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Inclusive research to promote gender and sexual self-determination for LGBTQ+ adults with intellectual and developmental disabilities

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INCLUSIVE RESEARCH TO PROMOTE GENDER AND SEXUAL SELF-DETERMINATION FOR LGBTQ+ ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

by

OSCAR EVE HUGHES

B.A., Green Mountain College, 2012
M.Ed., Bridgewater State University, 2016

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Approved by

First Reader

Zachary Rossetti, Ph.D.
Associate Professor of Special Education

Second Reader

Elizabeth Bettini, Ph.D.
Associate Professor of Special Education

Third Reader

Ariel Schwartz, Ph.D.
Research Assistant Professor, Institute on Disability
University of New Hampshire

Fourth Reader

Sarah Miller, Ph.D.
Senior Lecturer of Sociology and Women's, Gender and Sexuality Studies
Boston University, College of Arts and Sciences

DEDICATION

I would like to dedicate this work to my friend Pauline Bosma. As the founder and coordinator of the Rainbow Support Groups of Massachusetts, Pauline has been improving the lives of LGBTQ+ people with disabilities for decades. It was an honor to team up with her for this research project.

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INCLUSIVE RESEARCH TO PROMOTE GENDER AND SEXUAL SELF-DETERMINATION FOR LGBTQ+ ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

OSCAR EVE HUGHES

Boston University Wheelock College of Education & Human Development, 2024

Major Professor: Zachary Rossetti, Ph.D., Associate Professor of Special Education

ABSTRACT

Inclusive research based on collaborative partnership with people with intellectual and developmental disabilities has the potential to lead to relevant and meaningful research outcomes. An inclusive research approach is necessary for research endeavors which strive to improve the lives of LGBTQ+ people with intellectual and developmental disabilities, who experience layered stigma due to complex interactions between their disabilities, gender and sexual identities, and other sociocultural identities. In this dissertation, I present three research articles about the Rainbow Inclusion Speaking Up (RISE Up) Project, an inclusive research project with and for LGBTQ+ adults with intellectual and developmental disabilities to promote gender and sexual self-determination. In chapter one, I define relevant terminology, justify the importance of inclusive research, and synthesize previous research on the experiences of LGBTQ+ people with intellectual and developmental disabilities. In chapter two, I organize prior scholarship about planning inclusive research into five components and describe how I planned The RISE Up Project according to these components. Then, in chapter three, I present a qualitative interview-based study on the barriers and facilitators to gender and

sexual self-determination in the lives of LGBTQ+ adults with intellectual and developmental disabilities. In chapter four, I share practical lessons from The RISE Up Project on conducting gender and sexualities research consistent with core principles of community-based participatory research. Throughout this work, and in chapter five, I highlight implications for conducting meaningful inclusive research and for promoting gender and sexual self-determination for LGBTQ+ adults with intellectual and developmental disabilities.

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CHAPTER ONE – Introduction

Charlie is a gay Black man in his late 20s with an intellectual disability. No one in the group home where he lives is gay and he doesn't know any other LGBTQ+ people with disabilities. He had one supportive staff member who used to go with him to Pride events, but she doesn't work at his house anymore. The staff he has now don't say anything negative, but they make faces when he wears makeup and he can tell they are uncomfortable with gay people. The only LGBTQ+ center he knows about is on the other side of the city, but he doesn't drive and his staff won't support him with transportation to go there. Charlie wants to go on dates and meet a boyfriend, but his staff are worried that people will pretend to be gay to take advantage of him, so they won't allow him to go out on his own to meet a date. His aunt and uncle, who are the family members who raised him and continue to support him, had a hard time accepting that he is gay. They seem more accepting now, but they still think dating should only be between a man and a woman. Charlie has been feeling isolated and alone and wishes he had more support. What could improve access to gender and sexual expression for Charlie?[1]

John is a nineteen-year-old man with autism who attends a residential special education school for students with significant behavioral support needs. He communicates with gestures, words, and short phrases. John's parents purchase his clothes, and his group home staff decide what he will wear each day. John works in the school library and is allowed to make online purchases with the money he earns. John asked his teacher for help to purchase a princess dress. The teacher, who, as a

[1] This vignette summarizes some of the experiences of one participant from this dissertation study.

transgender person, valued choices about gender expression, helped John place the order. The school educational coordinator heard about the purchase and requested a team meeting. At the meeting, the educational coordinator expressed the belief that the student "could not understand appropriate gender expression because of his severe autism" and felt that the student should be instructed on what men should wear. The vocational coach was concerned that if the student was allowed to wear the dress, the student would want to wear it to work, and that would be unprofessional. The teacher cited a state mandate that school personnel do not reveal information about students' gender and sexuality to parents without the student's permission. However, the team felt that because of the student's disability, and because the student's mother was his court-appointed guardian, the state guidance did not apply. The team called John's parents, who decided that they did not want their adult son purchasing or wearing a dress. The dress was returned, and the student was told, "Boys don't wear dresses." What could improve access to gender expression for John?[2]

Defining Intellectual and Developmental Disabilities

Intellectual disability and *developmental disability* are disability categories which have been defined by state and federal laws to describe groups of people who are entitled to certain rights and protections (Schalock et al., 2019), and have been embraced by disabled people as personal identities (Caldwell, 2011; Gobbo & Shmulsky, 2016). In general, developmental disability refers to lifelong physical and/or cognitive disabilities which impact functioning in major life activities, such as self-care, language, learning,

[2] This is a constructed vignette based on a situation I was involved in as a special education teacher.

mobility, independent living, and/or economic self-sufficiency (The Arc, n.d.). Intellectual disabilities are a type of developmental disability typically defined by their impact on intellectual functioning and everyday living skills (AAIDD, 2022). For this dissertation, I use the category *intellectual and developmental disabilities* to describe a group of approximately 7.38 million individuals in the United States who have either an intellectual disability or developmental disability, or both, which includes people with autism spectrum disorder, Down syndrome, cerebral palsy, Fragile X syndrome, and other disabilities (Residential Information Systems Project, 2020). Many adults with intellectual and developmental disabilities need support with activities of daily living such as personal care, community participation, employment, medical care, or finances.

Support and Self-Advocacy

Supports for people with intellectual and developmental disabilities are "resources and strategies that aim to promote the development, education, interests, and personal well-being of an individual and enhance that person's functioning" (Schalock et al., 2019, p. 226). Adults with intellectual and developmental disabilities who receive the supports and services they need can live meaningful lives as full participants in their communities. Unfortunately, throughout United States history, people with intellectual and developmental disabilities have been denied basic civil rights and have been excluded and isolated without support. For example, beginning in the 19th century, many people with intellectual and developmental disabilities were placed against their will in large state institutions, supposedly for their own protection, where they were segregated from their communities without an education, did not have opportunities for meaningful

employment, and were not allowed to make decisions about their lives. In the early 20th century during the eugenics movement, people with intellectual and developmental disabilities were perceived as harmful to society and, as a result, institutionalization increased, while conditions in institutions worsened. During this period, many people with intellectual and developmental disabilities were subjected to forced physical labor, involuntary sterilization, and other abuses (Linton, 1998; Wehmeyer, 2013).

Self-advocacy describes a civil rights movement by and for people with intellectual and developmental disabilities, which began in the United States in the 1970s with the foundation of the organization People First and led people with intellectual and developmental disabilities to form self-advocacy groups across the country (Caldwell, 2010). People with intellectual and developmental disabilities have continued to come together to resist exclusion and oppression by speaking up for themselves and for the civil rights of people with disabilities (Test et al., 2005). Self-advocates have fought for and achieved: the closing of institutions where people with disabilities were mistreated, the nationwide use of more respectful language to refer to people with disabilities, and more access to inclusion in the community (TASH, 2020; Wehmeyer, 2013). For example, throughout the 1990s, the national self-advocacy organization Self Advocates Becoming Empowered organized the *Close the Doors Campaign*, which contributed to the closing of many state institutions for people with intellectual and developmental disabilities (TASH, 2020).

The term *self-advocacy* is also used by people with intellectual and developmental disabilities to describe the individual acts of resistance and advocacy that many adults

with intellectual and developmental disabilities engage in throughout their everyday lives to speak up for themselves and take back their agency. For example, many adults with intellectual and developmental disabilities refuse to be controlled by staff, family members, doctors, and teachers, and insist on making their own decisions about issues that impact them, such as what they eat or where they live (TASH, 2020).

Due to the advocacy of individuals with disabilities and their families, many people with intellectual and developmental disabilities have been able to move out of the restrictive and inhumane conditions of institutions, into smaller, more community-based settings (National Council on Disability, 2015). In a longitudinal study of residential and community services for people with intellectual and developmental disabilities between 1980-2015, Braddock et al. (2017) found decreasing trends in the number of adults with intellectual and developmental disabilities living in large congregate care settings of 16 or more people, and increasing trends in the number of adults with intellectual and developmental disabilities living in smaller settings of 6 or fewer adults with intellectual and developmental disabilities. Now, people with intellectual and developmental disabilities who need support receive a wide range of supports and services, in a wide range of settings (Larson et al., 2020; Wehmeyer, 2013). As shown in the findings of a 2013-14 national survey, most adults with intellectual and developmental disabilities in the United States live and receive supports in a family members' home, a group home, or their own home. Fewer adults with intellectual and developmental disabilities live and receive supports in institutional facilities compared to previous years (National Core Indicators, 2022). The supports and services that adults with intellectual and

developmental disabilities may need vary greatly, from extensive support to minimal or no support, and should be based on the needs and wishes of each individual with intellectual and developmental disabilities and their support network (Larson et al., 2020; Schalock et al., 2019).

