

# Intellectual and Developmental Disabilities

## Gender and Sexual Self-Determination in the Lives of LGBTQ+ Adults with Intellectual and Developmental Disabilities

--Manuscript Draft--

<b>Manuscript Number:</b>	IDD-D-23-00085R1
<b>Article Type:</b>	Research
<b>Keywords:</b>	gender identity; sexual orientation; LGBTQ+; self-determination; inclusive research
<b>Corresponding Author:</b>	Oscar Eve Hughes, Ph.D. Boston University Wheelock College of Education and Human Development Boston, MA UNITED STATES
<b>First Author:</b>	Oscar Eve Hughes, Ph.D.
<b>Order of Authors:</b>	Oscar Eve Hughes, Ph.D.
<b>Manuscript Region of Origin:</b>	UNITED STATES
<b>Abstract:</b>	Adults with intellectual and developmental disabilities have the right to gender and sexual self-determination, meaning they should have choice and control in how they express their gender and sexuality. In this inclusive research study, I interviewed 23 LGBTQ+ adults with intellectual and developmental disabilities from the United States to examine their perspectives on barriers and facilitators to gender and sexual self-determination. The participants described how societal attitudes, validation, acceptance, access to information, personal agency, and connections with the LGBTQ+ community could present barriers or facilitators to their gender and sexual self-expression. These perspectives have implications for improving practices and policies to promote the right to gender and sexual self-determination.

## GENDER AND SEXUAL SELF-DETERMINATION

### **Gender and Sexual Self-Determination in the Lives of LGBTQ+ Adults with Intellectual and Developmental Disabilities**

Running Head: GENDER AND SEXUAL SELF-DETERMINATION

## **Gender and Sexual Self-Determination in the Lives of LGBTQ+ Adults with Intellectual and Developmental Disabilities**

**Abstract:** Adults with intellectual and developmental disabilities have the right to gender and sexual self-determination, meaning they should have choice and control in how they express their gender and sexuality. In this inclusive research study, I interviewed 23 LGBTQ+ adults with intellectual and developmental disabilities from the United States to examine their perspectives on barriers and facilitators to gender and sexual self-determination. The participants described how societal attitudes, validation, acceptance, access to information, personal agency, and connections with the LGBTQ+ community could present barriers or facilitators to their gender and sexual self-expression. These perspectives have implications for improving practices and policies to promote the right to gender and sexual self-determination.

**Keywords:** gender identity, sexual orientation, LGBTQ+, self-determination, inclusive research

## **Introduction**

Self-advocates with intellectual and developmental disabilities continue to fight for self-determination, which they define as their right to speak up for themselves, pursue their goals, and have decision-making power in their lives (Self Advocates Becoming Empowered, 1996). Similarly, theoretical and empirical scholarship describes self-determination as “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference” (Wehmeyer, 2020). People with intellectual and developmental disabilities who experience more self-determination are more likely to achieve valued life outcomes, such as community participation and employment, and report higher overall quality of life as adults (Lachapelle et al., 2005; Shogren et al., 2015).

The right to self-determination should not be contingent on whether a person can demonstrate independent decision-making in all aspects of their life. People with disabilities who have significant support needs, including those with expressive communication disabilities, can be self-determined when they receive support based on their interests and preferences (Brock et al., 2020; Wehmeyer, 2005). Efforts to support self-determination are ongoing, as people with intellectual and developmental disabilities continue to encounter laws and policies, and individual family members and service providers that limit their decision-making control and prevent them from striving for their goals (Wehmeyer, 2013). The right to self-determination can be realized for all people with disabilities when they have opportunities to communicate their decisions and goals and receive the support they want and need to be causal agents in their lives.

## **Gender and Sexual Self-Determination**

Consistent with self-determination in other areas of life, people with intellectual and developmental disabilities should be causal agents in how they express their gender and sexuality

(ASAN et al., 2016; Friedman et al., 2014; Hughes, 2022; Sandman et al., 2015). This includes choice and control over how they would like to identify and present their gender (e.g., the clothes they wear, the pronouns they use, their body characteristics) and if, how, and with whom to be in intimate relationships. Gender and sexual self-determination are especially important for LGBTQ+ people because their gender and sexualities transgress heterosexual and/or cisgender norms, including identities such as lesbian, gay, bisexual, transgender, and queer. Unfortunately, research examining the experiences of LGBTQ+ people with intellectual and developmental disabilities has demonstrated the complex stigma and marginalization this community experiences due to the interactions between their disabilities, gender and sexuality, and other sociocultural identities (e.g., race, class; McCann et al., 2016; Santinele Martino, 2017).

Researchers have found that people with intellectual and developmental disabilities in general face misperceptions about their sexuality, such as the misbelief that they are not interested in sex, and experience barriers to sexual expression, including denied access to sexuality education and lack of privacy (Brown & McCann, 2018; Sinclair et al., 2015). Although no studies have focused on gender and sexual self-determination specifically, researchers have highlighted some of the ways in which LGBTQ+ adults with intellectual and developmental disabilities face compounded restrictions and barriers to expressing their gender and sexuality (McCann et al., 2016; Smith et al., 2022). For example, LGBTQ+ adults with intellectual and developmental disabilities have been viewed with complex misperceptions, such as the belief that they are confused about their sexuality because of their disability (Dinwoodie et al., 2020) or that their gender identity is a symptom of disability (Lewis et al., 2021; Strang et al., 2018). Because many people with intellectual and developmental disabilities rely on family members and service providers for daily support, some LGBTQ+ people with intellectual and

developmental disabilities are limited in their opportunities to express their gender identity or engage in the types of intimate relationships they desire because their caregivers have negative attitudes toward LGBTQ+ identities and/or place limits on their self-expression (McCann et al., 2016; Smith et al., 2022). For example, LGBTQ+ adults with intellectual and developmental disabilities have described caregivers who have prevented them from entering same-sex relationships or from engaging in sexual acts with same-sex partners (Wilson et al., 2018). Transgender adults with intellectual and developmental disabilities have described family members and service providers who have subjected them to gender training on how to be ‘normal,’ destroyed clothing they deemed ‘inappropriate’ for their gender, and punished them for transgressing gender norms (Barnett, 2017; Dinwoodie et al., 2020).

