirmed by people working in other agencies as well as when I have been providing support for trans people. - Survey Respondent



ASD & the system

experience, lawyers think, things, without, class, parents, victim, abused, sure, told, true, rights, contact, children, well, presented, Rosa, except, removed, Bad, assaulted, day, need, danger, shoddy, notes, users, helped, fair, neglect, occasion, related, victims, abused, care, CAP, Mostly, suspicious, wind, dealing, intervention, come, friend, even, find, okay, remove, much, used, divorce, care, crimes, get, None, end, law, ago, just, like, home, going, PAST, super, court, lab, one, positive, back, also, called, I'm, way, several, years, CPS, taken, identify, issues, cop, smoke, will, hit, read, avoid, times, phone, feel, yep, never, falsely, changed, higher, years, initial, favour, HIV, power, well-dressed, claiming, generally, color, custody, Pre-diagnosis, hospital, definitely, unprepared, managed, service, ask, unjust, treats, treat, suicidal, Eventually, seriously, worked, family, representation, accused, criminals, arrested

I know it treats people who have HIV like criminals and that's super not okay. - Survey Respondent

# Recommendation:

## Trauma informed care and restorative practice

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- **Trauma Informed Care (TIC)** is an approach, based on knowledge of the impact of trauma, aimed at ensuring environments and services are welcoming and engaging for service recipients and staff.
- **Restorative practices** is a social science that studies how to improve and repair relationships between people and communities. The purpose is to build healthy communities, increase social capital, decrease crime and antisocial behavior, repair harm and restore relationships.

# Recommendation: Sex Education & Abuse training

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## Part A

Use IEPs Individual Educations plans to facilitate conversations between parents and teachers ensuring ASD receives Sex Education

IEP GOALS SUMMARY				
Student Name: _____				
Classification: _____				
Record student goal in the table and quarterly progress notes in the corresponding column.				
MEASUREMENT: AVERAGE GOAL	NOV	DEC	JAN	FEB
Goal: _____				
Subject Area: Reading Math Writing				
Other: _____				
Schedule: _____				
Goal: _____				
Subject Area: Reading Math Writing				
Other: _____				
Schedule: _____				
Goal: _____				
Subject Area: Reading Math Writing				
Other: _____				
Schedule: _____				
Goal: _____				
Subject Area: Reading Math Writing				
Other: _____				
Schedule: _____				

## Part B

Put Sex Education online  
Provide Education about ASD needs and teach Case managers and Parent how to discuss sex with ASD people.



I feel like if we had a resource or sort of a person on guard sort of like they have with HIV umm, like someone to talk to about sexual health. I feel like they need one for online grinder who is just there to talk too if I just have a question about something. - Focus Group

I would say like a website or some kind of resource dedicated to online dating with people with ASD like this doesn't come, none of this comes natural to people.

- Survey Respondent

# Recommendation: Testing

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- People assume IDDS do not have sex
- High rates of Drug use, Sex work and Abuse
- People are unaware they have to ask for HIV testing if they have a Dr.
- IDDs who have been incarcerated are put in group homes with those who have not been provided adequate sex education and abuse training.
- Incarcerated are not screened for HIV when leaving prison, and are often unaware of their HIV status.
- High turnover of staff prevents effective training of APSWs and FSWs

# Questions?

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# Thank you

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## **Our Funder**

Toronto Urban Health Fund (TUHF), City of Toronto



**Join our Facebook Group:**  
**“Canadian Working group  
on HIV & Neuroinclusivity”**



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