Choices and Control

Despite the impact of individual and collective self-advocacy to promote access to positive and meaningful supports and services, people with intellectual and developmental disabilities continue to experience injustice, and push for ongoing positive social change in the lives of people with disabilities. Many people with intellectual and developmental disabilities continue to be subjected to marginalization and exclusion in our society, as they continue to face limited access to education, employment, and healthcare, and are denied access to choices and control in their lives (TASH, 2020). Guardianship arrangements, access to community-based services, and the roles of caregivers are a few factors that influence the level of choice and control that adults with intellectual and developmental disabilities have in their lives.

Guardianship. Guardianship refers to the process in which state courts can assign a guardian to make decisions on the behalf of an adult whom they perceive as unable to make their own decisions (Jameson et al., 2015). Rates of guardianship over adults with intellectual and developmental disabilities vary greatly by state and demonstrate overall that significant numbers of adults with intellectual and developmental disabilities have court-appointed guardians. In a 2017-2018 national survey of adults with intellectual and developmental disabilities, guardianship rates ranged from 5% of adults with intellectual

and developmental disabilities in Delaware having a court-appointed guardian to 89% of adults with intellectual and developmental disabilities in Nebraska having a court-appointed guardian. Across all fifty states, an average of 42% of adults with intellectual and developmental disabilities had a court-appointed guardian with full guardianship, meaning these adults with intellectual and developmental disabilities did not have decision-making rights in any areas, including healthcare, housing, employment, finances, and more (National Council on Disability, 2018). Guardianship arrangements have the potential to limit the choices and control of adults with intellectual and developmental disabilities, because some court-appointed guardians may make decisions that are not based on the desires and preferences of the adults with intellectual and developmental disabilities to whom they serve as a guardian (Millar, 2013; Stancliffe et al., 2000). Also, there is often little oversight of guardians and processes for changing guardians or transitioning off guardianship are often unclear, difficult to complete, or non-existent. As a result, some adults with intellectual and developmental disabilities find themselves trapped in unjustified or abusive guardianship arrangements (National Council on Disability, 2018).

Community-Based Services. The settings in which people with intellectual and developmental disabilities receive supports and services can limit or promote their opportunities to have choice and control in their lives (ASAN & CLPC, 2020). People who live in institutions or congregate care facilities often do not choose where they live, who they live with, or the staff who support them, and frequently have decisions made for them (Tichá et al., 2012). On the other hand, people who live in their own homes,

with family, or in small disability agency settings (with three or fewer residents), have more choices about what to do during the day, when and where to go out, who they live with, and who supports them. People who have moved from institutions to smaller community-based settings experienced an increase in quality of life because living in the community led to more freedom to make decisions (McCarron et al., 2019). For example, people with disabilities have reported that when living in the community, compared to living in an institution, they had more choice and control over their daily schedule, who helped them with personal care, what food they ate, and when to have privacy (Sheth et al., 2019). They also felt that providers in community-based settings were more likely to listen to them and treat them with respect. Additionally, adults with intellectual and developmental disabilities living in independent homes or family homes have reported more choice and higher quality life compared to adults with intellectual and developmental disabilities living in all other settings, including in comparison to small community-based settings owned by disability services providers (e.g. group homes; Friedman, 2019).

Caregiver Roles. People with intellectual and developmental disabilities, in a wide variety of settings and with all different support needs, continue to have family members and service providers who make decisions on their behalf (Wehmeyer, 2013). For example, some adults with intellectual and developmental disabilities have reported that their parents are overprotective and prevent them from making their own decisions (Shogren & Broussard, 2011). Mothers have expressed that they felt responsible for the well-being of their adult child with intellectual and developmental disabilities and were

concerned about the negative consequences of their adult child's decisions (Curryer et al., 2020). As a result, some mothers influenced their adult child to make what the mothers perceived to be the right decision, set limitations on choice, and made the final decisions.

Adults with intellectual and developmental disabilities have also described ways in which support staff impeded or supported their agency. Staff have limited the choices of people with intellectual and developmental disabilities by taking over control and making decisions for people with intellectual and developmental disabilities and by denying them control over their own money. Adults with intellectual and developmental disabilities have felt that they were unable to reach their goals when staff procrastinated or did nothing to follow through, and have been restricted by staff who were unhelpful, mean, manipulative, or coercive (Nonnemacher & Bambara, 2011).

Self-Determination

Self-advocates continue to fight for the right to self-determination, which they define as their right to speak up for themselves, make their own decisions, and have control in their lives (Self Advocates Becoming Empowered, 1996). In 1996 at the first U.S. national self-advocacy conference, self-advocates formally declared their right to self-determination when they wrote the following,

> We believe self-advocates are the professionals, ask us first, and we should be the decision makers and planners in all our daily living activities, such as working, voting, conferences, leadership development and taking financial control of our service and personal dollars. As a disability community, we are all one unified voice, we include everyone, we are not "special," we respect and trust each other

> and are willing to help each other in the fight for our rights (Self Advocates Becoming Empowered, 1996).

In other words, self-advocates insist that it is within their rights to exercise their agency, with the support they need, so they can have choice and control over decisions that impact them, such as where they work and who they live with. Efforts to be self-determined are ongoing, as people with intellectual and developmental disabilities continue to encounter laws and policies, as well as individual family members and service providers, that usurp decision-making control, thus denying their access to self-determination (Shogren et al., 2015; Wehmeyer, 2013).

Self-determination does not require that a person with intellectual and developmental disabilities is able to clearly articulate independent decision-making in all aspects of their life. People with disabilities who have significant support needs, including those with limited language and communication abilities, can be self-determined when they receive support based on their interests and preferences (Wehmeyer, 2005). Family members, professionals, and other caregivers can promote self-determination for people with significant support needs by seeking to understand and incorporate the disabled person's interests, preferences, and values into the support they provide, thus facilitating opportunities for the person to have agency (Brock et al., 2020). For example, many people with intellectual and developmental disabilities who have limited language and communication abilities, are able to indicate what they like and want or dislike and do not want by communicating with gestures and facial expressions, and using assistive technology (Olney, 2001). Caregivers can facilitate self-determination

to the greatest extent possible by promoting opportunities for the people with intellectual and developmental disabilities they support to communicate through whichever means work for them, and by providing support consistent with what has been communicated.

Educational research has confirmed what self-advocates continue to argue: that people with intellectual and developmental disabilities who are more self-determined are more likely to achieve valued life outcomes, such as employment and community participation, and report higher overall quality of life as adults (Lachapelle et al., 2005; Shogren et al., 2015; Wehmeyer & Abery, 2013). As a result, educational researchers and practitioners have developed best practices and educational interventions to promote self-determination for students and adults with intellectual and developmental disabilities (e.g. see Lee et al. (2015) on the Self-Determined Learning Model of Instruction). The U.S. Department of Education's Office of Special Education Programs (OSEP), the National Association of Councils on Developmental Disabilities (NACDD), and schools and disability service providers all over the country aim to promote self-determination in the services and supports they provide (National Association of Councils on Developmental Disabilities, 2022; Schalock et al., 2019; Wehmeyer, 2013).

Advocacy for Self-Determination

Many prominent disability advocacy organizations and research organizations (e.g. AAIDD, The Arc, TASH) advocate for greater access to self-determination for people with intellectual and developmental disabilities. These organizations' mission and values statements or position statements detail the significance of access to self-determination for people with intellectual and developmental disabilities. For example,

recently the Autistic Self Advocacy Network (ASAN) released a joint statement written in collaboration with twenty other disability advocacy and research organizations which named "self-determination, including setting their own goals and making decisions about all aspects of their lives" as a universal human right of every individual with a developmental disability, regardless of the significance of their support needs (ASAN, 2020). Advocates continue to push for policy change to promote self-determination, such as increased funding for home and community-based services and better alternatives to court-appointed guardianship (ASAN, 2016; Jameson et al., 2015; Wehmeyer, 2013). For example, Supported Decision-Making is a formalized process which allows people to retain access to making their own legally recognized decisions by choosing their own network of trusted supports, including friends, family members, or professionals, who they can reach out to for support with decision-making (Jameson et al., 2015).

Caregivers Promoting Self-Determination

Despite the history of caregivers denying agency and decision-making rights to people with intellectual and developmental disabilities, some family members have accepted and promoted the right to self-determination by facilitating access to choices and guiding their family members with intellectual and developmental disabilities through the decision-making process to make their own final decisions (Curryer et al., 2020). Rossetti et al. (2016) found that among adults with intellectual and developmental disabilities with significant support needs, those who experienced higher quality of life had parents who arranged activities based on their adult child's goals and interests. Supportive staff have also created opportunities for people with intellectual and

developmental disabilities to make choices and have encouraged choice-making by being approachable, trustworthy, and non-judgmental listeners and working with self-advocates to problem solve and take action (Nonnemacher & Bambara, 2011; Shogren & Broussard, 2011). Staff have promoted self-determination by contributing information so that self-advocates could make their own decisions. Individuals who work with and for adults with intellectual and developmental disabilities, such as family members and disability professionals, can learn to better promote self-determination in the supports and services they provide.

