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Alex McClelland MES , Sarah Flicker PHD , Denise Nepveux PhD , Stephanie Nixon PhD , Tess Vo , Ciann Wilson MES , Zack Marshall MSW , Robb Travers PhD & Devon Proudfoot MA

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Seeking Safer Sexual Spaces: Queer and Trans Young People Labeled with Intellectual Disabilities and the Paradoxical Risks of Restriction

ALEX MCCLELLAND, MES and SARAH FLICKER, PhD

Faculty of Environmental Studies, York University, Toronto, Ontario, Canada

DENISE NEPVEUX, PhD

*Centre on Human Policy, Law and Disability Studies, Syracuse University, Syracuse,
New York, USA*

STEPHANIE NIXON, PhD

*Department of Physical Therapy, and Health Economics University of Toronto, Toronto,
Ontario, Canada; and HIV/AIDS Research Division, University of KwaZulu-Natal, Durban,
South Africa*

TESS VO

Griffin Centre Mental Health Services, Toronto, Ontario, Canada

CIANN WILSON, MES

Faculty of Environmental Studies, York University, Toronto, Ontario, Canada

ZACK MARSHALL, MSW

Memorial University of Newfoundland, St. John's, Newfoundland, Canada

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Address correspondence to Dr. Sarah Flicker, Faculty of Environmental Studies, HNES 109, York University, 4700 Keele Street, Toronto, ON, M3J 1P3, Canada. E-mail: sarflick@gmail.com

ROBB TRAVERS, PhD

Department of Psychology, Wilfrid Laurier University, Waterloo, Ontario, Canada

DEVON PROUDFOOT, MA

York Institute of Health Research, Toronto, Ontario, Canada

Young lesbian, gay, bisexual, and transgender (LGBT) people labeled with intellectual disabilities have unique sexual health needs that are not being met. Denial by others of their right to pleasure and the exercise of heightened external control over their sexuality are commonplace. Current research indicates that these youth are at heightened risk for compromised sexual health. This study aimed to explore the ways in which social and environmental conditions influence vulnerability to adverse sexual health outcomes for this population. We used a community-based research approach to conduct qualitative interviews and focus groups with 10 young LGBT people (aged 17–26) labeled with intellectual disabilities. Participants reported multiple limitations on their autonomy that resulted in having sex in places where they did not feel comfortable and were unlikely to practice safer sex. Attempts by authority figures to protect youth through limits on their autonomy may be unintentionally leading to negative sexual health outcomes.

KEYWORDS *intellectual disability, HIV, sexual health, youth*

Youth labeled with intellectual disabilities are a heterogeneous group, whose pathways for sexual risks are shaped in part by their social locations along axes of race, gender, class, and disability (Andersen & Collins, 1992). More Canadian young people (defined as under the age of 29) are labeled with intellectual disabilities than the rest of the working-age population; 17% of young people report being labeled with intellectual disabilities (Human Resources Development Canada, 2001). The term *labeled with intellectual disability* acknowledges that the label of disability has been applied by another person and is not always owned by the individual with regard to whom it is used.

Young people labeled with intellectual disabilities may be at heightened risk for compromised sexual health outcomes because of economic, educational and social disadvantage (DiGiulio, 2003). They report higher rates of smoking, drug use, alcohol use, and suicidal ideation than their age peers and have significantly fewer protective resources (Blum, 2001).

Interrelated social and behavioral risk factors associated with HIV are increased for individuals labeled with intellectual disabilities and other

disability categories. These include poverty, lack of access to information on HIV, lack of education, limited access to healthcare, and elevated risk for substance use and sexual violence (Blanchett, 2000; DiGiulio, 2003; Groce, 2003, 2005; McGillivray, 1999). No research is available on HIV or other sexually transmitted infections (STI) prevalence among young people labeled with intellectual disabilities in Canada. In other countries their rates of STIs are presumed to be higher than for others their age (Southern Africa AIDS Information Dissemination Service, 2003).

