TRANSCRIPT- Let's Talk Disability and Sex Connection Day Event

Talk Theme 1: Early Intimate Relationships

Speaker: Dr. Loree Erickson

Hi, I'm Dr. Loree Erickson, and I'm really happy to be here with you all virtually today, um, my pronouns are she and her. I'm currently, just to describe myself a bit, I have vivid pink hair, pretty long hair. I'm wearing cat eyeglasses, that are purple and orange and some sparkles in the corner and a snakeskin halter dress. I am a wheelchair user, white, queer-fem. I do lots of work around the conjunctions of disability and sexuality as a professor, and as a researcher and scholar, and I make queercrip porn. And I also do a lot of research around collective care, and transformative justice work. I think that is a good introduction to me.

And so this talk that I'm sharing with you today is kind of some, a combination of pieces from my research around my dissertation, and also some new parts. So, without further ado, I will start.

> *I had been looking for a scene partner for months and was beginning to lose hope that I would find the right person: someone willing to make porn, with rad politics, who queered masculinity in a way that complemented my queered femmeness. Someone who I thought was a babe and who I thought was a babe. David suggested Sam and, when I saw his profile, I immediately recognized him as "the cute person" I had been checking out at various activist and academic events. I emailed him and a few weeks later we were at the Delta Chelsea in Toronto making want, my first queercrip porn video. For much of my life I felt excluded from the world of dating, sex, and romantic love. For days after shooting, I could taste the "otherwise" on my lips. I could feel the possibility on my skin from Sam's touch. My heart was beating with an expansive reciprocal desire.*

I grew up in the country, a place called Lucketts, in Virginia. My dad's house had a lot of windows that overlooked pigs, chickens, and a vegetable garden. There was a sliding glass door that opened to the wooden ramp I used to get in and out of the house. There were these mockingbirds with a particular habit that stayed with me. The birds would perch on the railing of the ramp and launch themselves directly into the glass door. Upon flying into the door, they would fall to the ground. Then, after maybe 30 seconds, though sometimes it was longer, they would return to the railing and do it all over again.

I did not fully realize how heavily I identified with those birds until much later; they stayed with me, showing up in moments of heartbreak and devastation. I felt their wanting and determination. I felt their pain and their sense of rejection at continually crashing into a cold glass wall of impossibility. By the time I was seven years old, I was convinced that no one would ever want to be with me because I was disabled. I have no way of explaining exactly where that message, which felt like an indisputable truth, came from because it was everywhere. It was there when I watched the Jerry Lewis Labour Day telethon and got terrified that I was going to die at the age of 10. It was there when, after I pierced my nose, my dad said, "why would you do that? You're already deformed enough as it is." It was there when at 13 my doctor told me to never have sex because if I got pregnant it would kill me (not true). It was there in my mom's voice when she consistently responded to me being rejected romantically by telling me, "it's better just to be good friends". I even heard it in the silence when no one ever asked if I was dating anyone.

This lifelong struggle doesn't mean I've had a life full of tragedy and woe, just as the birds were not always flying into the glass. At the same time that I was subjected to these harmful messages, I was also learning important lessons from my body about vulnerability, ways of living and knowing, the complexity of agency and interdependence, and the importance of structural realities, connection, communication, needs, care, and relationship. I used these lessons to build close friendships. I had older brothers who were equally skilled in care and classic big brother teasing that didn't skirt around my disability: they would regularly tip my chair back, rest it on its handlebars, and pretend to walk away. When I was little, my dad carried me around so I got see the world from 6'3", and my mom taught me the importance of questioning doctors and other authority figures. I went camping, played Glinda the Good Witch in a school play, and spent time at the beach. I loved school, animals (especially cats), watching movies, going to concerts, and spending time outside in the sun. I still do.

However, the voices of undesirability were never far away. I was surrounded by pity, pathology, and the threat of erasure; nonetheless, I had a lot of longing for dates, for a way out of Lucketts and the possibility of living otherwise. I used my school smarts as a way out: attending University granted me access to care, housing, and Gender Studies classes that, when combined with my organizing work in social justice communities, provided me new critical and practical frameworks with which to understand and explain my lived realities and the socio-political conditions of their emergence. These experiences also introduced me to the potential for truly transformative action. Once I found queer community, I witnessed everyone around me (none of my friends identified as disabled) date, hook up, break up, start families; while I had some really nice kisses and make-outs along with a few other sexually charged experiences, it seemed as though sex was on the other side of the glass wall. When I finally did have sex, that night was one of the first times I experienced a marked respite from the voices of undesirability. The impossible had happened: someone (and not just anyone, but a cute, genderqueer disabled person with a heart-melting smile and wicked politics) had wanted me.

Prior to this moment also an important shift happened: I started questioning and interrogating the glass door. What was on the other side of the glass that I could see but never access? I began identifying the barriers that made up the glass wall. Also in questioning what *I* wanted and needed, new possibilities came into view: I noticed there was a really sweet birdbath two feet from the ramp and some lovely trees. I work to challenge and transform cultures of undesirability because I want more birdbaths: more spaces that provide nourishment, building my capacity—and that of my communities—to shout back at the roar of so many indisputable truths. I see this work and the work of everyone here today as a continuation of activist, artistic, and academic work already being done to resist the structural practices that construct and constrain marginalized people as broken and unwanted, as both less than and too much.

"Cultures of undesirability" a concept I developed to talk about these multitude of lived experiences and structural practices that undermine and determine the collective worth and wellbeing of marginalized communities. The concept emerged out of my work on the conjunction of disability and sexuality and attempts to complicate the normative limitations of interrogating ideas of sexiness. How we determine who is valued, understood as desirable and granted the status of personhood is always a complex interlocking sociopolitical matrix. Cultures of undesirability as an interdependent concept seeks to bear witness to the historic and current systemic and interpersonal impacts of the Eugenic construction of "undesirable others" across and through multiple simultaneous regulatory systems, systems like white supremacy, capitalism, cisheteropatriarchy and disableism. Thanks to these regulatory systems marginalized people are subject to an ever-quickening cycle of poverty, violence, isolation, criminalization, and medicalization, I hope that cultures of undesirability provides an intersectional frame that enables us to address these violent cycles, the foundations of the glass walls.

In my research project, *Unbreaking Our Hearts: Cultures of Un/Desirability and the Transformative Potential of Queercrip Porn,* my queercrip research collaborators shared stories of regularly navigating multiple systems of power allowing me to identify four interrelated themes of the lived impacts of cultures of undesirability, those are, hyper/invisibility, shame, exclusion, and control. Cultures of undesirability do not manifest as a one-off experience. Romham one of my collaborators states, "they are literally everything." Collaborators shared multiple stories, echoing my own, testifying to the omnipresence of cultures of undesirability: on the street, public transit, at work, in doctor's offices, prisons, classrooms, and community spaces or with friends, lovers and allies, not to mention in our homes and hearts.

When I teach about cultures of undesirability, I start off with a slide that has a variety of charity and pharmaceutical advertisements arranged together forming a cultures of undesirability or dominant ideologies of disability collage or montage. I ask how many students have seen images like this? Nearly everyone raises their hand. I proceed to talk about the ways that cultures of undesirability are internalized through everyday encounters with messages represented in these advertisements that reinforce disability as a personal inferiority or tragedy located within the individual deficient body-mind. These messages are internalized by nondisabled people and disabled people alike. These countless systemic and interpersonal moments, advertisements, and inaccessible infrastructures are where disabled people learn about what disability supposedly is. This is also how nondisabled people learn about disability and who they are in relation to it. This happens young, it happens continuously through all of our lives. This has devastating consequences in terms of sexual health, and overall individual and collective well-being that I have no doubts my peers will be discussing with much more depth than I can get into right now. Here I want to note Abby Wilkerson's work on how political agency and sexual agency are fundamentally interconnected. She illuminates the multitude of ways that the sexuality of marginalized communities is regulated, either through pathologization and criminalization or sometimes the simultaneous pathologizing and criminalizing processes. After all, the quickest way to disempower entire communities of people is to convince them that they are unlovable, undesirable, and undeserving of equality, not to mention justice and liberation. And then create social systems and organization that reinforces that undesirability.