Gender and Sexual Self-Determination

Gender self-determination. Gender self-determination means that people with intellectual and developmental disabilities deserve to have choice and control over how they express their gender, such as the clothes they wear, how to style their hair, or what name to be called (Hughes, 2022). However, beliefs and expectations about how people should express their gender can sometimes lead caregivers to make assumptions about and place limits on the gender expression of people with intellectual and developmental disabilities. Self-advocates, queer and trans organizers, and their allies have begun to envision the conditions that could support greater gender self-determination for people with intellectual and developmental disabilities. For example, ASAN, in partnership with the National Center for Transgender Equality, and the National LGBTQ Task Force (2016) released a statement on the rights of gender-variant autistic people in which they insist that, regardless of support needs or communication abilities, gender-variant autistic people should have opportunities to:

- [receive] respect and dignity for the gender they know themselves to be;
- determine their day-to-day expression of their gender, such as their gender-related behavior and appearance;
- make medical decisions and access affirming health care, including transition-related medical care and trans-competent services related to autism; and
- receive full social and legal recognition for their gender, such as the right to make decisions about legal changes to their name and identity documents, decisions about any gender-specific programs and facilities they use, and decisions about their gender-related names and pronouns (2016).

Strang et al. (2018), in their examination of the experiences and perspectives of twenty-two gender-diverse autistic youth from the U.S., found that many of the participants described discomfort and emotional distress about imposed gender expectations, stating, for example, "when I'm forced to play the part of the girl and wear dresses and makeup I feel like crying" (p. 4047). The youth stressed the importance of self-determining their gender identity and expression, describing how they felt their life would be wasted or they might commit suicide if they could not present their gender as they desired.

In an article on gender self-determination, I provided examples of how family members and disability professionals can promote gender self-determination for people with intellectual and developmental disabilities who have significant support needs (Hughes, 2022). For example, a parent could support their adult child with an intellectual or developmental disability to choose clothes from any section of the store, rather than limiting them to only choosing clothing in one gendered section. Staff members at a

group home could facilitate opportunities for the group of women they support to explore a wide range of activities in the community, instead of assuming the group is most interested in activities they perceive as preferred by or more appropriate for women (e.g. assuming because they are women that the group would prefer to go to the nail salon instead of a sports game). Gender self-determination means that rather than being restricted to normative gender expression, there are expansive possibilities in which people with intellectual and developmental disabilities are supported to make their own decisions about how to express their gender.

Sexual Self-Determination. Included within the larger movement for self-determination, people with intellectual and developmental disabilities also advocate for access to sexual self-determination. Research has shown that family members and disability professionals often infantilize people with intellectual and developmental disabilities and assume that they are not interested in nor capable of sustaining romantic relationships (Sinclair et al., 2015). People with intellectual and developmental disabilities often do not have access to appropriate relationship support and have limited or no access to sexuality education. This lack of support and education also contributes to high rates of sexual abuse perpetrated against people with intellectual and developmental disabilities (i.e. people with intellectual and developmental disabilities are four to eight times more likely to experience sexual abuse compared to those without disabilities; McDaniels & Fleming, 2016). People with intellectual and developmental disabilities have expressed the desire for education, support, and privacy that would enable them to express their sexuality and to have personal agency in their romantic and sexual

relationships (Friedman et al., 2014). Specifically, self-advocates with intellectual and developmental disabilities have described wanting to have more choice and control in regards to dating, intimacy, and marriage, and would like to have sexuality education that respects their rights, so they can express their sexuality (Sandman et al., 2015).

Under the purview of self-determination, gender and sexual self-determination means that all people with intellectual and developmental disabilities, regardless of their gender and sexual identities or their disabilities and support needs, should have agency in their gender presentation and their romantic and sexual relationships. Just as supporters can facilitate self-determination in other aspects of life, they can also support people with intellectual and developmental disabilities to self-determine their gender and sexual expression by prioritizing the desires and goals of the individuals they support. Although gender and sexual self-determination should be afforded to all people with intellectual and developmental disabilities, it can be especially important for people with intellectual and developmental disabilities who have feelings and interests that transgress gender and sexual norms, including those who identify as LGBTQ+[3]. Access to gender and sexual self-determination has important implications for the well-being and civil rights of LGBTQ+ people with intellectual and developmental disabilities.

[3] I use the initialism "LGBTQ+" to refer to people who have diverse gender and sexual identities which transgress heterosexual and/or cisgender norms. This refers to people who identify as lesbian, gay, bisexual, transgender, and/or queer or who are questioning their gender and sexual identity. The "+" is to refer to a myriad of other gender and sexual identities, such as pansexual, asexual, intersex, and non-binary, and to include people who are creating new gender and sexual identities to describe themselves, and people who defy or transgress the identification of their gender and sexuality altogether. Additionally, I include under the LGBTQ+ umbrella, people who may not directly communicate an LGBTQ+ identity *in those terms*, but they otherwise express their gender or sexuality outside of heterosexual or cisgender normative expectations.

Experiences of LGBTQ+ People

LGBTQ+ people continue to experience marginalization and oppression because they do not meet dominant expectations of gender and sexuality. LGBTQ+ identities are sometimes perceived as immoral or unnatural and members of the LGBTQ+ community face stigma for their perceived gender and sexual transgressions. LGBTQ+ people continue to experience discrimination, social rejection and exclusion, harassment and violence and, as a result, are more likely to experience mental health issues, are more susceptible to drug misuse and suicidality, and are more likely to live in poverty and experience homelessness (McCann et al., 2016; Romero et al., 2020). For example, in a 2017 national survey, more than half of LGBTQ+ adults reported having been called slurs, and experiencing sexual harassment and other forms of violence (Casey et al., 2019). LGBTQ+ adults, especially those identified as transgender, experienced high rates of health care discrimination, and LGBTQ+ adults of racial/ethnic minorities were more likely to face employment and voting discrimination, and more likely to interact with the legal system.

In recent years, LGBTQ+ people have garnered some federal protections, such as the 2020 Supreme Court decision that the Civil Rights Act protects LGBTQ+ employees from discrimination based on sex (Totenberg, 2020). However, in many states, LGBTQ+ people still face limited legal protections, such as discrimination in adoption and restricted access to public bathrooms for transgender people (Human Rights Campaign, 2022). Healthcare access for LGBTQ+ youth has been an especially contentious topic in recent years, as many states have introduced or passed legislation to deny healthcare to

transgender youth (American Civil Liberties Union, 2022; Kremen et al., 2021) and many states have yet to ban "conversion therapy" for LGBTQ+ youth (Human Rights Campaign, 2022).

Experiences of LGBTQ+ People with Intellectual and Developmental Disabilities

People with intellectual and developmental disabilities show a diverse range of gender and sexual expression, including identities under the LGBTQ+ umbrella, such as lesbian, gay, bisexual, transgender, queer, non-binary, asexual, intersex, and pansexual identities (Bedard et al., 2010; Duke, 2011; McCann et al., 2016; Smith et al., 2022). LGBTQ+ people with intellectual and developmental disabilities have been referred to as a "double minority" that faces "layered stigma" resulting from the complex interactions between their disabilities and their gender and sexual identities, along with interactions with their other sociocultural identities (McCann et al., 2016; Santinele Martino, 2017; Wilkinson et al., 2015).[4] In addition to the marginalization and oppression experienced by the broader LGBTQ+ community, LGBTQ+ people with intellectual and developmental disabilities appear to face magnified and unique struggles at the intersection of disability and gender or sexual minority status (Duke, 2011; Hillier et al., 2020; Movement Advancement Project et al., 2019).

LGBTQ+ people with intellectual and developmental disabilities have shared

[4] In recent years, many researchers have drawn from *intersectionality* scholarship to understand the ways in which the complex interactions between social structures and people's multiply marginalized identities and social positions contribute to social inequality (Collins & Bilge, 2016). There is an important body of literature that grapples with the application of intersectionality to research that has limited analysis of race (Carbado, 2013; Carbado et al., 2013; Moges-Riedel et al., 2020). Although intersectionality scholarship is important work which has relevance to the topic of this dissertation, I chose not to draw directly from that work because my dissertation research does not center the intersection of race and racism with other marginalized identities.

their experiences and perspectives of gender, sexuality, and disability through many mediums, including in blogs, videos, and social media posts. To provide a few examples, self-advocates at the Self-Advocacy Resource and Technical Assistance Center have posted articles and videos about coming out as LGBTQ+ as a person with a disability (Caswell, 2019). Tuttletuttle (2020) created a video describing how their augmentative and alternative communication (AAC) device is their voice and thus part of their gender expression. The Prideability video series, hosted by disability advocate for the LGBTQ+ community, David Frye, features interviews that focus on the lives and advocacy of LGBTQ+ disabled people (Pride Center VT, 2022). Autistic Changeling, one of many LGBTQ+ Youtubers with intellectual and developmental disabilities, shares videos about their life, including content explaining how non-binary people present their gender and talking about their own experience getting chest surgery (*Autistic Changeling*, 2018).