People labeled with intellectual disabilities face multiple physical, social, and structural barriers to STI and HIV prevention opportunities. Nevertheless, little attention has been paid to their vulnerability to STIs and HIV. Although policies of deinstitutionalization and educational inclusion are pervasive in Canada, misguided assumptions, culturally rooted in historical segregation of such persons, persist. Common misconceptions include ideas that people labeled with disabilities a) are asexual or sexually inactive, b) do not identify as lesbian, gay, bisexual, transgendered, transsexual, two-spirited, intersex, queer, or questioning, and c) are unlikely to engage in substance use. Such assumptions contribute to the exclusion of people with disabilities from sexual health education and STI and HIV prevention and support services.

"Life, liberty and security of the person" are protected human rights in Canada (*Canadian Charter of Rights and Freedoms*, 1982). Within supported community settings, where many young people labeled with intellectual disabilities live, however, this principle is counterweighted by obligations to care for and protect persons considered to have diminished autonomy. Similar tensions occur when young people with intellectual disabilities reside with their parents into adulthood. In these contexts, denial of the right to pleasure, and the exercise of control over the sexuality of people labeled with intellectual disabilities are commonplace (Wheeler, 2007).

LGBT YOUNG PEOPLE AND INTELLECTUAL DISABILITY

Research investigating the complex vulnerabilities of LGBT youth to negative sexual health outcomes is growing. For example, evidence amply demonstrates that young gay men and other men who have sex with men face increased vulnerability to negative sexual health outcomes (Public Health Agency of Canada, 2006). Recent research suggests that young gay men, young lesbians and other women who have sex with women are up to three times more likely to be involved in a teen pregnancy than heterosexually-identified young women (Planned Parenthood Toronto, 2009; Saewyc, Bearinger, Blum, & Resnick, 1999). LGBT youth labeled with intellectual disabilities are an underresearched group. Comparatively little is

understood about their sexual experiences and sexual health needs. Program initiatives and policy discussions often exclude them.

Like other people, young LGBT people labeled with intellectual disabilities desire romantic and sexual connections (Abbott & Howarth, 2007). A number of factors, however, add to the barriers to sexual expression, health and wellbeing that youth with intellectual disabilities face. For example, care givers and service providers demonstrate discomfort with the sexual and gender identities of LGBT youth with intellectual disability as well as with their sexual and romantic relationships (Abbott & Howarth, 2007).

This research project investigated ways in which social and environmental conditions influence the sexual health outcomes of young LGBT people labeled with intellectual disabilities. This study did not measure the sexual health outcomes of the participants, but rather examined the sexual health knowledge, attitude and behaviors of the participants.

METHOD

The research team stemmed from a partnership between the Griffin Centre and various academic partners in Toronto, Canada. The Griffin Centre is a Toronto-based mental health agency that hosts a unique program for young LGBT people labeled with intellectual disabilities and their allies called ReachOUT.

This project used a community-based research approach (Minkler, 2003) to ensure action-oriented outcomes and support the realization of sexual and reproductive rights for project participants. To integrate community-based research principles, the research team met regularly with a youth research advisory team of seven young people labeled with intellectual disabilities who volunteered to provide feedback on research design and implementation. They supported the development of the qualitative interview guide and participated in a member-checking participatory analysis meeting. The member-checking meeting was held to share the research team's preliminary analysis with the youth participants. At the meeting, themes from the data were presented to the youth research advisory team and they were asked to discuss and assist with interpretation. Two Griffin Centre program staff were also engaged as research team members and participated in the refinement of research questions, data collection protocols, and analysis and interpretation of research data.

Study participants were ten 17–26-year-olds labeled with intellectual disabilities. The majority of the group had been diagnosed with other mental illnesses including mood/anxiety disorders. This small but diverse group included youth who self-identified as lesbian (3), gay (2), bisexual (1), questioning (1), and as having fluid sexual orientations (3). Regarding

the participants genders, six of the participants were cisgendered (4 male, 2 female) and four of the participants identified as having transgendered, transsexual or fluid gender identities, which included female-to-male transgender, male-to-female transgender, and gender queer. Due to the small sample and concerns around the participants confidentiality, we have intentionally decided not to disaggregate the data related to all the quotes in the findings summary. Where possible we have indicated participant's age, gender and sexual orientation.