Additionally, people with intellectual and developmental disabilities often have limited access to sexuality education, and when they do access this education, it rarely addresses the needs of LGBTQ+ people (Sinclair et al., 2015; Wilson et al., 2018). LGBTQ+ adults with intellectual and developmental disabilities have also expressed the need for more LGBTQ+ mentors and have reported feeling alone and unsure about how to find community and form relationships (Lewis et al., 2021; Santinele Martino, 2017). In the face of misperceptions, restrictions, and loneliness, LGBTQ+ people with intellectual and developmental disabilities have described that it is difficult to find welcoming and supportive spaces, as they often feel rejected from disability groups because of their LGBTQ+ identities and marginalized within the LGBTQ+ community because of their disabilities (Lewis et al., 2021; Wilson et al., 2018).

Despite these struggles, existing research literature also describes some of the ways that LGBTQ+ people with intellectual and developmental disabilities have been able to accept themselves, live authentically, and support one another (Dinwoodie et al., 2020; McCann et al.,

2016). For example, groups for LGBTQ+ adults with intellectual and developmental disabilities, especially peer-led groups, have been described as important spaces for promoting self-acceptance, finding community, and learning about sexual health (Elderton et al., 2014). Through these groups, LGBTQ+ adults with intellectual and developmental disabilities have reported feeling comfortable expressing their gender and sexuality, and valuing their connections with others who have shared identities and experiences (Tallentire et al., 2020).

Research on gender and sexual self-determination in the lives of LGBTQ+ adults with intellectual and developmental disabilities remains limited. Existing studies have been conducted almost exclusively outside of the United States and mostly include the experiences of white gay men with intellectual and developmental disabilities, with little information about the experiences of LGB women, transgender people, LGBTQ+ Black, Indigenous, and people of color, and people with other LGBTQ+ gender and sexual identities (McCann et al., 2016; Smith et al., 2022). Few studies have directly addressed the perspectives of LGBTQ+ adults with intellectual and developmental disabilities on barriers and facilitators to gender and sexual self-determination. Research is needed that occurs in partnership with diverse communities of LGBTQ+ people with intellectual and developmental disabilities in the United States.

### **Research Questions**

The purpose of the current study was to understand the perspectives of LGBTQ+ adults with intellectual and developmental disabilities on barriers and facilitators to gender and sexual self-determination, by addressing the following research questions:

1. What are the barriers to gender and sexual self-determination experienced by LGBTQ+ adults with intellectual and developmental disabilities?

2. What do LGBTQ+ adults with intellectual and developmental disabilities perceive as facilitators of gender and sexual self-determination?

By engaging in an inclusive research project in collaboration with LGBTQ+ adults with intellectual and developmental disabilities about gender and sexual self-determination, this research has the potential to illuminate the barriers to dismantle and the facilitators to promote, so that LGBTQ+ people with intellectual and developmental disabilities can ultimately express who they are and experience higher quality of life.

### **Method**

To understand barriers and facilitators to gender and sexual self-determination in the lives of LGBTQ+ adults with intellectual and developmental disabilities, I conducted an interview-based qualitative inclusive research study in collaboration with LGBTQ+ co-researchers with intellectual and developmental disabilities. I ground this work in a participatory epistemological stance, which centers the knowledge and reality constructed by the members of a community to, “solve real problems and produce concrete outcomes” (Peralta, 2017, p. 49). Conducting a study which centered participants with first-hand experience of these intersecting identities, guided by the insights of co-researchers who share these identities, allowed me to examine the complex ways in which LGBTQ+ people with intellectual and developmental disabilities experience gender and sexual self-determination in their lives (The QR Collective, 2023).

### **The Rainbow Inclusion Speaking Up Project**

The current study is part of the Rainbow Inclusion Speaking Up (RISE Up) Project, an inclusive research collaboration between the first author and a team of three LGBTQ+ self-advocate leaders. Inclusive research is a research approach in which people with intellectual and/or developmental disabilities address research questions they value through active



involvement in accessible research processes and outcomes (Garratt et al., 2022; Walmsley & Johnson, 2003). The RISE Up Project was initiated by [name], the founder and coordinator of the [organization name], to learn more about supporting LGBTQ+ people with intellectual and developmental disabilities. All research procedures were approved by the [university] Institutional Review Board. First, the co-researchers decided on interview questions based on their topics of interest. I then conducted interviews and organized the findings to present to the co-researchers. Based on the interview findings, the co-researchers decided to create a guidebook for caregivers, such as family members and disability service providers, about supporting LGBTQ+ people with intellectual and developmental disabilities (available at [website]). In this guidebook, the co-researchers wrote about self-determination as a human right for LGBTQ+ adults with intellectual and developmental disabilities. My personal and professional experiences as a gay transgender special education teacher have also highlighted the necessity of promoting gender and sexual expression for people with disabilities. For these reasons, I decided to conduct additional analysis of the interview findings to describe the current findings on gender and sexual self-determination. I decided to conduct the interviews and secondary data analysis without the co-researchers because I was not aware of accessible research ethics training options and I had limited funding available to compensate the research team for this work (Author, 2024).

## **Participants**

The participants for this study were 23 adults with an intellectual and/or developmental disability who identified themselves as a member of the LGBTQ+ community. I recruited participants using a written flier and video flier which I emailed to personal contacts and facilitators of support groups for LGBTQ+ people with disabilities, sent to sexuality and disability mailing lists, and shared with a group for LGBTQ+ adults with intellectual and

developmental disabilities via their online meeting and social media page. Individuals were invited to participate if they were over 18 years of age, lived in the United States, identified as LGBTQ+, and identified as having an intellectual and/or developmental disability. To increase the diversity of my sample, after the first 15 interviews, I sent reminder emails where I described that I was looking specifically for LGBTQ+ people with an intellectual and/or developmental disability who were also people of color and/or women. The participants were asked open-ended questions about their identities. A summary of participant demographic data is included in Table 1. The findings address each participant with a pseudonym. All participants were compensated with a \$25 gift card per interview and sent a list of LGBTQ+ resources after the first interview.