Some peer-reviewed research studies have also documented the experiences and perspectives of LGBTQ+ people with intellectual and developmental disabilities, mostly in countries outside of the United States, and mostly with participants who were gay cisgender men. For example, in a literature review of peer-reviewed articles published in English between 1995-2015 about the views and experiences of people with intellectual disabilities who identify as LGBTQ+, McCann et al. (2016) identified 14 articles on the topic, none of which were from researchers in the United States. Only five of these articles were studies that included the perspectives of LGBTQ+ people with intellectual disabilities. The LGBTQ+ participants with intellectual disabilities who shared their perspectives in these studies were from the United Kingdom (3 studies), Canada (1

study), and the Netherlands (1 study). In a recent literature review of peer-reviewed articles published between 2014-2019 addressing LGBTQ+, intellectual disability, and disability services, Smith et al. (2022) identified 9 articles on the topic, including only one study from the United States, which was a case study of one transgender woman with an intellectual disability. Although I was not able to identify literature reviews of peer-reviewed research describing the experiences of LGBTQ+ people with developmental disabilities other than intellectual disabilities, there have been a few recent research studies that include the perspectives of autistic LGBTQ+ people (e.g., Hillier et al., 2020; Lewis et al., 2021). Additionally, because studies examining the experiences of LGBTQ+ people with intellectual and developmental disabilities have used interviews, focus groups, and surveys, the research literature does not address the experiences of people with intellectual and developmental disabilities who are unable to participate in these types of research studies (i.e., people with intellectual and developmental disabilities who have limited verbal abilities to communicate their feelings and experiences).

Although the research in this area is limited thus far, I organized the available systematic literature reviews and additional recent research into themes related to the experiences of LGBTQ+ people with intellectual and developmental disabilities. Namely, LGBTQ+ people with intellectual and developmental disabilities face compounded misunderstanding, caregiver restrictions of their gender and sexual expression, and barriers to romantic relationships, including limited access to comprehensive sexuality education. Despite these struggles, LGBTQ+ people with intellectual and developmental disabilities have also described advocating for themselves and finding accepting

community spaces, so they can express who they are. Based on these experiences, researchers have described recommendations to improve support and quality of life for LGBTQ+ people with intellectual and developmental disabilities and have provided directions for future research. Below I elaborate on each of these themes I identified from the literature.

Compounded Misunderstanding. LGBTQ+ people with intellectual and developmental disabilities can face misunderstanding on many levels, as people may not understand their disabilities or their gender and sexual identities, or may misinterpret how these identities interact. For example, disability professionals have expressed the belief that people with intellectual and developmental disabilities who were interested in same sex relationships were confused or unaware of their options (Abbott & Howarth, 2007; Smith et al., 2022). LGBTQ+ people with intellectual and developmental disabilities have also reported that their parents and/or staff have expressed negative attitudes toward LGBTQ+ people (McCann et al., 2016; Smith et al., 2022). For example, Dinwoodie et al. (2020) conducted interviews with five LGBT adults with intellectual disabilities in the UK, and some participants reported that they encountered others who believed it was wrong or disgusting for people with intellectual and developmental disabilities to express their LGBTQ+ sexuality or others perceived them as incapable of understanding sexuality. Based on open-ended online surveys distributed to an international sample of autistic adults, Lewis et al. (2021) found that some participants felt others dismissed their asexual identities and invalidated their asexuality by assuming it was due to their autism. Asexual and gender-diverse autistic youth and adults in other studies have also reported

that their asexual identity or gender diversity has been perceived as a symptom or obsession related to their autism, rather than as a legitimate identity (Hillier et al., 2020; Strang et al., 2018). Some participants with intellectual and developmental disabilities, especially autistic participants, felt that communication differences related to their disability sometimes made it difficult for them to put their experience of gender into words (Lewis et al., 2021; Strang et al., 2018). As a result of these many misunderstandings, LGBTQ+ adults with intellectual and developmental disabilities have felt that disability professionals and mental health providers have not been qualified to provide them with the support they need (Hillier et al., 2020; Hogan & Micucci, 2020).

LGBTQ+ people with intellectual and developmental disabilities can find it especially challenging to find supportive and accepting spaces, as they can experience rejection from disability spaces as a result of their gender and sexual identities and marginalization within LGBTQ+ spaces because of their disabilities (Lewis et al., 2021; Wilson et al., 2018). For example, in a focus group with four white LGBTQ+ adults with autism spectrum disorder from the United States, Hillier et al. (2020) found that the participants felt rejected from the LGBTQ+ community because of stereotypes about autism and confusion about the diversity of the autism spectrum. One autistic participant interviewed by Lewis et al. (2021) described how they are perceived as ‘weird’ by the LGBTQ+ community because they are autistic. Burns and Davies (2011) administered surveys to women with intellectual disabilities in the UK, many of whom lived in group homes with others with intellectual disabilities, about their attitudes toward homosexuality. The majority of participants believed that homosexuality was disgusting

and some made hostile remarks about gay and lesbian people. Similarly, in interviews with 13 young adults with intellectual disabilities in Sweden, Löfgren-Mårtenson (2009) found that participants thought same sex relationships were inappropriate or funny.

As a result of this misunderstanding and isolation, LGBTQ+ people with intellectual and developmental disabilities have reported experiencing loneliness, bullying, substance abuse, depression, and anxiety (Hillier et al., 2020; Stoffelen et al., 2018). LGBTQ+ people with intellectual and developmental disabilities have described trying to deny or hide their gender or sexuality to avoid stigma, bullying, and harassment and have felt internalized negative self-perceptions (Dinwoodie et al., 2020; Strang et al., 2018; Wilkinson et al., 2015). Stoffelen et al. (2018), for example, interviewed ten lesbian and bisexual women with intellectual disabilities in the Netherlands who reported feeling alone in coming out, insecurity about their identities, and were not used to advocating for themselves (Stoffelen et al., 2018). Some researchers examining the experiences of LGBTQ+ people with intellectual and developmental disabilities have theorized that the stigma of disability means that people with intellectual and developmental disabilities feel additional pressure to have gender and sexual identities that are considered as 'normal' as possible, to avoid further stigmatization (Smith et al., 2022).

Caregiver Restrictions. People with intellectual and developmental disabilities have also faced barriers to gender and sexual expression due to restrictions and mistreatment by caregivers, such as their family members and disability service providers. Smith et al. (2022) found that service providers felt unprepared to support

people with intellectual and developmental disabilities with sexuality or assumed it was not within their role. Caregivers have also believed that people with intellectual and developmental disabilities cannot or should not be LGBTQ+. When people with intellectual and developmental disabilities have received support around gender and sexuality, the support was often shaped by reluctance and stigma, and tended to promote heteronormative gender and sexual expression. For example, service providers in the UK expressed that they did not have experience and did not feel confident addressing LGB sexuality (Abbott & Howarth, 2007). Many of these staff were anxious about supporting LGB sexuality, wished their organizations had clear policies to follow, and felt that lack of training on the topic prevented them from providing adequate support.

LGBTQ+ people with intellectual and developmental disabilities have described many caregivers as preventing their sexual expression, causing dissatisfaction and increased risks (McCann et al., 2016; Smith et al., 2022). Family members and service providers have restricted the sexual expression of LGBTQ+ people with intellectual and developmental disabilities by discouraging same sex relationships, preventing them from entering same sex relationships, and forbidding sexual acts with same sex partners (Wilkinson et al., 2015; Wilson et al., 2018). People with intellectual and developmental disabilities have also experienced harassment and abuse from caregivers because of their same sex attractions and have described hiding their same sex relationships from caregivers (Abbott, 2013; Dinwoodie et al., 2020).

McClelland et al. (2012) conducted interviews and focus groups with 10 LGBT youth with intellectual disabilities in Canada to examine the influence of social and

environmental factors on sexual health risks. The findings provide a compelling example of the potential health risks of caregiver restrictions. The participants all lived with parents or in group homes and were interested in romantic and sexual relationships but were subjected to rules that attempted to prevent them from engaging in sexual activity. As a result of these restrictions, many of the youth engaged in sexual activities in secrecy, outside of their homes, often in public places such as alleys and parks. The youth felt that these settings were unsafe places to have sex because they could be caught breaking the law and were less likely to use condoms. They felt that their homes would be safer and more comfortable settings to have sex but were not available because of rules imposed by parents or staff members.

Caregivers have also exerted control over how people with intellectual and developmental disabilities are able to express their gender. For example, Barnett (2017) reported experiences of autistic adults who were trained or coerced on how to perform normative gender. One genderqueer participant described a vocational program that tried to coach her on changing the way she dressed. Another participant described how family members had repeatedly tried to teach her how to "walk like a girl" and one woman reported that she was forced by her mother to shave her armpits for a wedding (p. 1218). Dinwoodie et al. (2020) reported the experiences of one transgender woman with intellectual disability in the UK whose support staff in her group home threatened to cut up her clothes if she dressed up as a woman. Tragically, Bedard et al. (2010) presents a case study of a Black Canadian transgender woman with a developmental disability whose mother physically abused her and threatened to castrate her for wearing women's

underwear. The mother referred her transgender daughter to a gender identity clinic, where the clinicians recommended that she be assigned a male support staff to serve as a male role model to her.

In his book about the members of an LGBT support group for people with intellectual and developmental disabilities, Allen (2003) wrote about the experiences of one group member, Ben, who enjoyed cross-dressing[5]. After years of manipulation and mistreatment from state-assigned service providers, Ben hired his own private staff who supported him to dress as he pleased. Ben expressed that he wanted to publicly dress in feminine clothing and go by the name Barbara, but only felt safe doing so in his own home. Unfortunately, even the author, Allen, the founder and facilitator of the LGBT support group that Ben attended, writes his opinion that Ben does a poor job looking like a 'real' woman and describes about how he discouraged Ben from wearing a dress and going by Barbara at a public event. Similarly, Parkes et al. (2009), in their review of the clinical records of people with intellectual disabilities in the UK who cross-dressed, found that participants described feeling afraid to cross-dress in public, wishing they could live alone so they could cross-dress more, and having their clothes thrown away by staff. Unfortunately, LGBTQ+ adults continue to face limitations on their gender and sexual expression.