Later on in my lectures, in the same lecture, I show two other montages of images. The first one is of various pictures of disability activism in action. So there are images from the Gallaudet protest that shutdown the University until the demands of the Deaf students to replace the current hearing president with a Deaf president, there are pictures from mad pride celebrations in Toronto, pictures of protesters in Central America agitating for disability benefits that actually allow them to live, and images from social media of hashtag this is what disability looks like. I ask again, how many of you seen images like this? Maybe a few students raise their hands, even fewer raise their hands when later I ask how many of you have seen images of queer disabled people flaunting their sexy selves? This lack of exposure is not an accident – it's systemic. These representations of disability challenge the dominant ideologies surrounding disability at its core. They show disabled people as important, necessary, valued members of diverse communities. They show disabled people as agitators, innovators and leaders creating the blueprints for ways of organizing our worlds and spaces that are caring, interdependent, accessible and leave no one behind. They show disabled people and our bodies as sites of pleasure, joy, and love.

When ways of being and imagining worlds don't fit in our reality or are causing us significant harm, it is time to tell new and different stories. The very stories that cultures of undesirability make largely unknowable. We need to use these stories to create new ways of living and being together. Just as cultures of undesirability create a world that is violent and difficult, if not impossible, for marginalized people to navigate, radical access and fostering moments of Mia Mingus' concept of access intimacy are key to creating worlds that make space for the things written out and written over by cultures of undesirability; worlds where we don't just get to show up, we get to flaunt and thrive.

> *Tiny, fluffy purple feathers cover the sofa and the floor. The purple dollar store boa, a delicate teacup perfectly matching the boa, Afrofuturist comic books all sit carefully on a small table nearby. A radiant blue cane rests on the couch, joined by a dismantled boom pole. Laughter, ideas, and warmth fill the room. And of course, my cat is sitting right in the middle of everything. My living room has been transformed. I have been transformed. My collaborators and the other people involved have been transformed. And when I say transformed, I do not mean in a way that is finished, measurable, or finite; I mean something subtle yet significant, deeply felt and always moving…*

The above statement describes a moment following the shooting of one of the queercrip porn scenes that were part of the above-mentioned research project. During this project we came together to make collaborative queercrip porn scenes to make necessary epistemological and political interventions that open opportunities to build, live and flaunt otherwise, pushing against the harm, erasure, and exclusion of cultures of undesirability. Together we smashed the glass wall, recorded and shared fluffy purple feathers of possibilities, knowledges and imaginaries vital to queercrip flourishing. And you know those feathers, like glitter, they get everywhere and are really hard to get rid of.

Thank you.

TRANSCRIPT- Let’s Talk Disability and Sex Connection Day Event

Talk Theme 1: Early Intimate Relationships

Speaker: Gabriella Carafa

Hello everyone, my name is Gabriella Carafa and I'm going to be chatting with you today about intimate relationships. The pronouns I use are she and her. I have COVID-long, very long, brown hair and I'm wearing a black dress with lace cap sleeves. I'm in my office right now and behind me there is a white wall with a calendar on it. I'm not sure if you can see the picture but the writing says, “we can do hard things” and I'm just at my office at work, so happy to be here.

In today's talk, I will reflect on my own experiences growing up, particularly how it relates to early intimate relationships and sprinkle in some wisdom from my work as a social worker in pediatric rehab.

But first, who am I, this is a picture of me holding my sister's dog, Benji, it’s a Shih-Poo, I'm actually a cat person but cats don't stay very long in photos, but anyways.

So, I am someone who has a congenital disability, which means from birth, my educational background is, I have a certificate in rehabilitation services. I am a registered social worker, I previously worked in pediatric rehab full time and I'm passionate about supporting youth and their families, in the transition to adult services. I'm currently working in perinatal social work, and I also have, I'm a therapist and a consultant in private practice.

So I grew up in an Italian family and lived in an Italian prominent neighborhood. I am the youngest of three. My older sisters are 18 years older than me, and 12 years older than me. So to say that there was a big age gap is a bit of an understatement.

I was lucky in that way because my sisters helped me grow up and mature in a way that I don’t think would have been possible if they weren't around. They also exposed me to a lot of different people and things.

My parents were pretty traditional Italian parents. We weren't really allowed to talk about sex and sexuality, we did eat very well though. Growing up, you know, my mom still teases me today and says that even as a little kid I was a little bit boy-crazy as she says, which I still think it's pretty funny and somewhat true. When we're working with families, we really need to consider the impact of culture when asking parents to have these conversations. We need to be able to recognize the role that culture and religion plays in this area, and be able to support parents, but also support the information that the child and youth might need.

And so being, coming from an Italian background, like it wasn't really appropriate to have these kinds of conversations with me as parents, at that time, and so I really relied on my sisters to sort of answer my questions and teach me about things that I needed to know.

I was the only child with a disability in my school, that was integrated into the mainstream classroom. It's really hard to think back and try to remember everything that I thought, or believed about myself or the world, but I do remember some things. And I remember always wanting to grow up and get married and have a baby which is also a cultural influence. In this picture I'm at Wonderland, I think I cut off Fred Flintstone’s head, and I'm holding my favorite doll, her name was Christina. I took her everywhere, and basically I've always had dolls around me when I was a kid and you know pretend they were my real life babies and took it very seriously. Because I didn't really know anybody else with a disability and I didn't really understand anything about my disability, it really made me confused about who I was as a person. But because I had older sisters, we always talked about the things that I needed to know. I never realized that I really had a disability or I guess what that would mean, when I was younger, as I had gotten older, I never really understood that like people might see me differently because I had a disability.

My older sister, she got married when I was only six years old, I was obviously her flower girl, did a really great job. One of my favorite Halloween costumes growing up was also me pretending to be a bride, so this was something I really focused on. And again, culture comes into that, where you start to, you know, see what your family's doing and everyone's getting married and having babies and that's what you want, except really nobody expected that from me.

There's some memories that still bother me when I was growing up, particularly, you know, at school. There was a boy in my class in Grade two that told me that I would never get married because I was in a wheelchair. In Grade two. This shook me. I remember crying about it, and I remember going home and crying about it some more. Was this true, why would say that to me? What did being disabled have to do with anything? Of course, just because I didn't think that I was different, didn't mean that other kids didn't notice that I got around a little bit differently, and that I needed more help than they did. All of this was true, but, again, why would this impact my future intimate relationships? Why would this make me less lovable?

When I think about my parents, I don't necessarily think that they knew what to expect from me in my future. They were coping with having a child with a disability and all that comes with it. I don't really know if they expected me to go to school, get a job, have relationships, have children. I know my dad, he used to say, I really want you to have a simple life, contribute, try your best, and have the easiest life as possible. My parents never spoke to me about what kind of future I may have in terms of intimate relationships. And I think that this sometimes affected how I felt about myself.

Moving on to talking a bit about friendships, when I was a baby, my mom tells me this story of how an occupational therapist came to our house, and told her to put me in daycare, pretty much immediately, so that I could be around other children and practice socializing and learning, learning things.

So now of course, I was blessed with the gift of gab, and I’m going to blame my name for that. And I made friends quite easily. Making friends has never really been a challenge for me. And when I was younger I took that for granted. And I realized when I entered the Social Work field and started working pediatric rehab, how many young people with disabilities struggle to make friends and feel understood and accepted.

Children and youth may need formalized opportunities to practice social skills, which can help with regards to building relationships in the future. They may need to attend programs or need support, facilitating play dates, and opportunities for them. It is difficult to make friends, or to be as social as one might want to be when you need sometimes, physical assistance, or assistance to participate due to a developmental concern. When parents expressed concerns that, you know, their child’s social skills, they really want their child to have more friends, they wanted to work on these social skills, I really tried to highlight as a social worker how important it is to find opportunities in their day to day life to work on those skills, in combination with attending whatever program might be helpful for them.

My elementary school was a Catholic elementary school, and we had some exposure to sexual education, because it was tied into religion, I was able to attend those classes. There's generally a lack of exposure to sexual education courses for individuals with disabilities in the school curriculum. This could be because they are tied to gym class, which a lot of youth with disabilities, like myself, would get exempt from. In addition, the curriculum does not meet individual developmental needs. So, children and youth with disabilities may not feel like their needs are represented in the sexual education curriculum, it may not be taught in a way that they understand, and they may not feel comfortable asking questions that they have. A lack of exposure to sexual education is a huge barrier in this area. And that's why it is so important that we're having this conversation today.