### **Data Collection**

Data for this study consisted of two rounds of semi-structured interviews, which occurred over video or phone call and were audio recorded. For the first-round interviews with all 23 participants, I used a semi-structured interview protocol, which was developed through conversation with the research team. For example, one co-researcher was especially interested in the struggles that LGBTQ+ people with intellectual and developmental disabilities go through, which led us to include the question, “Is there anything difficult about being an LGBTQ+ person with a disability? What is difficult?” Another co-researcher was interested in participants’ experiences with LGBTQ+ support groups, so we added the questions, “Have you been to a LGBTQ+ support group? What was your experience like?” The final interview protocol included questions about the participants’ personal experiences with coming out, acceptance, dating, discrimination, supports, and pride, and about their perspectives on how to help LGBTQ+ people with disabilities. To promote accessibility in the consent and interview processes, I used plain

language and visual supports, rephrased questions, and asked participants if they wanted to receive the interview questions in advance (Nicolaidis et al., 2019).

I developed the second-round interview protocol based on the specific goals for the guidebook resource project, with concrete questions such as, “What topics should someone learn about if their job is to support LGBTQ+ people with intellectual and developmental disabilities? What topics should we include in our guidebook?” All 23 original participants were contacted and 19 agreed to participate in second-round interviews. Seven participants chose to answer the second-round interview questions in writing via email. Interviews were between 9–58 minutes and I transcribed each interview verbatim.

### **Data Analysis**

The initial analysis of the findings was based on the inclusive research team's interests and I used an inductive thematic analysis process consisting of first-cycle coding and pattern coding, as described by Miles et al. (2020), shaped by practices recommended to increase accessibility for adults with intellectual and developmental disabilities (Kidney & McDonald, 2014; Nicolaidis et al., 2019). For first-cycle coding, I coded each transcript by highlighting segments that described either (1) a struggle, (2) positive support, or (3) ideas for improving lives. I then wrote a short, plain language statement summarizing each coded participant point. After categorizing and summarizing statements for the first 10 interviews, I engaged in pattern coding by sorting all the statements into related themes. For example, many of the struggles that participants described related to rejection by family members. These statements were grouped together under the theme *Rejected by Family*. As I categorized and summarized the remaining 13 interviews, I sorted statements into these themes, or added new themes when I noticed other

patterns in the participants' responses. I then sought to present the initial findings in plain language, with clear organization, and emphasis on the major points, to support the co-researchers to ask questions and share their perspectives.

For the current study, I returned to the themes and categories from the initial coding process to identify codes which specifically addressed aspects of gender and sexual self-determination, such as choice and control, decision-making, and pursuing goals related to gender and sexual expression. For example, the participant statement, "They [my parents] tried to talk me out of taking testosterone. They even tried to call my doctor, tried to complain about it.", which had been coded as "Controlling gender expression", was identified as a code relating to gender self-determination. Each code was then sorted into themes related to specific aspects of gender and sexual self-determination, and whether the code described a barrier or facilitator to gender and sexual expression. For example, the "Controlling gender expression" code above was also sorted under the new theme *Personal agency–Controlled by others* and was identified as describing a barrier to gender self-determination. After I identified all gender and sexual self-determination codes and sorted them into themes, I interpreted the experiences within each theme as falling on a continuum between being entirely a barrier or facilitator of gender and sexual self-determination. In summary, the current findings are based on an initial collaborative data analysis process with the inclusive research team, followed by my own interpretations of how the findings relate to gender and sexual self-determination.

### **Credibility and Trustworthiness**

I strove for credibility and trustworthiness throughout the research process through collaborative work, triangulation, research reflexivity, peer debriefing, and by providing thick

description of the data with frequent use of direct quotes (Brantlinger et al., 2005). The collaborative nature of this research project promotes the trustworthiness of the thematic findings because I discussed each of the themes and patterns from the participant interviews with the members of the research team. Data triangulation has been an important aspect of the inclusive research process, as the co-researchers shared how their own personal and professional experiences related to the themes we discussed. For example, when I shared that many of the participants described hiding their gender or sexuality due to fear of rejection, all three co-researchers shared their own varying experiences of being rejected for their LGBTQ+ identity and hiding their identity from others. I also strove to engage in self-reflection to remain attentive to the purpose of the research and center the voices of LGBTQ+ people with intellectual and developmental disabilities (The QR Collective, 2023). I engaged in peer debriefing by soliciting critical feedback on the thematic analysis from the research team and experienced qualitative researchers in disability and gender and sexuality studies who were members of my dissertation committee. Finally, the findings include thick, detailed descriptions and participant quotes to provide evidence of my thematic interpretations.

### **Findings**

The participants described how various factors in their lives were barriers or facilitators to their gender and sexual self-determination. Many participants shared their perceptions of potential facilitators to self-expression and made recommendations to promote gender and sexual self-determination in their lives and the lives of other LGBTQ+ people with intellectual and developmental disabilities. Specifically, the participants described their perceptions of how their gender and sexual self-expression was impacted by societal attitudes, validation, acceptance,

access to information, personal agency, and connections with the LGBTQ+ community. I present each of these themes as a continuum and share how they could present barriers or facilitators to gender and sexual self-determination.

### **Societal Attitudes**

Many participants described their awareness of broader societal views about gender and sexual diversity and LGBTQ+ people, ranging from oppression by society to feeling valued by society, which impacted the extent to which they felt they could express their gender and sexuality. Specifically, many participants expressed the feeling that society in general did not accept or value gender or sexual diversity, and this led to fear of coming out and hiding their LGBTQ+ identities because they anticipated discrimination or negative reactions. For example, Richard stated about being open about his gay identity, “I think most straight men are discriminatory and prejudiced...I think that they react badly and that kind of is something that I wrestle with, being open.” For many participants, seeing the ways that other LGBTQ+ people were mistreated, led them to stifle their own gender and sexual expression. For example, Vincent described, “I see people get rejected, I see people get thrown out their homes, I see parents, just, straight rejection. So, of course, that went through my head...the biggest fear was losing everyone in my life.” Some participants described how broader societal attitudes have changed over time, such as Casey who stated that they hid their transgender and queer identities when they were younger because they grew up at a time before the Internet when few people understood those identities.