[5] I use the term "cross-dress" when this is the descriptor provided by the authors. I would like to note that the use of the word "cross" reinforces the belief that there are two distinct genders, and that the appropriateness of particular clothing items is determined by the sex assignment of the wearer. I do not share the belief that certain clothing items are more appropriate for certain people based on their sex assigned at birth.

Lack of Access to Sexuality Education. LGBTQ+ adults with intellectual and developmental disabilities have also described barriers to forming and maintaining romantic and sexual relationships. Hogan & Micucci (2020) and Lewis et al. (2021), in interviews with primarily white samples of autistic adults from the United States and European countries, found that many participants reported struggling to understand LGBTQ+ dating norms and difficulties communicating their romantic and sexual feelings. Many participants felt that navigating LGBTQ+ dating and relationships can be less clear than heterosexual dating and relationships, because there are fewer models of LGBTQ+ dating norms and because LGBTQ+ flirting and dating is sometimes more subtle or discreet in response to potential stigmatization. Also, for some LGBTQ+ autistic adults, sensitivities and sensory overload impacted which places autistic participants felt comfortable meeting dates and sometimes led to discomfort with physical interaction. Many of these adults expressed the need for support and education related to navigating LGBTQ+ relationships and sexuality.

Researchers have demonstrated that LGBTQ+ youth and adults with intellectual and developmental disabilities often have less sexual health knowledge than their heterosexual and non-disabled peers, and can gain this knowledge with access to accessible sexuality education (Duke, 2011; McCann et al., 2016; Sinclair et al., 2015). However, when people with intellectual and developmental disabilities have access to sexuality education, it rarely adequately addresses the educational needs of LGBTQ+ people (Sinclair et al., 2015; Wilson et al., 2018). In fact, researchers have found that sexuality education for people with intellectual and developmental disabilities often

focuses exclusively on biology and safety; does not address sexual identity, relationships, or pleasure; and is typically biased toward heterosexuality (Brown & McCann, 2018; Sala et al., 2019). LGBTQ+ people with intellectual and developmental disabilities who want information about relationships and sexuality may not feel comfortable bringing their questions to family or staff members. For example, lesbian and bisexual women with intellectual disabilities in the Netherlands interacted with many different service providers, often for short periods of time, so they did not feel comfortable discussing sensitive topics, like same-sex intimacy (Stoffelen et al., 2018). Instead, they had to figure out for themselves how to be sexual with another woman. Without access to comprehensive sexuality education, LGBTQ+ adults with intellectual and developmental disabilities are further prevented from understanding themselves and reaching their relationship goals. Because of these many complex struggles, LGBTQ+ people with intellectual and developmental disabilities are often isolated and without acceptance or support (Santinele Martino, 2017).

Joy and Community. Most existing research related to the experiences and perspectives of LGBTQ+ people with intellectual and developmental disabilities describes the restrictions and barriers faced by this community, thus engaging primarily in 'documenting damage' (McCann et al., 2016; Smith et al., 2022; Tuck, 2009). Although less often documented, there have also been reports of LGBTQ+ people with intellectual and developmental disabilities accepting themselves, living authentically, and supporting one another (Dinwoodie et al., 2020; Lewis et al., 2021; McCann et al., 2016). For example, one transgender woman described making the self-determined choice,

despite violence and lack of support, to live her life as a woman. She expressed the belief that others treated her poorly because of their own lack of access to self-determination, stating that those who harassed her were jealous and that, "they can't be who they want to be so they take it out on me" (Dinwoodie et al., 2020, p. 9). Some autistic youth and adults have felt that the intersection of their gender, sexuality, and neurodiversity helped them feel less pressure to conform and allowed them to better understand and value different types of people (Lewis et al., 2021; Strang et al., 2018). For example, as one participant described,

> We all have our unique differences and being a lesbian with ASD are some of mine. They contribute to who I am as a person, and I believe it is our inherent differences as people that make life special and worth living. (Lewis et al., 2021, p. 2329)

Elderton et al. (2014) share how one support group, consisting primarily of white British LGBT men with intellectual disabilities, shared stories of being brave, having fun in life, feeling stylish, overcoming adversity, and finding love.

LGBTQ+ adults with intellectual and developmental disabilities have reported finding acceptance and joy through connections with the LGBTQ+ community, especially with other LGBTQ+ people with intellectual and developmental disabilities (Hillier et al., 2020; McCann et al., 2016; Stoffelen et al., 2018). Tallentire et al. (2020), for example, engaged in a participatory research project with LGBT adults with intellectual disabilities attending an LGBT support group at a hospital setting in the UK. The research team found that the support group was a place where they could 'come out'

and share their LGBT identities and feel welcomed for who they are. By meeting other LGBT people and talking about sexuality, many members felt that the group helped them feel proud of themselves. Many members were also enthusiastic to help others accept themselves and felt that this gave them a sense of purpose. Elderton et al. (2014) engaged a group of LGBT adults with intellectual and developmental disabilities in a narrative therapy group and found that telling personal stories to one another promoted participants' positive identity formation. Online groups have also been valued spaces for LGBTQ+ adults with intellectual and developmental disabilities to discover their gender and sexual identities and find community (Moore et al., 2022). Participants have valued groups for LGBTQ+ adults with intellectual and developmental disabilities because they were places to be understood, feel empowered, learn about sexual health, and support one another (Dinwoodie et al., 2020; Hillier et al., 2020; Withers et al., 2001).

Researcher Recommendations. Based on the experiences of LGBTQ+ people with intellectual and developmental disabilities, researchers have provided recommendations for improving supports and promoting gender and sexual self-determination. One such recommendation is to challenge caregivers' stereotypes and negative attitudes toward LGBTQ+ identity and expression among people with intellectual and developmental disabilities (McCann et al., 2016; Smith et al., 2022). Supporters should use "positive, strengths-based, and affirmative practices," and validate individual's identities (Hillier et al., 2020; Hogan & Micucci, 2020, p. 182). Researchers have also recommended that disability service providers act open and accepting toward LGBTQ+ adults with intellectual and developmental disabilities, and promote a culture of

respect at their agencies (Tallentire et al., 2020). Specific details are still needed to describe what positive, validating, and respectful support for LGBTQ+ people with intellectual and developmental disabilities should look like in practice.

Many researchers have recommended increased access for youth and adults with intellectual and developmental disabilities to comprehensive sexuality education, which includes LGBTQ+ identities and relationships (Duke, 2011; McCann et al., 2016; Smith et al., 2022). LGBTQ+ people with intellectual and developmental disabilities may need to learn about topics not typically included in sexuality education, such as information about interpreting subtle cues related to sexual identity and flirtation in the LGBTQ+ community, 'coming out' as LGBTQ+ to potential partners, and responding to homophobia (Lewis et al., 2021). Also, as Löfgren-Mårtenson (2012) recommends, sexuality education should not only address risks, as is typically the focus for people with intellectual and developmental disabilities; it must also address pleasure, desire, and intimacy.

In order for people with intellectual and developmental disabilities to access quality supports and comprehensive sexuality education, researchers have recommended education and training for families and service providers, based on the lives and perspectives of LGBTQ+ people with intellectual and developmental disabilities (McCann et al., 2016; Smith et al., 2022). More opportunities to connect with the LGBTQ+ community, including through groups for LGBTQ+ adults with intellectual and developmental disabilities, has also been recommended (Hillier et al., 2020; McCann et al., 2016; Smith et al., 2022; Tallentire et al., 2020). These groups are seen as especially

valuable when they are led by LGBTQ+ mentors with intellectual and developmental disabilities, and support participants to increase their self-advocacy skills (Smith et al., 2022; Withers et al., 2001). Although these researchers have highlighted injustices and provided recommendations for action, few studies have described the process of taking action in pursuit of improving the lives of LGBTQ+ people with intellectual and developmental disabilities.

Additionally, although most authors of the existing literature have provided recommendations based on their own interpretations of the research findings, many have emphasized the importance of research and supports that are developed in collaboration with LGBTQ+ people with intellectual and developmental disabilities (McCann et al., 2016; Smith et al., 2022; Strang et al., 2019). For example, based on their review of the literature, Smith et al. (2022) wrote of research related to supports for LGBTQ+ people with ID, “Co-design research is also lacking in this space and there is room for research that starts with LGBTQ people with intellectual disability setting the agenda as well as being involved as peer researchers and authors" (p. 56). These co-designed projects should include members of the LGBTQ+ and intellectual and developmental disabilities community who have been less often included in the research literature, such as women, people of color, transgender people, and asexual people (McCann et al., 2016; Smith et al., 2022). Researchers have recommended inclusive and community-based research approaches to engage in meaningful projects, in collaboration with diverse groups of LGBTQ+ people with intellectual and developmental disabilities, to improve support and resources for their community (McClelland et al., 2012; Strang et al., 2019; Tallentire et

al., 2020).