My experiences with working with individuals with disabilities start from before I became a social worker. My first job I worked as a mentor at Holland Bloorview and as a youth facilitator at Holland Bloorview, and then began working as a social worker, once I obtain my Master's degree.

When I was working at Holland Bloorview, I worked with children who had cerebral palsy, teenagers transitioning to adult services, individuals who had spina bifida, spinal cord injuries, cleft lip and palate, and genetic conditions. Some of my work was directly with the child and youth themselves, but a lot of times it was with parents and caregivers.

I have experienced co-facilitating several workshops on supporting parents and caregivers and learning about how to have conversations about early intimate relationships with their son or daughter. As awkward as these conversations can be, they need to start at home. And I want to say this is especially true if you have a child and youth with a disability, as they may not get the same exposure to other kinds of information, social interaction, and we need to ensure their safety as well. It is so important for children and youth to learn about their body, especially because so many children and youth with disabilities need a lot of assistance around their personal care. Learning about your body and body parts, that's a huge aspect of sex and sexuality. It is important that children and youth are able to direct their own care over time as much as they can developmentally. This can be as simple as picking out what the child wants to do next in their routine, what they want to wear, learning how to direct their transfer or which body part to wash first. Allowing choice, and asking for consent, even as parents and caregivers is such an important piece and models the things that we need children and youth to learn.

A lot of parents I worked with want to be the only person their child talks to about everything. And I think that's regardless of whether the child and youth has a disability. I have always said, and I work with parents even today in a different capacity, your child may not feel comfortable speaking to you about everything going on in their life and communicating some of these concerns or questions. For example, I didn't really feel comfortable talking to my parents, I preferred talking to my sisters. It is important that children and youth are exposed to role models and adults that they can speak to if they have questions or concerns, or if they're in trouble and don't know what to do.

Letting parents know it doesn't always have to be them, but that it’s important to have a child have somebody to talk to, somebody the parents or caregivers trust. That might be a member of the healthcare team or another relative or a family friend. It is never too early or too late to start having these kinds of conversations. We want to make sure that the conversations and the information that's being relayed is developmentally appropriate, and that you can build on this information over time. This is not one of those like, we had the conversation, the conversation is done, pat yourself on the back, but more like, let's start these conversations early and build on them as the child and youth gets older and starts to experience their own things and wants to talk about that.

This is me as an 18 year old, I think I've just done high school at this point. Being a teenager, it was tough. I recently actually this past weekend, coincidentally, came across something I wrote when I was 14 years old, so going into high school. And it talked about my high school dreams and goals and the things that I wished would happen. It talked about my desire to be popular, whatever that means, and to have relationships and dating. But it also highlighted that I didn't even really know what was possible for myself. And I again, I had no one to look up to and I didn't have anyone that had a disability that I could talk to. It wasn't until I entered high school, we had a teacher who uses a wheelchair after a spinal cord injury. I remember seeing her in the hallway and I thought to myself, oh, I should talk to that person. I didn't realize that she was a teacher right away. Anyways, since I never took any art classes, she was never my formal teacher. And, you know, but I was still able to talk to her about what was going on in my life. And you know what was going on with me and how school was going. And I told her that I was really worried that I would never find someone to date because I had a disability, and I remember what she said to me, because it sticks with me even today. She reminded me that someone's value does not lie in having a relationship and that I shouldn't base any value on that. She reminded me that I should be more concerned about having a healthy relationship than just simply having one for the sake of it. This highlighted for me how important it is to have positive mentors, and that she didn't reassure me that I would find the perfect partner, she reassured me that I was valuable regardless.

Privacy is important for any teenager, usually teens demand it. But when you’re a teen with a disability, parents and caregivers, need to make room for privacy. It sometimes can be an effort to allow your youth to have some alone time. And I think it's, it's definitely something that needs to be incorporated in that youth’s day to day.

People always said that children don't really listen to what you say, they listen to what you do. And that's why it's so important to model, healthy relationships and for our children and youth. This doesn't necessarily have to be an intimate relationship, but could look like, how you manage conflicts with friends or having discussions about individuals on TV or in movies, and their dynamic. It can be about how you apologize for your mistakes, how you resolve conflicts. Children and youth with disabilities also need to practice and work through these things. Life skills programs for youth can be really helpful for them to practice this in a safe, social setting, and practice the skills that they need, without having parents or caregivers around.

I wanted to spend some time talking about the importance of exposing children and youth to positive examples of relationships that include an individual with a disability. Besides the teacher who had a spinal cord injury like I said, I didn't really have any exposure growing up, and I swore that I would never date anybody who had a disability.

There have been many stories recently around couples where one person has a disability, and the other person appears not to. There's been Instagram accounts made, YouTube channels, and you know, I think it's really helpful that we have more and more exposure of individuals with disabilities in relationships. I want to highlight though that these tend to be seen as the success story. A person with a disability dating somebody without a disability, or I should say without a visible disability, because we don't know if those individuals have invisible disabilities that are not being shared. I think that when we're seeing this as a success story it takes away from the fact that they're not in a relationship with someone because they do or do not have a disability, but rather they should be in a relationship because of who that person is. And I think it's more important to teach children and youth with disabilities that the success story isn’t dating someone who doesn't have a disability, but rather knowing yourself well, and finding a partner that loves and respects you, if that's something that you want.

But how do we do this? I used to be a social worker in the immersive life skills program called the Independent program. One of my favorite activities I facilitated was around learning about preferences in a relationship. This activity evolved over many years of the program, it didn't start with me, and it extended beyond intimate relationships, and was applicable to friendships as well. On the screen you can see a star, a checkmark, and a trash can. So a star would be a bonus, checkmark must have, and trash can is trash. It was an activity where youth pulled out a characteristic or behavior and they got to decide whether this was a must have, a bonus, or it was not healthy and belongs in the trash. For a lot of these youth, this is the first time they were ever able and offered to reflect on what kinds of characteristics matter to them. And when we do this activity as a group, the youth are able to see that people have different preferences and what might be a must have for somebody else, is a bonus for someone else. Some of the examples might be, they would pull up like willing to listen, supports your choices, someone who can make you laugh. And then some were unhealthy ones, takes your money, always wants to know where you are. These are really good conversation starters but why some of these characteristics are healthy relationship characteristics and why some are not. There's also might be something, there was one about has a car, well that might be really important to someone, and for another person that's just a bonus that would be good or not good, it didn't really matter. This is just one example of how to talk to a group of youth about healthy relationships, it's not the only way.

A lot of people get caught up in focusing on the sexuality piece, that we really need to spend a lot more time talking about healthy relationships, which comes from again helping that youth to know themselves, and being able to have different kinds of relationships and experiences, to learn what they like, and what they don't like.

Some takeaways, start early, recognizing everyone here has a role to play in these conversations, and know, we learned that trusted adults and mentorship are important, so get children and youth connected to a mentor as soon as you possibly can. Disability representation matters, start to expose children and youth to disability in the media, there's now lots of accounts that people can follow where they can see different kinds of disabilities and different kinds of ways that people are living their lives, and this stuff is really important in terms of allowing children and youth to see possibilities for their future. And you don't always have to be the expert, there's tons of community agencies that can support, Holland Bloorview being one of them, and other professionals as needed. And of course the disability community has a wealth of experience in this topic. And so if you're looking to reach out, there's always options to try to figure out who can support you in having these conversations.

Because we can't really get far without talking about, you know, social media, I wanted to highlight some accounts that you guys can follow, like, retweet, where they all have something to do with disability, and they share different stories and like research and opportunities to get involved. So I just thought that I would share these pieces as well, and this quote, “disability doesn't make you exceptional, but questioning what you think you know about it does.” (Stella Young). It really goes to highlight how much work we all have to do, and always being willing to be curious, question your own biases, and be willing to learn, and continuously learn different things about this population, and keep an open mind.

Thank you so much.