A large proportion of the participants had been labeled by physicians or in academic settings as having mild intellectual disabilities, and two as having learning disabilities. A majority had been additionally diagnosed with mood disorders, anxiety disorders, pervasive developmental disabilities, attention deficit and disruptive behavior disorders. All had participated in Toronto's ReachOUT program, an ongoing support and education intervention that exposed them to a range of sexual health information sessions, outings to sexual health clinics, and workshops by sexual health educators from numerous AIDS service organizations. All resided in the Greater Toronto Area. Most had lived in shelters, provincial institutions, or residential group homes and had participated in programs focused on transitioning to work, education, and independent living. One had experienced homelessness. Four older participants, all of whom had lived in institutions or group homes, or both, were now living independently, with support from intellectual disability service providers.

During a weekend research retreat in May, 2010, youth participated in 10 semistructured interviews and two focus groups with five participants in each, which aimed to educate their knowledge, habits, and experiences in relation to sexual health, particularly HIV and other sexually transmitted disease risks. Questions focused on issues related to sexual orientation, gender identity, sexual health history, dating and relationships, experiences of accessing STI testing and negotiating their daily lives. Interview and focus group data were audio recorded and transcribed verbatim. Four members of the research team developed a preliminary coding scheme based on emerging themes identified across the transcripts. Two of them then coded the transcripts using Nvivo qualitative data management software. The same four members reviewed the coded data and created nodes and summary documents of main themes and ideas. These were presented in June–July 2010 to the larger investigator and youth research advisory teams for feedback and additional comments, which were then incorporated into the analysis. The member-checking exercise with youth advisors was particularly helpful in drawing the connections explored in this article, as youth confirmed and added specificity to the research team's hypotheses about the relationships between autonomy restrictions, the places where youth were having sex, and their ability within these encounters to engage in safer sex practices.

RESULTS

How LGBT youth labeled with intellectual disabilities experienced and managed restrictions on their social lives and sexual expression arose frequently in our interviews. Two themes are discussed in this section. First, participants reflected on experiences of restrictive rules, most often in the context of residential services or co-residing with parents, and second, they described the sexual consequences of this restriction particularly on the spaces where they could be sexual.

Living Arrangements, Rules, and Autonomy

Youth, whether living in group setting or with their parents, described explicit behavioral controls as an omnipresent reality in their lives. Their reactions to them were mixed. Participants cited many adults who had control over aspects of their lives, including parents, group home staff, social workers, counselors, foster parents, siblings, roommates, and partners. Often, young people indicated that more than one person had authority to make decisions in their lives, enforce rules, and apply controls over their autonomy. For example, one young man had two foster parents, a social worker, and his mother, all applying rules over aspects of his life.

Similarly, those living with parents reported that a variety of rules limited their ability to choose where and how they spent their time:

There are rules in place and all that stuff, so I have to obey by the rules . . . well if you don't follow the rules, they try and take away whatever game system you have or anything that amuses you. (20-year-old, lesbian young woman)

An 18-year-old young lesbian identified woman living at home with her parents said, "[W]hen I was younger my mom was like 'you have to be home at this time,' but now because I am becoming an adult she is giving me more freedom than she did when I was little."

Participants mentioned a variety of structured expectations that governed their everyday routines, including curfews, having to be out of the house during the day, not acting out, and behaving appropriately by going to school, eating properly, and not damaging property. While some participants felt uncomfortable with and annoyed by these rules, others saw behavioral limits as supportive and part of a necessary learning process. One participant recalled:

When I was younger . . . I was in a group home setting where there was almost a thousand rules and regulations where I had to be in sight

of staff. That sort of thing was to, I think, trying to teach me. I don't really know what the real reason was, but it was more like a very strict sort of group home and I think they were trying to teach me life skills, things, and as I looked back I realized I needed that help and I needed that structure or I would be walking over everyone. (19-year-old, gay-identified male)

He also experienced limitations such as curfews to be helpful:

I have a curfew that is at like 11:30 p.m., but during the day, I have to be out of the house from 9 to 3, more likely just to get me out of the house and just be productive during my days and I think it's another way of trying to teach me how to be responsible and how to control what I do. (19-year-old, gay-identified male)

Another 19-year-old who lived at home spoke of his parents' reactions to his going downtown alone: "My parents couldn't let me go alone because I wasn't ready for the world; I had anxiety attacks and stuff."