Inclusive Research

Traditional research approaches have denied self-determination access to people with intellectual and developmental disabilities through exploitative and dehumanizing treatment as experimental 'subjects' and through the development of theories and practices that have harmed or controlled people with intellectual and developmental disabilities (McDonald et al., 2013). In fact, many efforts of the self-advocacy movement have been in direct response to the misconceptions and inhumane actions of medical and educational researchers who have perpetuated low expectations, segregation, and abusive treatment of disabled people (TASH, 2020). In one horrid example, at Walter E. Fernald State School, MIT researchers and the company Quaker Oats fed radioactive material to children with disabilities without consent in order to study the nutritional value of oatmeal (Wehmeyer, 2013). Harmful research at Fernald and similar institutions motivated self-advocates to make deinstitutionalization and community living top priorities in their advocacy efforts.

The perspectives of people with intellectual and developmental disabilities have been excluded from the research literature by some researchers who have perceived them as incapable of providing meaningful perspectives and unable to consent to participation (McDonald et al., 2013). When people with intellectual and developmental disabilities are considered eligible for research participation, the accommodations are often insufficient for them to meaningfully share their perspectives (e.g., written surveys may not be accessible to some people with intellectual and developmental disabilities who do

not read or write independently). Also, people with intellectual and developmental disabilities have often been excluded from accessing research findings, as research is often published in academic journals and written in academic jargon, which is inaccessible to many people with intellectual and developmental disabilities. Despite this exploitation and exclusion, people with intellectual and developmental disabilities have expressed that, if there is trust and accessibility, they are interested in participating in research that could improve quality of life for people in their communities (Kramer et al., 2011; Schwartz, Kramer, et al., 2020).

Inclusive research is a research approach consistent with self-determination and the call for research that improves quality of life for disabled people. Inclusive research is based on the participation of people with disabilities in the research process in order to produce knowledge and action for social change (Walmsley & Johnson, 2003). This research approach is participatory in that it occurs in collaboration with communities typically excluded from academia, in recognition that their expertise from lived experience is crucial to knowledge production. In inclusive research, movement toward disability justice is evident not only in the research outcomes, but throughout the research process as well (Kincheloe et al., 2011). The participatory nature of this approach reflects the advocacy efforts of people with intellectual and developmental disabilities to serve as "decision makers and planners" in issues that impact their lives. An inclusive research approach also emphasizes the necessity of research that leads to concrete and meaningful action that can improve material conditions for the community engaged in the collaboration (Bradbury-Huang, 2010). Thus, inclusive research has the potential to

promote self-determination in the research process and forward the movement for the rights of people with intellectual and developmental disabilities.

Engaging in inclusive research in collaboration with co-researchers with intellectual and developmental disabilities is valuable to the research process because it brings the skills of academic researchers and people with intellectual and developmental disabilities together, "to generate new knowledge that neither group could do alone" (Bigby et al., 2014, p. 8). This knowledge can then be shared in accessible and practical ways within the intellectual and developmental disabilities community in addition to circulation within the academic community. Researchers have collaborated with people with intellectual and developmental disabilities on inclusive and community-based research projects addressing a wide range of topics, such as peer-mentoring for people with intellectual and developmental disabilities and mental health diagnoses (Schwartz, Young Adult Mental Health/Peer Mentoring Research Team, et al., 2020), gender-based violence (Platt et al., 2017), health disparities impacting Latino adults with intellectual disabilities (Jurkowski et al., 2009), self-advocacy group capacity (Garcia-Iriarte et al., 2009), and sexual health outcomes (McClelland et al., 2012). Collaborative research projects have also aided researchers in developing assessment tools and interventions that are more effective and of higher value to people with intellectual and developmental disabilities (Nicolaidis et al., 2015, 2020; Oschwald et al., 2014; Schwartz, Kramer, et al., 2020).

To understand the unique and complex experiences of individuals with intersecting LGBTQ+ and disability identities and to develop supports and resources that

promote gender and sexual self-determination in the lives of LGBTQ+ people with intellectual and developmental disabilities, it is necessary to center the experiences and perspectives of LGBTQ+ people with intellectual and developmental disabilities themselves (Blanchett, 2002; Santinele Martino, 2017; Strang et al., 2019). In their discussion of community-based participatory design research that impacts autistic and gender-diverse people, Strang et al. (2019) noted the importance of the perspectives of autistic and gender-diverse people in research projects related to their lives. The authors, many of whom were autistic co-researchers, describe the potential for non-autistic and non-gender-diverse researchers to misinterpret the complex identities and experiences of their community. Collaboration with LGBTQ+ adults with intellectual and developmental disabilities throughout the research process is more likely to prevent misinterpretation and address the needs and priorities of their community. For example, while most studies on autism and gender diversity have focused on rates of co-occurrence, research collaboration with community members has led to projects that emphasize the experiences and support needs of this community. Thus, to understand their experiences and develop desired supports, research projects should be based on the interests of diverse groups of LGBTQ+ people with intellectual and developmental disabilities who are included throughout the research process.

Purpose

It is critical to understand the struggles and desired supports of LGBTQ+ adults with intellectual and developmental disabilities to develop the resources they want and need, and thus promote their gender and sexual self-determination and reduce the

injustices they face. The purpose of this inclusive research project was to better understand the experiences of LGBTQ+ adults with intellectual and developmental disabilities and develop a resource, grounded in their priorities, to promote gender and sexual self-determination. Additionally, this project strove to provide a detailed model of impactful inclusive gender and sexualities research in collaboration with people with intellectual and developmental disabilities and their supporters. In this dissertation, I present three research articles, which address the following research questions:

- What was the process for planning an inclusive research project in partnership with LGBTQ+ adults with intellectual and developmental disabilities? (Chapter 2)
- How did team-level and contextual factors influence the process of planning an inclusive research project? (Chapter 2)
- What are the barriers to gender and sexual self-determination experienced by LGBTQ+ adults with intellectual and developmental disabilities? (Chapter 3)
- What do LGBTQ+ adults with intellectual and developmental disabilities perceive as facilitators of gender and sexual self-determination? (Chapter 3)
- What were the practical lessons learned for promoting meaningful collaboration in inclusive and community-based participatory gender and sexualities research with LGBTQ+ people with intellectual and developmental disabilities? (Chapter 4)

Method

The Rainbow Inclusion Speaking Up (RISE Up) Project was an inclusive research project to understand and promote gender and sexual self-determination in the lives of LGBTQ+ adults with intellectual and developmental disabilities. The RISE Up Project occurred in collaboration with a team of three self-advocate leaders from a local community organization run by and for LGBTQ+ people with intellectual and developmental disabilities. With the research team, I took an inclusive research approach consisting of phases of action and reflection to conduct an action research project to help improve access to gender and sexual self-determination for LGBTQ+ people with intellectual and developmental disabilities (Bradbury-Huang, 2010; Peralta, 2017). The three articles in this dissertation are based on three different components of this broader project. In the method section below, I provide an overall description of the method for The RISE Up Project, referencing how the method led to each of the three articles and citing when more detailed method information can be located within the articles.

Researcher Reflexivity

When I was first discovering my own trans identity, it was a group of self-advocates who taught me that each of us should be able to speak up for who we are and direct our own life journeys. Later, as an out trans special education teacher, many LGBTQ+ students with disabilities came to me looking for information, for someone to confide in, or for someone to support them to express themselves. They faced teachers and family members, as well as broader systems-level factors, which controlled and limited their gender and sexual expression.

Disabled communities and trans communities share many points of solidarity. We have bodily configurations that do not meet dominant expectations. Many of us have bodies which are not expected or understood, some of us have shared scars, daily pills, weekly injections, and surgeries. Disabled people and trans people have been denied agency over our own expression and bodies, especially within a medical system that ignores our needs and determines for itself which, often violent, "treatments" are appropriate. Disabled people and trans people encounter stigma and marginalization, assumptions and lack of understanding, disdain and disgust, violence and discrimination. We exist in a range of visible to invisible. We exist in environments that were not designed for us, faced with binaries (male/female, able/disabled) and physical spaces (bathrooms, housing, schools) that exclude and police us.

Disabled and trans identities and communities are also a source of resilience, of radical inclusion and acceptance. We dismantle insufficient and restrictive norms and binaries and create something more expansive and liberating than others could hardly imagine; our very existence and survival demands it. This is my *theory in the flesh*[6].

What I brought to this project is the understanding that LGBTQ+ people with disabilities carry with us rich insight into the creation of an inclusive and accessible future. I brought passion for and perspective into the historical and current cultural wealth that LGBTQ+ and disabled people continue to bring to our world. Sometimes I brought

[6] First described by Moraga (1981), "theory in the flesh means one where the physical realities of our lives–our skin color, the land or concrete we grew up on, our sexual longings –all fuse to create a politic born out of necessity" (p. 53). For other examples of theory in the flesh, see Cruz (2013) and Fernández (2018).

shared understanding, and other times I brought enthusiasm to learn something new. I strove to engage in the 'heart, hand, and head work' to challenge traditional power dynamics, by acknowledging my own values and emotions, forming trusting reciprocal relationships that lead to meaningful action, and reflecting on how my own experiences and interests impacted the process and outcomes of the project (Fernández, 2018). With that, I hope this project can be an act of love which advances the queer, disabled vision of self-determination.