TRANSCRIPT- Let’s Talk Disability and Sex Connection Day Event

Talk Theme 2: Meaningful sexual lives and sexual rights

Speaker: Dr. Shaniff Esmail

Hello Everyone, I’m Shaniff Esmail. I am an occupational therapist, I’m also a Professor at the University of Alberta, Department of Occupational Therapy. My research focus is in the area of sexuality and disability, and I also teach the human sexuality course to the general University population, but also I teach the sexuality and disability course to the occupational therapy students, I teach to the physical therapy students, I’ve also assisted with the medical students programs. So in terms of myself, just for the people with lower vision, well I wear glasses, I’m wearing a blue shirt, and I have lots of hair, I’m just kidding, I’m quite clean shaven on top. So, anyway, that’s me, and my pronouns are he/him, and all of that.

So today we are going to talk about sex, and disability, specifically looking at research and how to look at healthy sexual expression. So, I’m going to talk about some definitions, I’m going to talk about asexuality and stigmatization and how that can impact how we look at things. I’m going to talk about research around sex and disability. We’re going to talk about healthy sexual expression and also how to promote healthy sexual expression. So let’s get started, of course, we’re not going to have a Q and A session right now but we will have one later and also this afternoon there is a panel so we can have some chance to have some further discussion. What I’m hoping to do is give you some food for thought for all of this.

To begin with, let's talk about sexuality, now I teach courses in sexuality and all these young students come in and they want to learn about doing “it”.

And I've been teaching “it” for 30 years and I still don't know what “it” is. Well in reality when you talk about sexuality it's more than physical expression, so, if you look at my chart here, physical expression is just a small component of sexuality, you have to look at body image, self image, gender roles, socialization, personality, communication.

All of that comes together in terms of our experiences, what we learn, but bottom line is, you have to look at the individual. What is important to the individual, what is there values and belief systems and then we can work outside from that, and basically look at sexuality. So it’s more than just doing “it”.

Now, the World Health Organization has done a really good job of looking at sexual health. They look at it, as a state of physical, emotional, mental and social well being in relationship to sexuality. They don't just look at it as harm reduction or all the negative aspects. They're also looking at it as a positive thing that can enhance people's life, quality of life and well being.

The other thing is a lot of people use terms kind of differently, handicap, impairment, disability, so what's the right terms?

So when you talk about impairment that's something wrong with the system, so if I was riding my bike today to work and I got hit by a car and I suffered a spinal cord injury, that would be my impairment, the spinal cord injury would be my impairment. The disability would be the functional limitations caused by the impairment so, for example, if I'm not able to walk, that would be my disability, I'm not able to have an erection, that would be my disability. Handicap can be either social or physical barriers that prevent me from doing things so, for example, if I'm not able to enter a building because of my spinal cord injury, then the building, if it doesn't have a wheelchair accessibility, then the building is handicapping me. Or if my parents decide oh, because I have a spinal cord injury and I have a disability, I shouldn’t be getting sex education or the school decides I shouldn't be getting sex education that would be an attitudinal barrier that's preventing me from accessing information and education, so that would be a handicap. Okay, I just wanted to clarify those things.

Now I love using this (cartoon picture) I use this a lot when I do presentations, it says, “nice to see her go out with a guy I don't have to worry about, after all he is in a wheelchair.” So when you're looking at this, you look at mom and dad looking, he's smoking (dad), which is an old picture you can tell, they're looking at their daughter going out with a young guy, and they're saying oh she's safe, he's not going to take advantage of her. But if you look at his face he's going to get some tonight. And just because you have a disability, does not change who you are, you know, if you want to have sex and you want to whatever, then that's who you are.

It makes me think about a story I tell my students, but I have a friend who suffered a spinal cord injury when he was 16, this was 30 years ago, and he was in a rehab unit and in those days, people grew up in rehab units. Anyway, this was in Edmonton, and he basically was allowed to have weekend passes when his rehab was moving along and he was from a small town in Alberta so his girlfriend actually lived in Edmonton. So what would happen on weekends is his girlfriend, with her parents, would come up, bring him home, and he would spend the weekend with his girlfriend.

The thing is, they set up a bed in their daughter's room in the basement and they would literally carry him down so he spends the night there and then comes up in the morning, etc.

Now tell me how many parents today, let alone 30 years ago would have allowed their 16 year old daughter to spend the night with her boyfriend? But they looked at him as being safe, asexual. They're not, he's not going to do anything. Well let's just say my friend, before his injury, he did not have sex, but after his injury in those nights that he spent with his girlfriend he learned a lot about his body. And let's just say he never used that bed, they'd mess it up in the morning so that parents would think that he used it but really he didn't.

So I say we live in an attitudinal umbrella of reproductive bias regarding sexuality. So what do I mean by that? Basically, when it comes to our society, who has a green light to have sex? It's young married heterosexual couples. Children well they're not supposed to have sex, older adults well that's just not right according to attitudes, and then people with disabilities well they're not supposed to be sexual and people who are gay or lesbian well there's a discomfort to that so they're not. So when you look at research, looking at programming, and all that, it tends to be for young married heterosexual couples and we need to change that.

So, let's talk about asexuality and stigmatization. Generally, what they're finding is social cultural barriers may be more disabling than the pyramid itself. So attitudes around disability and a stigmatization of people with disabilities, can be more harmful than the disability itself. So sexuality of expression of love and pleasure is not recognized for individuals, people with disabilities and also it's suggested that people with disabilities actually internalize these notions of asexuality, because people don't treat them as sexual, they don't see themselves as sexual and basically avoid the whole issue.

So let's look at from a historical perspective, generally, what you find is research was focused from a medical perspective. They were trying to reduce the problem and basically they focused on fixing the problem in terms of physical function, doing "it".

The medical model also focused on harm reduction, how do you prevent and control sexuality? So you're trying to stop all the harm aspects of sex, not the positive aspects. And also there tends to be a social resistance from a historical perspective towards people with disabilities developing relationships and even having sex. So all of these really prevented a holistic approach of looking at sex and sexuality.

So the social model, which was developed by the Union of Physically Impaired Against Segregation way back in 1976. Basically, they said that disability was a result of social structures which function to exclude certain people from accessing employment and social resources and positive identities, etc. And they're saying that we should be focusing on public's response to individuals with disabilities. So we want to remove environmental and social barriers, so what I had mentioned earlier, how we can look at how there's handicap, so what we're trying to do is remove the handicap, so we are trying to remove physical barriers and societal barriers.

Now, by doing this, if we remove these, think about if you got rid of all the environmental barriers and if people's attitudes of that change and there weren't any biases against people with disabilities, would there really be any handicaps? There wouldn't, there would only be disability, but people would be able to function in society and be able to live productive healthy sexual lives.

All right, let's look at myself. I don't know how long ago, I was applying for a research grant and I wanted to look at sex education guidelines for individuals with disabilities. So then I said, okay let’s look at that. So the first thing I did, is I go into the literature and I start digging through and reading, doing a lot of reading, and what was interesting is first off there was not a lot of research on sex education guidelines, I mean there was, but it was very limited and I started to see a pattern. When it came to physical disabilities what I found was there was lots of literature and research on function and response, because of the disability you're not able to do this, this, and this, this will be prevented, your sexual functioning will be low, so it focused on anatomy, physiology, and all those kind of things and then there's some research on fixing the problem. How do you deal with sexual dysfunction, try to fix it, but there was very little on promoting healthy sexual expression.

Then, on the other side, I noticed there's not many programs, but then I looked and there's lots and lots of programs for individuals with cognitive or intellectual disabilities, and I said well that's great and I started looking at the programs more deeply and I said wait a minute. All of these programs focused on things like harm reduction and there's lots and lots of programs on dealing with inappropriate sexual behaviors, again very little promoting healthy sexual expression. So I said, well what's going on here.

Okay, think about it, someone with a physical disability, they internalize the notion of asexuality, they don't bring it up, they kind of see themselves as very limited having a sexual life. So bottom line is they don't talk about it, they don't bring it up, so no news is good news, so really it's not a problem to society or anybody so really it's avoided.

Then you have people with intellectual and cognitive disabilities, they may mature normally or typically in terms of hormones, drive, etc, but cognitively they may not be able to fully understand their behaviors and be able to control things, etc. So they might act out or do things that society would deem as quote unquote inappropriate or deviant behaviors. So then, what do you do it's a problem, so, then they try to fix the problem, how do you fix the problem, by controlling the behavior, so they develop programs, not for a healthy expression, but more around prevention of inappropriate sexual behaviors or harm reduction. Because also individual with intellectual or cognitive impairment are at greater risk for unplanned pregnancies, STI’s, being victims of abuse or assault or perpetrators. So again it's harm reduction, nothing about healthy expression.