Additionally, all five Black or biracial participants described the complex ways in which attitudes toward disability and LGBTQ+ identities intersected with race and racism, which impacted self-determination in their lives. As Andre stated, “the color of my skin, being Black is

hard enough already. Like we go through so much already enough because of the color of our skin. So don't add on the fact that you're gay. Because that's a double whammy.” As Sasha, on the other hand, described,

I think being Black, made it easy to realize that I was queer because it's like, okay, I'm already used to being treated kind of differently for that. And then being Black and queer made it really easy to be autistic because I'm like, I'm already used to getting crap for these two things and this is no problem to just add on one more.

Adam shared that while his disability and sexuality were not visible, he was more likely to be perceived as Black and that racism was “the number one thing” that led to the discrimination he experienced.

In response to negative societal attitudes about disability, gender and sexuality, and race, many participants advocated for a more accepting and inclusive society, where people were not judged for who they are and thus could express themselves freely. As Melissa advocated, “We want just to live, and be who we are, and not be pigeonholed by people who don't understand us.” Participants believed that attitudinal changes could be achieved with more education and research about gender and sexual diversity among people with disabilities, and more visibility of LGBTQ+ people with disabilities, including positive representations in the media.

### **Validation**

Many of the participants described how their gender or sexuality was either dismissed or believed to varying degrees. This became a barrier to self-determination for participants who were not believed by people who were supposed to provide them with support. For example, when Judy told her family she was bisexual, her family tried to convince her that it was a phase and refused to help her join LGBTQ+ support groups. Mike shared about his parents, “they

thought because I have a disability, I didn't understand what I was doing." Mike's parents called the doctor that Mike was seeing for gender transition and told the doctor not to prescribe gender-affirming hormones to Mike. Because Mike was an adult and his parents were not his court-appointed guardians, Mike was still able to access gender transition. In response to dismissal of their identities, many participants advocated for believing what people express about their LGBTQ+ identity, regardless of disability, so that they can live as their authentic selves. As Benjamin described,

There's some people, they come out to their sexuality, they may not be taken seriously because like, "Oh, yeah, you're just being manipulated." I say, "Wrong!" That could be really who they are...If you see somebody coming out, you need to take that seriously.

### **Acceptance**

The participants reported a variety of reactions from others to their LGBTQ+ identities, ranging from ongoing rejection from all or most people in their lives, to unconditional love and acceptance from everyone. Almost all the participants experienced some rejection in their lives because of their LGBTQ+ identity, often by family members, and this prevented them from expressing themselves. As Yasir shared, "My dad's family don't like gay people either, so I have to hide it...They think it's disgusting and it's a sin." He contrasted this with his sister's response, "I told my sister that I want a boyfriend. She said, 'Okay.'" Scott reported that he came out to his grandmother and parents as a lesbian and then as a transgender man many years ago and they stopped speaking with him completely. A few participants attributed experiences of rejection to family members' religious identities. Whether it was for a long time or a short time, feeling rejected by family or other people was described as hurtful to almost all the participants, and meant that some received less support or decided to hide aspects of their identities. Some people



said that they had low self-esteem, felt depressed, and/or thought about suicide because of how terrible it felt to be rejected.

On the other hand, participants reported that they were better able to express themselves when they received accepting reactions to their LGBTQ+ identities. Some participants stated that they felt they could express themselves when others—such as family members, friends, and coworkers—embraced them for who they are and loved them unconditionally. Jordan shared, for example, that he was accepted by his friends and family when he came out as gay in high school. Tim stated about coming out to his family,

I don't want to live like this and be in the closet for the rest of my life without having some kind of acceptance and it was like a ton of bricks had lifted off my chest when I told [my parents] and they were both accepting.

When asked how the world could ultimately become a better place for LGBTQ+ people with intellectual and developmental disabilities, many of the participants spoke to the need for more acceptance of disability and of gender and sexual diversity. This was similar to their advice for supporters, which often emphasized communicating love and acceptance. Mike suggested, for example, “I think [parents] should love their child no matter what. Be there for them, tell them they love their child.”

### **Information**

The extent to which participants had access to information about gender, sexuality, and the LGBTQ+ community impacted their experiences of gender and sexual self-determination. Many participants described how, without information, they struggled to figure things out on their own, and this caused barriers to their self-expression. For example, when many participants first experienced LGBTQ+ feelings, they did not have the awareness or the words to make sense

of these feelings or describe them to others. However, learning about LGBTQ+ identities and the vocabulary to describe them allowed them to be more self-determined. Liliana shared that she was socially isolated growing up and this meant that she, “never even knew what being transgender was” until she went to a festival where she saw people cross dressing and identifying as genderqueer. She said, “this gave me this open invitation to kind of reevaluate and reassess myself.” About learning the word “transgender” from a friend, Liliana stated, “Once I did find that emotional vocabulary, I was able to put that magnifying glass deep to my heart and all that and identify with exactly who I am. It was very liberating.” Andre shared that he had sexual feelings for men for many years and thought it was only a fantasy. It was not until he saw pornography of two men having sex that he realized gay relationships could be a reality. Casey described how lack of awareness limited their self-expression when they shared, “I knew I wasn't a man or woman since middle school, but I thought there was only men and women binary genders,” and later added that they came to describe themselves as asexual after learning that word from their mother. Once they learned the word asexual, Casey was able to join asexuality Internet forums and learn about other people's experiences. For many participants, learning about gender and sexual diversity allowed them to realize who they were and how they wanted to live their lives.