Planning The RISE Up Project

The RISE Up Project began when Pauline Bosma, the founder and coordinator of the Rainbow Support Groups of Massachusetts, expressed interest in learning more about how to support LGBTQ+ people with intellectual and developmental disabilities. I then suggested that we collaborate on a research study to understand the experiences and desired supports of this community. We received Institutional Review Board (IRB) approval and were awarded a graduate student research grant to conduct two rounds of interviews with LGBTQ+ adults with intellectual and developmental disabilities. Pauline and I invited two LGBTQ+ self-advocates to join the research team. I served as the principal investigator and Pauline and the two other self-advocates served as co-researchers on the team. We decided to meet regularly as a research team to design the research study, analyze the data, and develop an action research project. Chapter 2, which was accepted for publication in the AAIDD journal *Inclusion*, provides a detailed description of how I initiated the project, determined team member characteristics and roles, built and sustained relationships with the research team, promoted accessibility in

the research process, and planned for meaningful research outcomes (Hughes & Schwartz, in press).

Developing The Rainbow Guidebook

To develop a meaningful action research project that could improve the lives of LGBTQ+ adults with intellectual and developmental disabilities, we decided as a research team to conduct an interview-based qualitative research study examining the experiences and perspectives of LGBTQ+ adults with intellectual and developmental disabilities from across the United States. For the first-round interviews, the co-researchers expressed interest in the struggles that LGBTQ+ adults with intellectual and developmental disabilities have experienced, positive supports they have received, and participants' perspectives on what could help improve the lives of LGBTQ+ people with intellectual and developmental disabilities. I used a semi-structured interview protocol developed with the research team to conduct 23 narrative interviews with LGBTQ+ adults with intellectual and developmental disabilities. (See Chapter 3 for more information about the interview process and detailed participant demographic data; see Appendix A for the first-round interview protocol.)

I then presented findings from the first-round interviews to the co-researchers by conducting a partial inductive thematic analysis consisting of a multi-step coding process of first-cycle coding and pattern coding, based on the analysis methods described by Miles et al. (2020), and shaped by practices recommended to increase accessibility for adults with intellectual and developmental disabilities (Kidney & McDonald, 2014; Nicolaidis et al., 2019). I sought to present the findings in plain language, with clear

organization, and emphasis on the major points, by sharing slideshows with themes related to struggles, positive supports, and ideas for improvement. (See Appendix B Chapter 4 Supplementary Material for examples of accessibility strategies I used when engaging in data analysis with the research team; Hughes & Santinele Martino, 2023.)

As we reviewed the initial thematic findings, the co-researchers shared their perspectives and related experiences. We then discussed potential action projects that could address the struggles described by the participants and promote the positive supports that the participants had experienced or desired. By consensus, the research team decided to create a resource for supporters, such as disability service providers, family members, and educators, about the lives and support needs of LGBTQ+ people with intellectual and developmental disabilities. The team wanted the guidebook to teach about gender and sexual diversity in the intellectual and developmental disability community, share personal stories written by LGBTQ+ self-advocates, and to give advice on how to improve support and education. We decided to call this resource: *Our Lives, Our Choices, Our Rights! The Rainbow Support Group Guidebook for LGBTQ+ and Intellectual and Developmental Disabilities,* or *The Rainbow Guidebook* for short.

We continued to work together as a research team to create The Rainbow Guidebook, with the support of a program grant from Boston University Diversity & Inclusion. I developed a structured second-round interview protocol based on the goals for The Rainbow Guidebook, including 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?" (see Appendix C for the

second-round interview protocol). I contacted all 23 original participants and 19 agreed to participate in second-round interviews. I sorted the responses to the second-round interviews by interview question and shared a summary with the research team. Then, we reviewed the thematic findings from the first-round interviews and the topics shared in the second-round interviews to create an outline of the chapter topics for The Rainbow Guidebook.

The co-researchers agreed that all decisions about The Rainbow Guidebook should be made by consensus from all four members of the research team. The team then collaboratively developed an iterative process for writing the guidebook chapters. First, we would meet as a team and the co-researchers would choose a chapter topic and share major points for the chapter, while I took notes. Then, I would write a draft of the chapter, incorporating the interview findings and notes from the team. We would then meet again so I could read the chapter aloud and the co-researchers could suggest chapter edits. For example, because many participants described the need for more access to sexuality education, the team decided to include in The Rainbow Guidebook a chapter about teaching accessible and LGBTQ+ inclusive sexuality education. The co-researchers expressed that this chapter should discuss how to make sexuality education content accessible to students with intellectual and developmental disabilities and should include topics such as LGBTQ+ terminology, consent, and sexual health. Based on these notes, I then referred to the interview findings, especially the answers to the second-round interview question “What do you think sex ed classes should teach for LGBTQ+ people with I/DD? ”, to draft the chapter content and add relevant participant quotes. We read

the chapter aloud at the next research meeting and the co-researchers provided suggestions about the information and clarity. Based on one co-researcher suggestions, for example, the team agreed that we should add the statement on teaching about the availability of HIV-prevention medications.

After writing 12 chapters through this process, we decided to move forward with posting the first edition of The Rainbow Guidebook online. The research team also decided to create an introductory video and take photos to be included in the guidebook. I contacted LGBTQ+ self-advocates about writing a personal story to be posted on the guidebook website and collected four stories from people outside of the research team. The research team then met to discuss how to solicit feedback, and we decided to each nominate specific people to provide feedback on chapters relevant to their expertise. For example, Pauline had connections to two sexuality educators and decided to request their feedback on the chapter about sexuality education. Another team member wanted feedback from a gay friend about the chapter on gender and sexuality. We discussed all feedback as a team and came to an agreement on any revisions to the guidebook. Two sexuality educators, one staff supporter of self-advocates, and one LGBTQ+ person dually-certified in social work and special education provided constructive criticism which was incorporated into The Rainbow Guidebook. All other feedback we received was positive.

After we had written the content, added the videos and pictures, posted the stories, and incorporated the feedback, The Rainbow Guidebook was made available online at RainbowGuidebook.com in May 2023. We began distributing it by emailing

organizations, posting it on social media, and passing out flyers at conferences and LGBTQ+ Pride events. It is also available on the Rainbow Support Group website and has been shared by the research team at multiple webinars and conference presentations. (See Appendix D for an example flyer advertising The Rainbow Guidebook, which includes a direct link to the website.)

Examining Gender and Sexual Self-Determination

During the initial analysis of the interview findings, one prominent theme was participants' experiences of denied self-determination and the importance of promoting self-determination in gender and sexual expression. In the process of creating The Rainbow Guidebook, the research team decided to write a chapter on the human rights of LGBTQ+ people with disabilities, which included the rights of gender and sexual self-determination. The interview participants' and co-researchers' perspectives on this topic resonated with my own personal and professional experiences. For these reasons, after completing and distributing the first edition of The Rainbow Guidebook, I decided to conduct additional analysis of the original interview data to write an academic article on gender and sexual self-determination in the participants' lives. Thus, Chapter 3, which was submitted for peer review to the AAIDD journal *Intellectual and Developmental Disabilities*, is an interview-based qualitative research study in which I examined barriers and facilitators to gender and sexual self-determination in the lives of LGBTQ+ adults with intellectual and developmental disabilities. (See Chapter 3 for a more detailed description of the method; Hughes, under review.)

Reflections on Community-Based Participatory Gender and Sexualities Research

Throughout The RISE Up Project, with permission from the research team and with IRB approval, I recorded the research meetings, wrote memos about our collaborative process, and informally solicited the team's feedback about the project. In reviewing the recordings, memos, and feedback, I felt there were practical methodological findings which could be of value to future community-based participatory gender and sexuality research endeavors. Through discussion with second author Dr. Alan Santinele Martino, we identified reflections on how we each strove to embrace core principles of community-based participatory research throughout our related research projects and developed recommendations for future collaborative research that addresses gender and sexuality in the lives of people with intellectual and developmental disabilities. I presented these reflections and recommendations to The RISE Up research team, who provided feedback and suggestions which were incorporated into the article. Chapter 4, which was published in the *International Journal of Qualitative Methods*, discusses practical lessons for engaging in meaningful research collaboration with LGBTQ+ people with intellectual and developmental disabilities (Hughes & Santinele Martino, 2023).

CHAPTER TWO – Planning Inclusive Research: A Comparison of Two Inclusive Dissertation Research Projects

Oscar E. Hughes, M.Ed.

ohughes@bu.edu

Boston University, Wheelock College of Education & Human Development

Department of Teaching and Learning

2 Silber Way

Boston, MA 02215, United States

631-487-4571

https://orcid.org/0000-0003-4722-5832

Ariel E. Schwartz, PhD, OTR/L

University of New Hampshire

Institute on Disability

10 West Edge Drive

Durham, NH 03824

https://orcid.org/0000-0002-4051-8870

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Abstract: Planning inclusive research should center meaningful engagement of co-researchers with intellectual and/or developmental disabilities to address issues that are important to their communities. There are a variety of approaches to planning research projects consistent with the guiding principles of inclusive research. We describe components of planning inclusive research by comparing two inclusive dissertation research projects. We organize our comparison into five sections: (1) initiating the projects, (2) team member characteristics and roles, (3) building and sustaining relationships, (4) accessibility in the research process, and (5) outcomes. We then discuss how contextual and team-level factors influence the process of planning inclusive research.