So what are some basic assumptions about persons with disabilities. So this is kind of the foundation that we should be using. All persons regardless of disability are sexual persons, the person with the disability has a right to all information about sexuality that he or she, that they can understand, including the right to a full range of expression and, finally, the person with a disability, has a right to develop relationships with others and to express affection and sexuality in the same way that's acceptable to others.

So what is healthy expression? Now if we were doing this live I would love to have a discussion on healthy expression, but maybe during the panel we can talk about this or during the Q and A. But think about what elements you think should be included in healthy sexual expression. I got a nice little table which you can look at on your own. Hopefully these slides will be made available to everybody, but it can give you what healthy expression is as well as healthy sexuality compared to abuse and addictive sexuality.

Then, in terms of defining it, what is healthy expression, it's involving, well is recognizing and celebrating that everyone is sexual. Emotional and social communication and connection, it's not just physical and, finally, the CERTS model by Wendy Maltz and she basically said it should include consent, equality, respect, trust and safety. Now, the issue of consent also becomes quite problematic for individuals with cognitive disabilities, because in Canada anything between two consenting adults is legal, however, if a person's capacity consent is limited, are they, it really limits what they can do and what they're allowed to do. So I'm doing a lot of work in the area of consent right now, and just published or sent a paper for publication, but we don't have time to do that today, but hopefully during the panel, it can come up.

So let's talk about the importance of promoting healthy sexuality.

Now family members, service providers, often view sexuality as a source of risk, “oh no, things might go wrong” etcetera and they do not acknowledge that sexuality is a healthy and normal part of adult development. So caregivers are often found to be against providing sex education and blah blah blah, because if you do that, it opens a can of worms and it might create desire and all these other problems, so better not to deal with it. But actually what they found is sex education can actually have positive, it results in positive changes in sexual expression and identity. It actually promotes appropriate expression of needs and decreases inappropriate behaviors and improves social behaviors. And generally we find that there's no adverse effects such as promiscuous behavior, pregnancies, etc, etc.

Now, if you don't promote healthy sexual expression what happens? Unhealthy or abusive forms of sexuality may prevail. Also, it may cause worsening of mental disorders such as anxiety, depression, other disorders, and other forms of acting out might happen physical, as well as emotional acting out. And finally, it may put a person at higher risk for sexual abuse, exploitation, HIV, STIs etc.

So, we're all sexual and how do you facilitate healthy expression? Well, first off, you should approach it from a strength based rather than a deficit based approach. And a lot of times when working with people with disabilities, we focus on what is the disability, no, we should focus on what is the strengths. We should tailor specifically, these programs should be tailored specifically to each individual. The other thing is acceptance and honesty, don't sugarcoat. So what I'm talking about here is a lot of times, when service providers are talking about sex, “oh don't worry things will get better” and all that kind of stuff, no, you want to be upfront and honest. Yes, you have a disability and yes it's going to cause some difficulties in terms of relationships and sexuality and how people treat you, but this is what you can do. What they find is that actually helps with coming to terms and moving forward. And the other thing is repeating, sexuality is more than just physical expression, you need to look at coping with urges, loneliness, also looking at other parts of life in terms of clubs, exercise, healthy occupations, activities and bottom line is modeling healthy sexual expression.

So, in summary, sexuality is a human right that is important to all individuals, regardless of age, gender, orientation, or developmental level. To broadly address development of healthy sexuality for individuals with disability, the issue needs to be normalized, not ignored or avoided, which means involving parents, staff, researchers, and professionals. And research must focus on the positive aspects, not just function and harm reduction.

So, I look forward to the discussion we're going to have this afternoon, as well as during the Q and A.

And I love this cartoon too, “Sure you came first, you always come first, that's why I never come at all”. So basically it's a chicken talking to an egg so it's chicken and egg, which one comes first.

Anyway, thank you very much, I look forward to our discussion, later on.

Thank you.

TRANSCRIPT- Let’s Talk Disability and Sex Connection Day Event

Talk Theme 2: Meaningful sexual lives and sexual rights

Speaker: Rainbow Hunt

Hello everyone, my name is Rainbow, I use the pronouns of she and her.

I basically I identify myself as a transgender woman, labeled with an intellectual disability, and I'm also the project Executive Director of Rainbow Pride Scarborough, which is basically a project that I started back up, along with my team members, back in 2011, which is basically a nonprofit project that works and serves the QTBIPOC community, youth who identify themselves as queer,trans, black, indigenous, people of colour. And so we started this project up back in 2011 because of the needs of having and creating a space in the Scarborough community. Just like east of Toronto, because of the lack of support and services that the youth basically wanted to see more of like a pride celebration and more of like diverse community getting together to create, work together and activities and brainstorm ideas.

The importance of the effect came together with lived experience with their disabilities and their sexuality, really put a tear to my eye when I basically fell in love with all the data that we collected from each youth who wanted to basically see more services in Toronto, because of the lack of support and the lack of ways of getting downtown Toronto where there is more services, more than Scarborough.

So my team and I got together in 2011 and we sat down and we talked about, what can we do, what should we try to do to reach out to people in the Scarborough community and to reach out, which is a big thing, we're reaching out to people that are isolated, when they can’t come to us we can go to them.

So my team and I decided then to brainstorm for a couple months on different ideas of like okay, we need, obviously we need staff with lived experience ourselves. We also need allyships in this project because we work with allies, that's a very big piece. And also, creating that staff team of support, love, and care and accessibility is a huge issue that we use with the work that we do. So we got together and decided to host barbecues in the park, that's close to Thompson park in Scarborough, and that was a big success.

At the time we didn't have funding, because of the lack of support that we had ourselves, it was like a trustee and like holding our funding and the work that we’ve basically been doing. So, we've been, I'm personally me, I've been forking money out of my own pocket, I'm on ODSP (Ontario Disability Support Program).

So forking money out of my own pocket, and I didn't care if I struggled myself. I just wanted to see the youth in the community to be able to access the services and supports and mental health services. So we did our first barbecue, and that was a big success we were able to create flyers. I'm very artistic, I created the flyers and shared it with different agencies that I was connected to. And then they, some of the agencies had their youth that live in Scarborough so we were able to reach out to 30 plus people with like only like a barbecue for like, 200 bucks of the budget.

And that was a big, huge success and it just, it just made me feel like, oh wow we did our job, we did our work. After that we then started hosting more barbecues more things, more of that.

And then I finally reached out to SKETCH Working Arts which is an art space downtown Toronto, nonprofit, art space down by Argyll, and they basically were so supportive and decided to be our trustee from 2015 up until now. And so they've been holding our funding, the whole entire time.

So after that we started reaching out to our partnerships and different collaborations and we get that growing and growing and it's just a huge success of our project that just started from very little money up until now, it's like, I'm like, the grant master of writing grants, I was learning my own, my own skills, and people with disabilities, actually, like, obviously you can write grants, there's no, you know, slap on the wrist you can't do this because you're, you know, you're not smart, it's not true. A lot of people with disabilities can do stuff that they put their mind to, with the support that they need. It's a huge, if I can do it they could do it. Um, and so we created our team and our team is just an amazing team with little experience, proper training around a lot of stuff that we trained ourselves to. And we just support the youth and hear what they have to say. Their voices are very valid and their concerns are very valid. So that's basically our process that we basically work with Rainbow pride in Scarborough, in Scarborough.

We basically, yeah we did our first, the stuff that we serve and the stuff that we came up with for the youth, they came to me and wanted to do more activities around, expressing themselves through sexuality and the arts, and I thought it was very, very, very interesting because I did it myself as a drag queen performer.

When I first came out as a, as transgender back in 2009, before I even started the project. And I use the art as a way of like expressing my sexuality. And also, like in a, in a positive way of talking about sex and like feeling good about myself inside and out, like very sexy. Because a lot of people, sorry youth that we work with, that are basically face a lot of de-sexualization because they're either disabled or they are labeled as not sexual active in wheelchairs or, or with like a mobility device, and it's basically like a yeah this de-sexualization, de-sexualizing them, if I say this right.