Sex and Sexual Spaces

All participants reported that others—particularly, parents and service providers—exercised some control over their personal time and space to explore their sexuality, whether with themselves or others. For instance, some said they were not allowed to masturbate, especially in shared spaces (including their bedrooms). Others said they were forbidden from having sex at all, and they recalled being explicitly told that they could not have sex at their place of residence. Youth reported a number of consequences for breaking the rules, including being grounded, or having their privileges withdrawn.

One youth, a 19-year-old who had lived in a residential home, said, "The rules were, no sex and no having sex with other roommates, and if you had to, you couldn't have sex, the rules were No sex and you couldn't bring any friends over."

A 23-year-old recalled:

When I was in a group home, I wanted to have sex with [another resident] but the group home wouldn't let us . . . I really wanted to get into sex because I guess I was ready at that point. I was 19. But the group home wouldn't let us. I was kind of upset and frustrated.

One 19-year-old gay young man who lived at home with his parents said: "It was just, 'no sex,' my mom said, 'whatsoever.'"

Most interviewees were sexually active, and all expressed desire to have sexual and romantic relationships. During member checking, a majority of

the young people present identified their home or in a sexual partner's home as the most comfortable place to have sex:

You are safer there because you know where you are.

I like having sex at my place more . . . there are condoms beside my bed.

When you are at your partner's house and you know that person well, and you trust that person and you love that person, then the relationship is good.

Asked where they would be most likely to use condoms, member checking group participants identified their homes and their partners' homes as the best places. One remarked, "At my house at least you know that you have condoms."

Participants saw the presence of their parents as a barrier to having sex: "I can't do it at my house, because of my parents. If I had a partner, I wouldn't do it at his house either, because mostly the people I date are around my age and they live with their parents"(18-year-old, young trans woman).

Young people also spoke about a wide range of places outside the home where they had been sexual. One 19-year-old male participant who lived in a group home said, "I've gotten laid in parks, back alleys, behind stores, anywhere. You can practically name it."

Other young people listed a number of spaces outside their homes where they had sex, including bathhouses, the street, parks, and out in public. Regarding these alternative sexual environments, one 19-year-old gay male group home resident spoke of the complications of weather conditions and his fear of getting caught:

The first time I had sex with someone we went to this park that was nearby and that time I had only half an hour to go on free time so I would have to be back. I hated it . . . it was in the winter . . . I was freezing cold and it was like, I was so afraid I was going to get in trouble.

Another young trans woman associated these risks with the limitations imposed by group home rules: "If the group home isn't going to let you have sex in the group home, you are probably going to have sex outside."

Significantly, while youth identified their (or partners') homes as the most comfortable places to have sex, they reported more often engaging in sex in places such as bathhouses and outdoor spaces, which they regarded as less safe and less comfortable. Moreover, participants cited parks and outdoor spaces as the places where they would be least likely to use a condom.

Young people described outdoor places as less private spaces where they were also less free to make decisions about condom use.

Gay male participants and male-to-female transgendered participants frequently mentioned bathhouses in their list of sexual spaces. Often they discussed concerns around the use of condoms in these environments. Participants expressed ambivalence about bathhouses, describing them as safe and comfortable, yet, also unsafe and uncomfortable places to have sex. One trans-identified participant said that the ready availability of condoms in bathhouses conveyed a sense of safety. Another participant, however, had concerns about the anonymity of his sexual partners there, reflecting, “(Y)ou may not know who you are having sex with and they may have an STI or HIV and not know it, or not tell you.”

While less-safe spaces influenced youths’ risk-taking behaviors, participants mentioned additional reasons why they may not use condoms, including sexual desire and curiosity:

Some people use condoms so many times and then they want to experience what it is like to have sex in the bum without a condom, they think it’s more hot.

It is hard for some people because they don’t want to get AIDS, but they still want to do it.

DISCUSSION

This article explores how, in the context of virtual prohibition of their sexual activity within their homes, and a dearth of accessible alternatives, LGBT youth labeled with intellectual disabilities resort to uncomfortable and risky physical and social spaces for romantic and sexual encounters. It considers sexual health implications and offers recommendations for promoting the sexual health of LGBT young people labeled with intellectual disabilities.