Participants also shared that access to LGBTQ+ inclusive sexuality education affected how they expressed their gender and sexuality. Most participants reported little access to sexuality education, and when they did, it was about heterosexuality and did not include information about LGBTQ+ relationships. Some participants attributed this lack of access to assumptions about their disabilities, such as Liliana who stated, “I was kind of shielded from anything resembling sex education because it's like, ‘Oh, she's disabled, she's not going to know

any better””. This was a barrier to participants reaching their dating and relationship goals, as some participants described confusion about relationships, having to “learn the hard way,” and getting taken advantage of because they did not have the information they needed. Tim shared, “I experimented. I didn't get that info. You had to figure that out on your own. I had to figure out on my own so I had sex with men, but then I had a girlfriend and I got married,” later adding, “It would have really really helped to have the criteria, of like, what would be in a homosexual life.” Many participants suggested that LGBTQ+ content in sexuality education could facilitate gender and sexual self-determination. They suggested teaching about topics such as self-respect, attraction, LGBTQ+ terminology, pleasure, safer sex between same-sex partners, consent in LGBTQ+ relationships, and HIV and STI prevention and testing.

Lack of information on behalf of caregivers also served as a barrier to gender and sexual self-determination. Participants shared that their family members, teachers, staff, and other caregivers did not understand LGBTQ+ identities or how to be supportive of LGBTQ+ people. Many participants expressed that caregivers should learn about gender and sexuality in the lives of people with intellectual and developmental disabilities and advocated for family and staff training on the topic. Important topics for caregivers to learn included: the prevalence of LGBTQ+ identities among people with disabilities, gender pronouns, LGBTQ+ current events, and where to find resources. Many participants expressed that learning directly from the personal stories of LGBTQ+ people with disabilities was the most important way to understand their community.

### **Personal Agency**

Participants shared how gender and sexual self-determination was influenced by whether they were controlled by others or received the supports and services they needed to have choice

and control in their lives. Many participants faced direct restrictions on personal choice and control of their gender and sexual expression, often by family members or service providers within congregate care settings, such as state institutions and group homes. Transgender participants specifically described caregivers who attempted to control the clothing they wore and their access to medical transition. Liliana shared how her mother, whom she lived with at the time, “raided” her closet and took away all her feminine clothing. Liliana’s father then threatened her by telling her, “Either you correct yourself or you’ll be corrected.” Similarly, Casey’s grandparents continued to buy women’s clothing for Casey even though they knew that Casey wore men’s clothing. When Casey confronted their grandparents about this, their grandparents replied, “You’re in a female body, you should wear women’s clothes.” Similarly, transgender participants who wanted to pursue medical steps in their gender transition faced barriers to accessing medical care. Katherine, for example, reported that she had wanted to take female hormones for decades, but none of the staff at the state institution were willing to set up an appointment for her to begin the process.

Participants also described direct limits placed on their sexual expression. Will described how after staff at this group home saw him consensually kiss a man at a Pride parade, they refused to take him to other Pride events because they said that it was inappropriate. Staff would also not allow him to meet dates because they were concerned that men would pretend to be gay to lure him out and take advantage of him. Randall had a roommate walk in on him while he was having a same-sex sexual encounter with a man he met online. When staff at the group home learned about this, they told Randall that he was not allowed to invite men into his bedroom. In response to this restriction, Randall said, “If I’m not allowed to have guys over, it’s like, I should go back in the closet and just stay there,” adding, “Reverse the situation, and put a girl in...[my

staff] would be totally fine.” Although the specific details varied depending on the participants’ gender and sexual identities and living situations, many participants were denied choices and control over how to express themselves, and participants described this as unfair.

Some participants provided examples of receiving the supports and services they needed to strive for their own goals related to their gender and sexual expression. Gabe shared, for example, that his mother helped him with setting up dates and social interactions, and Katherine shared that her social worker was helping her to create an online dating profile. Casey, whose grandparents first tried to force Casey to wear women’s clothes, eventually bought men’s clothes for Casey, about which Casey stated, “I’m going to keep them all [the men’s clothes] for the rest of my life.” Will spoke of a former supervisor of his group home who would go with him to Pride events and Mike described his shared living roommate as, “always there if I need to talk.” Additionally, some participants reported that they needed to advocate for themselves to access the supports and services they needed to express their gender and sexuality. Examples of this advocacy included: advocating to a parent about having their same-sex partner at the house, reminding people to use they/them pronouns, reporting harassment and violence, and convincing their college to allow them to stay in dorms that aligned with their gender identity. Overall, participants described the value of speaking up for themselves to self-determine their lives as LGBTQ+ people with disabilities.

### **LGBTQ+ Community**

Isolation from the LGBTQ+ community created barriers to gender and sexual expression, while connections with other LGBTQ+ people supported participants to be self-determined. Some participants shared that they did not know other people with a similar LGBTQ+ identity, and that this meant they had no one to talk to about their feelings or to learn from about

expressing their identity. Will shared, for example, that he did not have any gay friends or group home staff, and therefore, “I don't have nobody to talk to about my sexuality. I just keep that to myself.” Similarly, Richard described the struggles of not having role models, noting, “I've never seen other gay couples...It's not really modeled to a lot of us. So we don't know what it is. We're winging it, doing it our own way.”

Many participants shared how attending support groups and going to LGBTQ+ events did or could facilitate self-determination. Participants described positive experiences meeting people and becoming more accepting of themselves by going to LGBTQ+ spaces such as a youth pride group, a gay college club, gay bars, and a gay skiing event. Still, multiple participants described a lack of understanding of disability within LGBTQ+ spaces and advocated for more LGBTQ+ events to improve accessibility and inclusion of people with disabilities. A few participants shared the value of LGBTQ+ support groups specifically for people with intellectual and developmental disabilities, where they felt seen and understood. Additional barriers to participating in LGBTQ+ events or to meeting and connecting with other LGBTQ+ people included: living in suburban or rural areas with fewer LGBTQ+ spaces, support groups that ended due to limited funding, COVID-19 restrictions, lack of access to transportation within congregate care settings, and inaccessibility of online dating options.