So basically, they feel like they're not really sexual active in a way. So we use art around that way of escaping that stigma around art. So what we did was we apply for one grant that allowed 10 participants in the Scarborough community with, who are disabled, who feel like that they're facing discrimination around de-sexualization and racism and homophobia, transphobia. And we got together and created a portrait project, where each member wanted to take their portraits into like a different level of feeling sexy and you know filling very sexy and power in a wheelchair, to tell people you know what just because I’m in a wheelchair, I'm sexy and I could still be in a relationship, I can still enjoy myself, I can still be safe. And that encouraged them then to be more powerful with their portrait, and each of them got their portraits. They're pretty big sizes, very very very visible, sorry not visible, what’s the term I’m looking for, very shown, as like huge.

So that was one of the projects that we did.

And then we came up with other ones with like basically the youth wanted to create their own costumes and their own clothing to perform in on stage in wheelchairs, which that was a big success so we did a couple of workshops.

Our project works on any types of workshops, anybody that wants to learn about different things about our work. It could be anything. Sex, disability, LGBTQ, anything. We also deliver one to one support, Big Brother/Big Sister, resume building for people who need jobs for youth.

We work around harm reduction and harm reduction in different ways. Either it's like testing or HIV or and then other stuff like proper training around that, um, Naloxone or it could be like safer sex. We talk, a lot of youth talk about sex and the different ways as like appropriate and consent and consensual and, in a healthier way that's also appropriately and fun to talk about with more of a sensibility around language that youth like to use. In a fun, creative way, so then that way, yeah, so like basically talking about cucumbers, you know, practicing safer sex, you know, and all that, like, all that kind of stuff like that, that's like more of a fun way because of their disabilities. We don't use like the high class sex contents. But we talk about, like, workshops or learn about that.

Um, so yeah that's our basically our project has been around for almost 10 years right now. And what we're going to be doing right now is we are working on a grant right now that's actually due tomorrow.

And it's for Community One Foundation and we are going to be basically designing a educational documentary for participants to come and talk about their experience and about being part of being part of the projects, and how this project really benefits them in their, in their own communities. And then what we're going to do with that documentary is basically use it as like a workshop, educational workshop, and then do like a grand event launch, if it has to be virtual, it's virtual for this year, November. And yeah so that’s the project that we basically work with, with Rainbow Pride Scarborough. Other little projects that we had out of Rainbow Pride Scarborough were called different titles and different names, just to be like very creative and funky. The youth come up with the names of everything of the projects, they come up with all the ideas, they come up with all the activities, they come to me and me and my team and say we want to see this we want to do this.

So when we talk about and evaluate each part of the activities that we do, evaluation is a big thing, because if it's especially when you're working with people with disabilities. Evaluation needs to be very accessible for them to understand what they're filling out either if it's a survey, or if it's like a monkey survey or a piece of paper, or if it's a couple of questions with emojis that's very understandable for them to understand what they're answering, which we, we basically do a lot of that around accessibility and disability activism. Just like talking about that, yeah like about that, which is very important because a lot of agencies, not a lot like in a bad way, but a lot of I find agencies that I've been to it wasn't really accessible for myself as a transgender with a disability. It's different when you work with somebody who is who doesn't have a disability versus somebody who does have one.

And if you have like a mix of those groups in your space of like a group or, or a program, how can you be accessible for everyone who comes into your space and how can you basically, oh, you know this person needs more accessibility support, and this person might not need that much support. So how can you like basically shuffle and you know make sure that it's safe or comfortable for everyone who's coming into your space, this is I think it's very important because if you're serving LGBTQ, it can be, there can be different groups of the LGBTQ community. Either your sexual identity or sexual orientation or your disability or the different types of mental health, or it could be so much different things out there, and coming from me with a lived experience, I would talk to somebody who does not have that lived experience and then they learn so much and then they come to me and say, Oh, do a workshop for us please, I would like you to do a workshop.

So we do like a lot of stuff and it's, it's very humble and very empowering having youth with lived experience actually do the work and talk about their experience versus somebody who speaks for them, which is not that much of a good, it's not that much of a difference. Sorry, it's a different feeling that people get in the audience, like you know you watch people with lived experience it's like oh wow this person has lived experience versus like oh someone's talking on behalf of somebody or which is very amazing, it's, it's much more amazing, it's more powerful for the audience to learn more.

Yeah, so I came out myself as bisexual, then gay, then trans, there was a long journey for myself and learning about myself and my experience, growing, growing up as a, as a bisexual person, and then coming out as gay and then trans so that was a big step by step by step process I was figuring out myself and my, my identity and my sexual orientation, it took a while but I basically looked deep down inside my soul, my heart, and said you know what, I'm happy being a woman, this is what I want to be, this is what I want to see myself as. And then when I basically came out in 2009 and had that amazing relationship with my family and lucky to be very fortunate to how the supports, sometimes it's not that lucky. So it's, but the person should not be alone.

Yeah, and just coming out and then just creating and giving back to my community, which I think I just really love to do and this is something I really enjoy doing if this is something I really enjoy doing.

And it's it's tough for me to stay at home and being so you know bored, I just want to do something that really makes a difference in the community especially Scarborough for youth that I don't want to see them go through what I've been through with, basically with my life. Bring up as an individual person facing a lot of, you know, relationship violence and stuff like that, and so I just think, you know what I want to do something for my community and the youth. They deserve a supporting staff team and they deserve more programs and services in Scarborough because there’s not that really much out here in Scarborough for pride stuff and for, you know, for, for black history or for in general, anything. Not, not that I know of, I don't see that much flyers, or anything around, like the bus stops and everything, so it's like it's very like minimum and not that much rainbow stuff.

So I also reached out to Scarborough Town Center, which is one of the shopping malls here in Scarborough and spoke to the CEO. And this was like two years ago in the summer before the pandemic started, so I was very happy.

And I spoke to the CEO and I said, “oh hi my name is rainbow, and we work at Rainbow Pride in Scarborough, and we want to, we wanted to let you know, we wanted to ask if it's possible if one day, or whatever around pride time, Scarborough Town Center, if you can promote some more rainbow pride stuff around the mall or make sure your stores are very accessible for transgender people to access what proper clothes or proper this or feel good about shopping in the, in the women's section or men's section or gender neutral washrooms.”

And so I spoke with them and they came up with a big plan, and now it's like around Pride time, a lot of stores have like rainbow purses, rainbow clothes, like they actually display it in the window. And then they have like gender neutral washrooms, and then in the middle of the mall, they allow, now, a pride decoration of like a performance every year so.

All it takes is just to reach out and talk about your work that you do to basically want to see something happen in that, you know, in your community, by not being scared to reach out and requesting an important thing that you know youth or anybody who is from the community can actually go to a shopping mall and see like a rainbow symbol, and feel good about themselves inside and out and say wow, this is a safer space and we don't tolerate you know, any kind of like discrimination or anything. So that's something that we did two years ago and I'm very happy about that.

And so I'm very flattered and very, I'm very like flattered that our team is basically like doing the best we can and supporting the youth, making sure that they're safe, thinking that the youth are safe first, before us. That’s how you create a team, that’s how you build a community and that's how you build youth engagement and making sure that you know that their voices are heard and that their voices are valid. And what what's the most important thing right now in the community is that it needs more supports and groups like ours to create, to make it like more of like a welcoming and accessible Scarborough for like around Pride education. I think it's very important.

And this is something I'm going to keep on doing and doing because I really love it, and it makes me happy and it also decreases my own mental health as well. And it's it's a very awesome tip and awesome medicine, medicine, if I'm saying this right. That decreases my own mental health because I really love doing stuff like this.

Yeah, and this is a basically the great experience that I wanted to share and with the work that we do up here in Scarborough and my own experience of my journey as well, of coming out, as transgender with my disability, and I use a lot of the art. Like I was saying, around my disability to express myself on stage in front of like 300 people, 500 people, by creating very crafty and funky funky costumes. If it has to be like disco light bras, or, or sunglasses with real nails coming out of it, or barbed wire high heels or, I don't do any meat dresses, I don't do that. But like I don't judge but, um, but like anything that I find that is funky and crafty and sexy for me to express myself. You get the audience like wow. Whoa. I think I perform and you know and a lot of my youth now they love to sing, dance, rap, make their own music, they, they're just really extremely talented here.