The group of research participants and coresearchers spoke openly about their sexual lives and desires. Like most young people their age, and contrary to stereotypical assumptions, they are discovering and exploring their sexuality. Because of their perceived intellectual abilities and their status as residents or clients of intellectual disabilities services, these youth experience more external controls over their autonomy than others their age. Despite these limitations, and the denial of their sexual lives and identities by persons with authority over them, the majority of these young people have and will continue to have sex. Among the participants who were not yet sexually active, most expressed a strong desire to soon become active. Both those who are currently, and not yet, sexually active affirmed that restrictions on opportunities to realize their desires may in fact contribute to their engaging in sexual risk taking. Limits on freedom and privacy, including

the time and space to be sexual, lead young LGBT people labeled with intellectual disabilities to make decisions about where to have sex: often in uncomfortable and unsafe places. The consequences of being sexually active in these places—which participants experience to be among the few sexual spaces available to them—include less physical safety, reduced opportunity for healthy decision making, less privacy, and unprotected sex.

Given the small number of participants and the particularities of our sampling strategy, care must be taken in considering the transferability of these results to other LGBT young people labeled with disabilities, and the specific concerns of young women labeled with intellectual disability may not have been as apparent as those of their male-identified counterparts. Additionally, significant exposure to sexual health information may have resulted in these youth receiving greater supports and being more connected to the larger LGBT community in downtown Toronto compared to youth not connected to services, or in rural and remote areas where there is no visible LGBT community. Nonurban youth may be even more vulnerable to HIV given their lack of exposure to group support, HIV information sessions, and safer sex counseling. It is noteworthy that despite their relatively high exposure to sexual health information, these young people still spoke of many sexual risk-taking experiences. Future work should continue to explore how the intersecting identities of being young, LGBT and labeled with an intellectual disability may compound vulnerability to HIV and STI.

This preliminary work highlights the resilience and vulnerability of these young people. It also illustrates that attempts by authority figures to create protective environments through regulations and limits on autonomy may be backfiring. The picture is a complicated one, however. In some instances, young people in our study felt that regulations and autonomy limitations were justified and even helpful to their learning and maturation. Self-advocacy and community living movements such as the People First of Canada and the Canadian Association for Community Living emphasize that, rather than abridging rights or making choices on their behalf, families, communities, and service providers must support the self-determination of persons, including youth labeled with intellectual disability. But in order for self-determination to be supported, the lived realities of these young people must be understood and respected, and supportive infrastructures developed (Young & Quibell, 2000). Few educational materials have yet been developed to help youth, parents, and service providers discover how to support the sexual autonomy of persons labeled with intellectual disabilities. More sex-positive supports and guidelines that support and respect the diverse sexualities of this young group could foster safer sex behaviors in healthier environments. This, in turn, would help encourage more positive sexual health outcomes. Support and education to help this group navigate complex sexual environments such as bathhouses is also needed. Since those labeled with intellectual disabilities may find it difficult to make sense

of the concept of risk and the potential consequences of particular sexual acts (Cambridge, 1998), it is even more imperative that these young people are offered supportive environments for health promoting behaviors.

Recommendations

Aligned with the community-based research approach (Minkler, 2003), the research team, and youth research advisory team jointly proposes the following action-oriented recommendations to support and promote the sexual rights young LGBT people labeled with intellectual disabilities. Both young LGBT people labeled with intellectual disabilities and those who work with them need educational resources that are accessible, honest, and relevant. There is a need for training curricula and resource materials to enhance the ability of frontline staff, including support workers, child and youth workers, case coordinators, service coordinators, social workers, and residential program staff to accommodate these youths' sexual health needs. Additionally, information about homophobia and transphobia, sexual, and reproductive rights (including the rights of their clients to be sexual and have sex), and safer sex information should be integrated into the work that frontline workers undertake with this group. Along with this should come the development of accessible comprehensive sexuality education materials that recognize and incorporate the complex lived experiences of queer and trans youth labeled with intellectual disabilities, thus, helping them to reduce risks associated with HIV and STIs. Additionally, young LGBT people labeled with intellectual disabilities should be engaged in the development and design of materials, programs and initiatives to meet their unique sexual health needs. Finally, in collaboration with self-advocacy movement groups, we call for the development of policy statements that will guide development of sex-positive environments for LGBT youth labeled with intellectual disabilities in service settings.

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