Participants also shared examples of individual friends or mentors who shared an identity in the LGBTQ+ community, and who were thus better able to talk with them and support them with their gender and sexual self-determination. Rachel shared that she spoke with a staff member who was also a lesbian about dating women, and Judy described how her gay brother understood her and took her to clubs where she met people like herself. Tim described fun experiences with his gay friend, “Him and his good friends took me to P-town, I wouldn't have

never been to P-town in my life, and took me to different bars, and, oh my god, it was just so much fun.” Overall, many participants described valuable experiences through connections with others in the LGBTQ+ community and expressed the belief that relationships with others with shared identities and more accessibility and inclusion in the LGBTQ+ community could support LGBTQ+ people with intellectual and developmental disabilities to live self-determined lives.

### **Discussion**

LGBTQ+ adults with intellectual and developmental disabilities described a lack of gender and sexual self-determination in their lives, because they often did not have choice and control in their gender and sexual expression and did not receive support to strive for their goals related to gender and sexuality. The participants were prevented from being causal agents in the expression of their gender and sexuality due to negative societal attitudes, dismissal, rejection, limited information access, denied personal agency, and isolation from LGBTQ+ community. These findings expand our understanding of how the right to self-determination applies to issues of gender and sexuality (Self Advocates Becoming Empowered, 1996; Wehmeyer, 2020) and echo previous literature which has described some of the ways in which LGBTQ+ adults with intellectual and developmental disabilities have experienced restrictions on their gender and sexual expression (McCann et al., 2016; Smith et al., 2022).

Normative beliefs about ability, gender, and sexuality interfered with participants' gender and sexual self-determination. For example, assumptions about the capabilities of people with disabilities were used by caregivers and educators as the justification for invalidation of their identities, lack of adequate sexuality education, and restrictions on their choices about gender and sexual expression. As other scholars have noted, traditional rigid beliefs about heterosexuality and binary gender served as a foundation for others' acts of discrimination,

rejection, and control (Barnett, 2017; Santinele Martino, 2017). Thus, as many participants described, challenging assumptions and changing attitudes about disability, gender, and sexuality has the potential to promote gender and sexual self-determination in the lives of LGBTQ+ people with intellectual and developmental disabilities.

In response to the limitations they faced, many participants expressed that LGBTQ+ people with intellectual and developmental disabilities could be more self-determined if they were valued, believed, and accepted and had access to information, control over their lives, and relationships with others in the LGBTQ+ community. Even when participants came to openly express their LGBTQ+ identities, they often still did not receive the acceptance or support needed to strive for their goals related to their gender and sexual expression. Participants' positive experiences of support and their recommendations on improving access to gender and sexual expression reinforced previous researcher recommendations on improving quality of life for LGBTQ+ people with intellectual and developmental disabilities (McCann et al., 2016; Smith et al., 2022). For example, the participants advocated for more representation of their community, education for caregivers about gender and sexual diversity, and improving everyday supports related to gender and sexual expression. Additionally, participants shared the value of support groups, accessibility and inclusion within LGBTQ+ spaces, and self-advocacy.

The continuums identified in this study have the potential to serve as a useful framework for identifying and addressing the individual and contextual factors that create barriers to gender and sexual self-determination in the lives of adults with intellectual and developmental disabilities. The barriers and facilitators described by the participants in this study were not experienced as binaries (e.g., either complete rejection or unconditional love). Instead, the participants' experiences are better represented along continuums, because participants described



varying levels of barriers and facilitators in different aspects of their lives. LGBTQ+ adults with intellectual and developmental disabilities and their supporters could consider the continuums presented here as a tool to identify ways to better access gender and sexual self-determination. For example, a bisexual woman with Down syndrome may find that lack of family acceptance prevents her from expressing her sexuality. However, she could exercise personal agency with support from her direct care worker to access information via an LGBTQ+ inclusive sexuality education workshop or connect with community by joining a local queer women organization.

The current study also has direct implications for laws and policies to protect the right to gender and sexual self-determination. The participants' perspectives highlight the importance of access to comprehensive LGBTQ+ inclusive sexuality education for students and adults with intellectual and developmental disabilities. As researchers have found for other areas of self-determination, participants described barriers to gender and sexual self-determination that arose due to living in congregate-care settings, such staff restrictions on their choices, limited transportation options, and lack of privacy for sexual expression (Friedman, 2019; Sheth et al., 2019). Disability advocacy which strives to promote self-determination more broadly, such as access to home and community-based services and alternatives to guardianship, should directly address how these laws and policies can and should promote gender and sexual expression as important aspects of self-determination (ASAN et al., 2016).

Scholars have argued that inclusive research approaches have the potential to prevent misinterpretation and lead to meaningful outcomes shared beyond academic audiences which promote the needs and priorities of people with disabilities (O'Brien, 2022; Walmsley & Johnson, 2003). Many participants, in discussing how to improve the lives of people in their communities, advocated for more opportunities to share their stories, which they believed could

teach people about the value and importance of accepting gender and sexual diversity. As part of the broader RISE Up Project, the LGBTQ+ co-researchers with disabilities on the research team decided to use the interview findings described here to create a free guidebook for disability service providers, people with disabilities, and their families about understanding and supporting LGBTQ+ people with intellectual and developmental disabilities. By engaging in inclusive research and creating the Rainbow Guidebook as an educational resource, the RISE Up Project led directly to outcomes that the research participants believed could improve quality of life for LGBTQ+ people with intellectual and developmental disabilities.

### **Limitations and Future Research**

Research about the lives of LGBTQ+ people with intellectual and developmental disabilities has rarely included diverse perspectives, often focusing on white participants without significant support needs. The current study is the largest study to-date which has described the experiences of LGBTQ+ adults with intellectual and developmental disabilities in the United States. The findings contribute diverse and detailed specifics on how gender and sexual self-determination can be realized for this community. However, there are many identities and experiences which are not reflected in this work. For example, participants from many cultural and racial groups in the United States did not participate in this study. Participants were from regions of the United States which are generally more accepting of LGBTQ+ identities (e.g., the Northeast) and all were out as LGBTQ+ to some people in their lives. All participants were able to verbally respond to interview questions. As the current findings and previous research reflects, the experiences of LGBTQ+ people with intellectual and developmental disabilities are impacted by complex intersections of their gender and sexualities, disabilities, and other sociocultural

identities, and thus, future research should uplift stories and perspectives from diverse communities of LGBTQ+ people with intellectual and developmental disabilities.