It's like whoa like we should create our own like TV show.

But yeah, so I think it's really great how we use ourself to express ourselves through sex, disability, mental health, depression, through arts, which is a great, it's a great thing like painting or beading or performing or acting or singing or dancing or it could be anything.

So that is the work that we do, and I’m just very happy to be part of this video and audio of sharing my experience, and the project we do, and the work that we do. And thank you so much.

TRANSCRIPT- Let's Talk Disability and Sex Connection Day Event

Talk Theme 3: Multiple and converging identities

Speaker: Dr. Alan Santinele Martino

Hi everyone, this is Alan Martino, pronouns he and him. I'm a 30 year old man, brown man with bald head and glasses, wearing a very flowery shirt. Not much behind me just a white wall with a degree. So, that's my description.

Thank you so much for having me as part of the meeting today. I'm very happy to tell you a little bit about the work that I've been doing and some of the potential consequences that we have in looking at this intersection.

So I'm calling this talk, Sexualities: Yes, in the plural, because this is something that I have been telling a lot of support workers and agencies and service providers, that we do need to understand sexuality as more than cisgender, more than heterosexual and monogamous and so on.

So first of all, who am I? So I've been doing this work around disability and sexuality since my undergraduate studies, when I started doing interviews with service providers around New York State. And what I found is that there was a lot of fear and hesitation when it comes to talking about sexuality in general. But most importantly, when it became to talking about sexualities in the plural, it became something that was seen as being just too much, or going too far.

When I first started doing this work, I was a member of this particular service provider, and I was participating in the arts-based program of it. And in one of the improvisation exercises with young man with down syndrome, he said, "Love is natural, we all love." The scene continued, people just kind of responded to the sentence with "Awe so cute", right, you could hear the awe sound in the room. But as the young man continued the scene talking about friendship, and then, love, he then drops the sentence, "S.E.X., that's what I want." Now, as soon as he said that particular sentence, then the energy and the vibe in the room completely changed. The rest of the room, including other people with intellectual disabilities, support workers, and volunteers, were extremely uncomfortable with that sentence. I remember people staring at each other, giggling with nervous laughter until one of the directors, the support workers, jump in and says, "Isn't the weather beautiful today?" And then he cuts the scene, and we move on, right, to another one.

And to me that was very troubling because, you know, it became this elephant in the room, right, that no one wanted to talk about, that was off limits, a topic that we shouldn't talk about.

And what I would expect is that we would encounter and deal with experiences and moments like that with more positivity, right, acknowledging people's feelings and desires for their lives. So that was really one of the big pushes that I got to start doing this work around disability and sexuality.

Now, I think one of the things that I find very fascinating, the work that I do is that, you know, it's a lot about bringing an intersectional lens to it, so thinking about sexualities in the plural.

We know that there is a growing body of literature and empirical knowledge, looking at the intimate lives of people with disabilities, but we still see a lot more focus on the experience of heterosexual and cisgender people with disabilities. So we're paying less attention to the experience of LGBTQ+ people with disabilities and that's a very significant gap. This is a group that faces very unique challenges and experiences when it comes to exploring their sexual identities, exploring their sexual lives, establishing relationships and being sexual.

What I've encountered, even in my field work and working with organizations, is that that level of infantilization and de-sexualization, especially experienced by people with intellectual disabilities, sometimes makes it seem as though sexualities in the plural are just a phase, right, and I've heard that from people already. And this is also being noted in the literature, where sexualities in the plural are seen as just a phase towards heterosexuality or a last resort, right, or simply a sign of close friendship with other people. So for example, I remember seeing Johnny and Michael, you know, walking holding hands, and even though we all knew they were in a romantic relationship, what people, the way they categorize or label it was, “oh, they're very close friends.” So we are speaking about it in ways that infantilize, de-sexualize, de-gender, you know all those things, in terms of the people that we're working with.

We also have a lot of work in the literature around how people with disabilities who are part of the LGBTQ community, are, tend to be undervalued and not have access to queer communities.

So there's a lot of work that should be done around queer spaces and how welcoming, they could be to people with disabilities as well.

So what we see here is that people that experience this particular social occasion, right of this intersection of disability and sexuality, but without a community in facing particular challenges and stigma on their own, trying to find information about sexuality on their own. Considering how a lot of the sex education and information that is available, tends to take a heteronormative approach. What I see and what is also in the literature is that there is a lot of social isolation, restriction, and surveillance, and my participants have talked about how they were often unable to access spaces that allow for relationships to emerge, to flourish, and to happen. Not only to you know, not even speaking about hookups for example.

So Randy was one of my participants that really spoke about it. He said, "It'd be great if there were places that if you're gay you could be safe, and more secure in, but that's going to take time." end quote.

This is a participant who identified as queer, and who was telling me how he would love to be a part of the queer community but never found welcome in those spaces and found that the loud music, the crowded spaces, that doesn't give the space that would be the most comfortable for him. So what we see here is that it's consistent experiences of invisibility, exclusion, lack of supports. Even in group homes or other services that we're often providing to people with intellectual disabilities, they often take a heteronormative approach.

We also need to understand that this particular experience of homophobia and transphobia that people are experiencing in the community. So I'll give you some examples of that.

Scott, a trans man tells me the experience that he has. He says, "Because of my trans life identity and everything like that and I've gotten spit at and called a hermaphrodite." Like these are forms of violence that unless we put into the conversation, gender and sex and sexualities, we wouldn't be able to fully understand his experience. And he's not alone, right. So Virginia also shared her own experiences of a trans woman, she says, "When people call me by the wrong pronoun, I turn around and say, I'm a female, thank you, have a nice day. Or sometimes when people have an attitude and they call me 'sir, you can't stand here in line, please go to the next one.' If I hear the attitude or rudeness, I turn around and say a comment which would get me into trouble. And the guy is like, 'oh, sir. this is the males, and this is the females, so please go get checked over here with the males. I looked at him and I was like, I'm a female, I have tits, I'm over here. And he's like, 'Oh, I'm sorry'. I'm like, yes."

So, again, and I talked to quite a few participants who were navigating those intersections, right of trans-ness and queer-ness and talking about instances of violence that they just didn't have any supports, even in their organizations, to help them navigate those experiences. They were getting a lot of supports when it came to their employment, their education opportunities, but a lot less when it comes to one their intimate lives, but also in terms of gender and sex identities.

Scott also talks about another yet example, he says, “Even in my Wheel-trans, I used to get the wrong pronouns, even by the other customers in the Wheel-trans. They would called me ‘she’, and I'd be like, excuse me, don't let my voice fool you, I go by male pronouns, thank you very much.” end quote. I mean what stands out to me too in these participants, is that they're able to really articulate and use their agency to push back on those interactions, but we know and we have so much data now on the violence that trans folks and, you know, sexual minorities experience so I can only imagine how challenging it must be for some people to push back on those experiences.

The other thing that I think will be great for us to discuss today is the gate-keeping that happens. So, for example, the gate-keeping that is done by ethics review boards. Ethics review boards that take a medical and reductionist approach to disability. I've had ethics review boards for example that reduce participants to their biology and disability labels, asking me why did I need to ask participants about their racial identity or their religion or sexual orientation. The assumption here is as though that disability label is the only label that matters in people's lives. But I think that that's indeed one of the things that we're missing here, right, is that intersectional lens.

The other piece around gate-keeping that I think is very important to consider is, you know, the idea that people with intellectual disabilities cannot contribute to research or be knowledge makers or be meaning makers of their own lives. So for example from different ethics review boards, one of the comments that I received is, why do you need to speak with people with intellectual disabilities? Just talk to parents and support workers. Again, I think that there's also some gate-keeping and there are conversations around vulnerability that we can also talk about today, that shouldn't be silencing people right, we shouldn't start from the perspective that every person with a disability is white, cisgender, and heterosexual and we need to make sure that those narratives are making to being a part of the dialogue here in our studies.

Even when I conducted a review of the literature with two colleagues of mine, what we found is that we don't have a lot of attention yet we don't have a lot of focus on this intersectionalities. So for example, when we looked at studies that have been addressing the intersection of disability and intimate lives or intimate sexualities. What we found is that some studies include lesbian folks and bisexual and gay, but we still don't know much about for example asexual folks, or folks who are questioning or fluid.

Same thing with around sex and gender, right, trans people that are participating in the studies about sexuality and disability, only 6.1%. Gender non-conforming only 2%, and intersex 1.2%. One could say that, you know, this numbers kind of remind us of the number, the proportion, maybe in our society, right, that it might make sense. But I think that they're still to me means that we're still not exploring those intersections, the way that we should. Right, we rarely see studies about trans disabled people, especially people with intellectual disabilities. Or even this intersection of race and ethnicity, and most of the articles that we looked at did not mention participants race or ethnicity. And so we know very little about how racialized and disabled identities intersect with sexualities. For example, in the articles that did mention race, 26 of them, 76% of the, the sample was white and Caucasian, with only 38% being black or Latin American. So that is just saying that we need more intersectional work.

Even in terms of service provision. We still have very few services and kinds of supports that are focused on the needs of queer people with disabilities or trans people with disabilities. I've spoken with people who have participated in women's and men's groups in ways that perpetuates gender dichotomies or a gender binaries, and even the lessons that they were learning this at different groups were very gendered.

It's also commonly assumed still today, that disabled people cannot identify as LGBTQ+, right. And that talking about sexualities in the plural is going too far as Stoffelen and colleagues have said (Stoffelen et al., 2013, p. 265). Sometimes when I talk to support workers they said come on you're already telling us that they’re sexual and that we should respect that and now we need to think about this in the plural even, that's going too far. That's too much. This notion of being too much.

We know the sex education information tends to be heteronormative. We have personal key care attendants that may hold heteronormative assumptions, as well as transphobic and homophobic understandings as well. We also know how queer identities may be ignored by service providers in their everyday practice. So for example, one of my participants articulated this by saying, “Growing up in a group home, it was ridiculous, no services, until I came out and said I am bisexual. That's when they kicked, kicked up the thing. That's when they kick it up. I had to say something for them to give me the services” end quote. Again, the heteronormative assumptions in our practice needs to be changed.

Here I'm going to, you know, end our conversation very soon by saying, referring to a conversation I had with one of my participants, where he talked about this limited menu of options when you go to McDonald's if you think that the only option is a Mac Chicken, you're always going to order a Mac Chicken. But if someone tells you that actually the menu of options is much broader than that, then you might end up picking for something else or trying something else. So, there is a very interesting parallel with sexualities here. If a heteronormative approach to sexuality and self-identity is the only kind of option that is given to people, of course that's the one that people are going to pick and think that is the normal or the only option. So we need to give people a better, more broad, and richer menu of options just like non-disabled people have.

Of course, people are trying to make a difference. So, I would point to the work of queer disabled activists who are drawing on their own lived experience and trying to make a difference, they're using different means like podcasts, online videos, blogs, campaigns, to really reach large audiences. They're advancing intimate citizenship and highlighting exclusions. And look at the examples here for example, Annie Elainey has done YouTube videos talking about her experience of coming out, or in her you know episodes on YouTube Jessica Fozard has also talked about her experience of being a disabled lesbian woman. So we see that there is work coming out from queer disabled people and I think that's the coolest part.

All right, so what I identified here today is a lot of different opportunities for us to talk further today. So what I would suggest is that we need future studies that make space for the rich array of sexualities and gender identities among the community. We need to take an intersectional lens. We need to understand sexual stratification, how do queer disabled people navigate, you know, sexual hierarchies in queer spaces. Service providers also need to step up beyond heteronormative, cisgender centered practices and policies. Within more inclusive sex positive spaces where LGBT people and youth can receive information and supports. And lastly, we need to actually talk about pleasure. We shouldn’t just you know, talk about you know, sexual health and end there, right. So unplanned pregnancies and sexual health, we need to talk about pleasure as well.

Alright, I will stop there but I hope that I was able to raise some interesting topics that we can talk a little bit more in detail today as a group.

Thank you.

TRANSCRIPT- Let’s Talk Disability and Sex Connection Day Event

Talk Theme 3: Multiple and converging identities

Speaker: Mari (Dev) Ramsawakh

Hi my name is Mari or Dev Ramsawakh, I use they/them pronouns.

I am a brown person with short reddish pink hair, red glasses, wearing red lipstick, with two nose piercings and my background has a rainbow flag behind me and some stickers of some ghosty things.

So hello, so I go by Dev, I am a disabled gender fluid, Indo-Caribbean neurodivergent and queer person. And all of those identities are really important to me and all kind of impact each other and that's sort of what I'm here to talk about today. And that is how all of these identities can work together to affect how disabled youth are, or disabled people in general, are impacted by our different identities, especially when it comes to accessing sexual health resources and especially what it means to not be able to access those things. I'm going to be drawing on a lot of my own personal experiences, as well as just things I've noticed from people within my own personal community.

So, as I mentioned, none of my identities can be separated from each other, my queerness can't be separated from my disability, which can't be separated from my race, which can't be separated from my neurodivergence or any of those things.

For example being a racialized and disabled queer has really affected my ability to really engage with the queer community whether it's because of accessibility reasons, whether it's because of racism that I’ve experienced within the community. There is no way to separate my identities and be like oh only this one thing impacts me in this way and nothing, none of my other identities do.

And so, in my experience what that has meant for me is that I haven't always been able to access sexual education. Especially with regards to things like gender or really anything that really reflects my own experiences and what would actually be important for me to know.

For example, in high school I wasn't actually able to access the more comprehensive sex-ed (education) because it's actually connected to the phys-ed (physical education) program in my curriculum or that's how it was when I was in school. And what that meant was because I wasn't physically able to do the physical education, I wasn't able to take phys-ed as a class in school.

And because of that I wasn't able to access the sexual health courses, or any of the other health courses that were connected to the phys-ed program. My guidance counselor really didn't have any solutions for me and really just said that's something you should look into outside of school. Even if I had gotten sex-ed because of my different identities, I don't think the sex-ed that I would have gotten in school, would have been as valuable to me anyways. I experience things like incontinence, I'm also, I also don't identify as male or female, and I have other different physical needs and so queerness, gender identity, and all of that weren't ever addressed in my sexual health education.

And, so, I never really, it took me a long time to really feel comfortable in my skin, in my body, and to know what it was like to feel comfortable in my body around other people. I didn't feel as though I could be a sexual person because of my disability or I couldn't really identify with my disability if I wanted to be considered a sexual person, especially a queer person who isn't necessarily able to access party spaces, or the club scene, which is a part, a huge part of the mainstream queer culture.

And the reason that all of this is really important to talk about and really important to address is because all of these identities also make me very vulnerable to a lot of different issues that aren't discussed enough and especially with regards to the disabled community as well as the other communities that I'm a part of.

For example, I am actually a domestic violence survivor and I have gone through a lot of sexual harm as well and when we're talking about identities it's important to talk about how like- these very vulnerable situations, so there isn't a lot of information out there on the complex intersections that I live in. There's no stats that I can draw to that will say brown, disabled, neurodivergent, queer and trans individuals experience this much violence. But, what we do know is that disabled women are 50 to 100% more likely to experience intimate partner violence according to DAWN Canada (DisAbled Women's Network Canada), compared to women without disabilities. And we also know that trans individuals have like roughly I think the statistic that I found from VAWnet (VAWnet.org) is that around half of trans individuals have experienced some type of sexual assault or intimate partner violence in their lifetime. And for those trans individuals those numbers are higher if you're also a trans person of colour. When you're taking all of that into account these identities can put you in a very vulnerable position.

For example, disabled women often have, aren't able to report their sexual assaults, because the disability is so de-sexualized. It's always assumed that disabled women are not having sex, regardless of whether or not that's consensual or not.

So, but we know that, because of the barriers that disabled women face and disabled people of all genders face, that they are at more risk because of things like not having financial independence, not being able to leave their partners insurance, or not having the ability to maintain their home without help from another partner. And those, and when you put into account the self-esteem issues that a lot of trans people face, they may not know that there are individuals who will treat them with love and care. And that can be taken advantage of as well, and when you combine all of these things together, they can really, really make people vulnerable to violence.

So, it's really important that we take into account all of the different identities that people have in order to address the issues that they have that are extraordinarily important and necessary to talk about.

And I think that is about all I have to say on that.

Thank you all for listening and I hope that you took something from this experience and were able to learn something from me.

Thank you.