We hope future projects will expand upon the themes and continuums identified in this work to create practical resources that can promote gender and sexual self-determination. The current research provides one example of how inclusive research and stories of lived experience can promote gender and sexual self-determination. However, I faced barriers to including the co-researchers with intellectual and developmental disabilities in all stages of the research process and outcomes. Researchers should look to the growing body of inclusive research scholarship (see, for example, O'Brien, 2022 special issue on inclusive research) to engage in inclusive research that includes researchers with lived experiences throughout the research process and leads to meaningful outcomes which can improve quality of life for disabled people.

### **Conclusion**

Information accessibility, personal agency, and connection with the LGBTQ+ community played pivotal roles in the gender and sexual self-determination of LGBTQ+ adults with intellectual and developmental disabilities. Many participants described the impact of information, or the lack thereof, on their self-understanding and self-expression. Participants described how caregivers and support systems could act as barriers to gender and sexual self-determination or provide essential acceptance and understanding. Participants' shared narratives underscore the importance of validation and connection, suggesting that fostering inclusivity within the LGBTQ+ community can improve their lives. While challenges persist, self-advocacy, supportive environments, and community connection can pave the way to self-determined lives for LGBTQ+ adults with intellectual and developmental disabilities.

### References

Author. (2024).

ASAN, National Center for Transgender Equality [NCTA], & National LGBTQ Task Force.

(2016). *Joint statement on the rights of transgender and gender non-conforming autistic people*. [https://autisticadvocacy.org/wp-content/uploads/2016/06/joint\\_statement\\_trans\\_autistic\\_GNC\\_people.pdf](https://autisticadvocacy.org/wp-content/uploads/2016/06/joint_statement_trans_autistic_GNC_people.pdf)

Barnett, J. P. (2017). Intersectional harassment and deviant embodiment among Autistic adults:

(Dis)ability, gender and sexuality. *Culture, Health & Sexuality*, 19(11), 1210–1224.

<https://doi.org/10.1080/13691058.2017.1309070>

Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children*, 71(2), 195–207.

<https://doi.org/10.1177/001440290507100205>

Brock, M. E., Schaefer, J. M., & Seaman, R. L. (2020). Self-determination and agency for all:

Supporting students with severe disabilities. *Theory Into Practice*, 59(2), 162–171.

<https://doi.org/10.1080/00405841.2019.1702450>

Brown, M., & McCann, E. (2018). Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature. *Research in Developmental*

*Disabilities*, 74, 124-138. <https://doi.org/10.1016/j.ridd.2018.01.009>

Dinwoodie, R., Greenhill, B., & Cookson, A. (2020). ‘Them two things are what collide

together’: Understanding the sexual identity experiences of lesbian, gay, bisexual and trans people labelled with intellectual disability. *Journal of Applied Research in*

*Intellectual Disabilities*, 33(1), 3–16. <https://doi.org/10.1111/jar.12252>

- Elderton, A., Clarke, S., Jones, C., & Stacey, J. (2014). Telling our story: A narrative therapy approach to helping lesbian, gay, bisexual and transgender people with a learning disability identify and strengthen positive self-identity stories. *British Journal of Learning Disabilities*, 42(4), 301–307. <https://doi.org/10.1111/bld.12075>
- Friedman, C. (2019). The influence of residence type on personal outcomes. *Intellectual and Developmental Disabilities*, 57(2), 112–126. <https://doi.org/10.1352/1934-9556-57.2.112>
- Friedman, C., Arnold, C. K., Owen, A. L., & Sandman, L. (2014). “Remember our voices are our tools:” Sexual self-advocacy as defined by people with intellectual and developmental disabilities. *Sexuality and Disability*, 32(4), 515–532. <https://doi.org/10.1007/s11195-014-9377-1>
- Garratt, D., Johnson, K., Millear, A., Picken, S., Slattery, J., & Walmsley, J. (2022). Celebrating thirty years of inclusive research. *Social Sciences*, 11(9), Article 9. <https://doi.org/10.3390/socsci11090385>
- Hughes, O. E. (2022). Supporting gender self-determination for people with intellectual and developmental disabilities. *Inclusive Practices*.
- Kidney, C. A., & McDonald, K. E. (2014). A toolkit for accessible and respectful engagement in research. *Disability & Society*, 29(7), 1013–1030. <https://doi.org/10.1080/09687599.2014.902357>
- Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M.-C., Courbois, Y., Keith, K. D., Schalock, R., Verdugo, M. A., & Walsh, P. N. (2005). The relationship between quality of life and self-determination: An international study. *Journal of Intellectual Disability Research*, 49(10), 740–744. <https://doi.org/10.1111/j.1365-2788.2005.00743.x>

- Lewis, L. F., Ward, C., Jarvis, N., & Cawley, E. (2021). “Straight sex is complicated enough!”: The lived experiences of autistics who are gay, lesbian, bisexual, asexual, or other sexual orientations. *Journal of Autism and Developmental Disorders*, 51(7), 2324–2337. <https://doi.org/10.1007/s10803-020-04696-w>
- McCann, E., Lee, R., & Brown, M. (2016). The experiences and support needs of people with intellectual disabilities who identify as LGBT: A review of the literature. *Research in Developmental Disabilities*, 57, 39–53. <https://doi.org/10.1016/j.ridd.2016.06.013>
- Miles, M. B., Huberman, A. M., & Saldaña, J. (2020). *Qualitative Data Analysis: A Methods Sourcebook* (4th ed.). SAGE Publications, Inc.
- Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M., & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, 23(8), 2007–2019. <https://doi.org/10.1177/1362361319830523>
- O’Brien, P. (2022). Inclusive research: Is the road more or less well travelled? [Special issue]. *Social Sciences*, 11.
- Peralta, K. J. (2017). Toward a deeper appreciation of participatory epistemology in community-based participatory research. *PRISM: A Journal of Regional Engagement*, 6(1).
- Sandman, L., Arnold, K., Bolyanatz, L., Friedman, C., Saunders, C., & Wickey, T. (2015). *In my voice: Sexual self-advocacy*. [https://sdc.ahslabs.uic.edu/wp-content/uploads/sites/19/2015/12/InMyVoice\\_SexualSelf-Advocacy.pdf](https://sdc.ahslabs.uic.edu/wp-content/uploads/sites/19/2015/12/InMyVoice_SexualSelf-Advocacy.pdf)
- Santinele Martino, A. (2017). Crippling sexualities: An analytic review of theoretical and empirical writing on the intersection of disabilities and sexualities. *Sociology Compass*, 11(5), e12471. <https://doi.org/10.1111/soc4.12471>

Self Advocates Becoming Empowered. (1996, 1997). *SABE definition of self-determination*.

SABE USA. <https://www.sabeusa.org/meet-sabe/policy-statements/self-determination/>

Sheth, A. J., McDonald, K. E., Fogg, L., Conroy, N. E., Elms, E. H. J., Kraus, L. E., Frieden, L., & Hammel, J. (2019). Satisfaction, safety, and supports: Comparing people with disabilities' insider experiences about participation in institutional and community living. *Disability and Health Journal*, 12(4), 712–717.

<https://doi.org/10.1016/j.dhjo.2019.06.011>

Shogren, K. A., Abery, B., Antosh, A., Broussard, R., Coppens, B., Finn, C., Goodman, A., Harris, C., Knapp, J., Martinis, J., Ne'eman, A., Nelis, T., & Wehmeyer, M. L. (2015). Recommendations of the self-determination and self-advocacy strand from the National Goals 2015 conference. *Inclusion*, 3(4), 205–210. <https://doi.org/10.1352/2326-6988-3.4.205>

Sinclair, J., Unruh, D., Lindstrom, L., & Scanlon, D. (2015). Barriers to sexuality for individuals with intellectual and developmental disabilities: A literature review. *Education and Training in Autism and Developmental Disabilities*, 50(1), 3–16.

Smith, E., Zirnsak, T., Power, J., Lyons, A., & Bigby, C. (2022). Social inclusion of LGBTQ and gender diverse adults with intellectual disability in disability services: A systematic review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 35(1), 46–59. <https://doi.org/10.1111/jar.12925>

Strang, J. F., Powers, M. D., Knauss, M., Sibarium, E., Leibowitz, S. F., Kenworthy, L., Sadikova, E., Wyss, S., Willing, L., Caplan, R., Pervez, N., Nowak, J., Gohari, D., Gomez-Lobo, V., Call, D., & Anthony, L. G. (2018). “They thought it was an obsession”: Trajectories and perspectives of autistic transgender and gender-diverse adolescents.

- Journal of Autism and Developmental Disorders*, 48(12), 4039–4055.  
<https://doi.org/10.1007/s10803-018-3723-6>
- Tallentire, L., Smith, M., David, L., Roberts, A., Bruce, Morrow, S., Withers, P., & Smith, I. (2020). Stories of people who have attended a lesbian, gay, bisexual and trans support group in a secure intellectual disability service. *Journal of Applied Research in Intellectual Disabilities*, 33(1), 17–28. <https://doi.org/10.1111/jar.12281>
- The QR Collective. (2023). Reflexive quality criteria: Questions and indicators for purpose-driven special education qualitative research. *Exceptional Children*, 89(4), 449–466.  
<https://doi.org/10.1177/00144029231168106>
- Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures*. Jessica Kingsley Publishers.
- Wehmeyer, M. L. (2005). Self-determination and individuals with severe disabilities: Re-examining meanings and misinterpretations. *Research and Practice for Persons with Severe Disabilities*, 30(3), 113–120. <https://doi.org/10.2511/rpsd.30.3.113>
- Wehmeyer, M. L. (2013). *The story of intellectual disability*. Paul H. Brookes.
- Wehmeyer, M. L. (2020). The Importance of Self-Determination to the Quality of Life of People with Intellectual Disability: A Perspective. *International Journal of Environmental Research and Public Health*, 17(19), 7121. <https://doi.org/10.3390/ijerph17197121>
- Wilson, N. J., Macdonald, J., Hayman, B., Bright, A. M., Frawley, P., & Gallego, G. (2018). A narrative review of the literature about people with intellectual disability who identify as lesbian, gay, bisexual, transgender, intersex or questioning. *Journal of Intellectual Disabilities*, 22(2), 171–196. <https://doi.org/10.1177/1744629516682681>



**Table 1*****Participant Demographic Data***

Characteristic	Frequency	Characteristic	Frequency
Age		Sexual Identity	
18-29	8	Gay	13
30-39	6	Pansexual	2
40-49	6	Asexual	2
50-59	2	Bisexual	1
60-69	1	Queer	1
		Homoflexible	1
State		Lesbian	1
Massachusetts	4	Pansexual demisexual aromantic	1
New York	4	(Not specified)	1
Rhode Island	3		
Illinois	3	Disability	
Vermont	2	Autism/Autism and other disabilities	11
Oregon	2	Intellectual disability	4
California	1	Cerebral palsy	4
Connecticut	1	Down syndrome	2
Michigan	1	ADHD, with other disabilities	1
Ohio	1	William syndrome	1
Virginia	1		
Gender Identity		Racial and/or Ethnic Identity	
Cisgender man	11	White or Caucasian	15
Transgender man	2	Black or African American	3
Cisgender woman	2	Biracial, Black and White	2
Non-binary	2	Hispanic/Latino and White	1
“Female, I guess”	1	Irish and Puerto Rican	1
Demiboy	1	Pakistani Muslim American	1
Transgender woman	1		
Half and half	1		
Genderqueer	1		
(Not specified)	1		