Keywords: planning, inclusive research, participatory research, dissertation research, intellectual disability, developmental disability

Introduction

There has been increased attention on the benefits of inclusive research to address rights, health, and participation disparities experienced by individuals with intellectual and/or developmental disabilities[7] (Jones et al., 2020; O'Brien et al., 2022; Walmsley et al., 2018). Inclusive research is an approach in which individuals with intellectual and/or developmental disabilities partner with academically-trained researchers[8] to conduct research. The term *inclusive research* was first coined by Walmsley and Johnson in 2003 (Walmsley & Johnson, 2003), and has been used as an umbrella term to describe the various approaches to active involvement of people with intellectual and/or developmental disabilities as co-researchers in the research process. Twenty years since they coined the term, Walmsley and Johnson, and colleagues, continue to emphasize five fundamental principles of inclusive research: (1) disabled people have ownership of the research problem, (2) the research furthers the interests of disabled people, (3) co-researchers with intellectual and/or developmental disabilities are involved in conducting

[7] Inclusive research scholarship has often focused specifically on research by and with people with intellectual disabilities. We use the term *intellectual and/or developmental disabilities* as this is the community that we engaged with in the research projects described throughout this article. We use the term *intellectual and/or developmental disabilities* to refer to people who identify with or who have been labeled with an intellectual disability, developmental disability, or both.

[8] Throughout this article we use the phrases *academically-trained researchers* and *academic researchers* to refer to researchers who have received formal academic training to conduct research. Academic researchers typically have advanced degrees and are affiliated with a university or research institution. We use the phrases *co-researchers with intellectual and/or developmental disabilities* or just *co-researchers* to refer to people who identify with or who have been labeled with an intellectual disability, developmental disability, or both, who serve as collaborators on research projects, and do not have formal training and advanced degrees related to conducting academic research. We chose this terminology because we feel it names a distinction between team members that is relevant at the time of publication and communicates respect for all members of the team. We expect that terminology to describe disability and inclusive research teams will continue to change and evolve over time. In some cases, individuals with intellectual and/or developmental disabilities have dual roles as academic researchers and co-researchers, but this was not the case in either study described in this article.

the research, (4) co-researchers exert some control over the process and outcomes, (5) and all aspects of the research are accessible (Garratt et al., 2022; Walmsley & Johnson, 2003).

How to plan, conduct, and disseminate research according to these principles is of ongoing discussion in the field of inclusive research (O'Brien, 2022). There is wide variation in the extent to which inclusive research teams plan to involve co-researchers at various stages of the research process, from soliciting input from advisory board members at a few predetermined stages of the study, to intentionally following the lead of co-researchers from beginning to end. A common focus of this literature is the extent and authenticity of co-researcher involvement in inclusive research projects. For example, Bigby and colleagues (2014) proposed a framework conceptualizing three different approaches to co-researcher involvement in various phases of inclusive research: advisory, leading and controlling, and collaborative groups. There is continued debate about what constitutes inclusive research, as some scholars question projects which claim to be inclusive, but document little to no involvement of co-researchers with intellectual and/or developmental disabilities, and therefore do not reflect the core principles of inclusive research (Stack & McDonald, 2014). Recently, inclusive researchers have sought to generate consensus statements (Frankena et al., 2019) and practice guidelines (Nicolaidis et al., 2019) to guide academic researchers as they embark on inclusive research partnerships.

Central to these inclusive research principles, frameworks, and guidelines is the importance of purposeful planning for inclusive research. For example, in a consensus

statement written by an international team of inclusive research experts with and without disabilities, Frankena et al. (2019) state as attributes of inclusive research, "deciding upon the research topic, research questions and methods by means of dialogue with team members" and "good collaboration starts before the onset of the study and continues through all stages of the study, as far as possible given funding and time constraints" (p. 6). Planning helps teams articulate shared understandings, determine roles, and establish processes for collaboration. There are a variety of approaches to how inclusive research is planned and who has power and control in the planning process. For example, inclusive research projects may be planned by various stakeholders, such as academically-trained researchers, governmental or non-profit organizations, or by individuals or groups of people with intellectual and/or developmental disabilities (Bigby et al., 2014; Jones et al., 2020). Additionally, some inclusive research projects are planned from the beginning with great specificity, with or without the initial involvement of people with intellectual and/or developmental disabilities, while other projects are planned broadly and then developed by the research team as the project progresses (Kim et al., 2022; White & Morgan, 2012). Planning for inclusive research often involves an ongoing process of continuous monitoring and feedback, in which roles, team processes, and goals are adjusted throughout the project. In all planning approaches, how and by whom inclusive research projects are planned impacts teams' processes and outcomes.

The planning of inclusive research is often influenced by team-level and contextual factors. Team-level factors that may influence decisions regarding teams' processes and activities include study design and the interests and skills of team

members. For example, Walmsley et al. (2018) argue that the decision whether to provide traditional research training about scientific research processes and methods to co-researchers with intellectual disabilities should be based on the design and aims of the study, as well as the skills and preferences of the co-researchers on the project. Contextual factors often greatly influence the extent to which teams plan to engage co-researchers. These factors include Institutional Review Board (IRB) requirements, funding, grant timelines, and institutional beliefs about the value and feasibility of inclusive research (Flicker et al., 2007; McDonald & Stack, 2016; O'Brien et al., 2022; Walmsley et al., 2018). For example, inclusive researchers have described how grant timelines and lack of bridge funding between projects can be a barrier to in-depth collaborative planning for some inclusive research teams (Frankena et al., 2019). Thus, the planning process for inclusive research is greatly influenced by multiple factors that uniquely interact in each project.

The purpose of this manuscript is to discuss components of inclusive research planning and the team-level and contextual factors that influence planning by comparing two different planning approaches. Specifically, we compare two inclusive dissertation research projects: *The Rainbow Inclusion Speaking Up (RISE Up) Project*, a collaborative group project that was initiated by a community organization run by and for people with intellectual and/or developmental disabilities, and *Developing a Peer Delivered Mental Health Intervention,* a project in which an academically-trained researcher recruited a team of co-researchers with intellectual and/or developmental disabilities to conduct foundation-funded research. First, we provide an overview of these two projects. Then,

we refer to inclusive research literature to describe five components of inclusive research planning: (1) initiating the projects, (2) team member characteristics and roles, (3) building and sustaining relationships, (4) accessibility in the research process, and (5) outcomes. For each of these five components, we compare how our projects were planned. We hope this comparison, grounded in inclusive research literature, generates reflection on the potential benefits and drawbacks of different approaches to planning for inclusive research. Furthermore, we hope that the presentation of two inclusive dissertation projects conducted by PhD students can help other students and academic mentors better understand and plan for early-career inclusive research.

Research Projects and Positionality

The first author, Oscar, was conducting *The RISE Up Project* at the time this article was written (Hughes & Santinele Martino, 2023). The project is his current dissertation research as a PhD student at Boston University within Wheelock College of Education & Human Development. Oscar is a former special education teacher of students with extensive support needs who pursued a doctoral degree with the hope of promoting self-determination for youth and adults with intellectual and/or developmental disabilities. He was unaware of inclusive research when starting the PhD program–his interest in self-advocacy led him to learn about and decide to conduct inclusive research, to strive for self-determination in the design and outcomes of his dissertation project. Through his involvement and employment with the self-advocacy organization Massachusetts Advocates Standing Strong and because of his own identities within the LGBTQ+ community, Oscar became involved with the Rainbow Support Groups of

Massachusetts (WeAreMASS.org/rainbow), which is a program that provides support groups, training, and resources by and for LGBTQ+ people with intellectual and/or developmental disabilities. Oscar is a white gay transgender man who does not have an intellectual or developmental disability.

Developing a Peer Delivered Mental Health Intervention (Schwartz, Kramer, et al., 2020) was planned while the second author, Ariel, was a PhD student also at Boston University within the College of Health and Rehabilitation Sciences. Ariel had entered graduate school with the goal of learning inclusive research approaches with young adults with intellectual and/or developmental disabilities, and her PhD training was centered on this goal. Prior to the present research, she had experiences conducting inclusive research with her PhD mentor but had not led inclusive research at the onset of her dissertation. Ariel, herself, has no disabilities, and her interests in inclusive research stemmed from her background in Disability Studies and disability rights advocacy.

Both Oscar and Ariel attended Boston University in different departments, with Oscar beginning his graduate program the semester after Ariel had graduated. Of note, Ariel's PhD mentor used an inclusive research approach in her own work with young adults with intellectual and/or developmental disabilities. However, Oscar's PhD mentor was new to this approach, and Oscar largely drew upon the literature, including the work of Ariel, to guide his thinking about inclusive research. The authors met for the first time during the first year of Oscar's PhD program to discuss his emerging interest in inclusive research. At the time the current article was written, Ariel was serving as a member of Oscar's dissertation committee.

Comparing Planning Approaches

In the sections below, we describe how planning for inclusive research can involve initiating the project, determining team member characteristics and roles, building and sustaining relationships, preparing for accessibility in the research process, and planning inclusive research outcomes (Frankena et al., 2019; Nicolaidis et al., 2011). We draw from the inclusive research literature to justify the importance of these five components of planning inclusive research, then provide narrative examples comparing how each of our projects were planned. Finally, we discuss implications of the similarities and differences in our planning approaches and highlight planning considerations for future inclusive research projects.

Initiating the Projects

Inclusive research teams have documented a variety of approaches to initiating inclusive research projects. Many inclusive research projects are initiated at universities or governmental organizations by academically-trained researchers, who then recruit people with intellectual and/or developmental disabilities to serve as advisors to the project or as collaborators on the research team (Bigby et al., 2014; Frankena et al., 2019; Jones et al., 2020; Stack & McDonald, 2014). Projects that are initiated by academically-trained researchers and later recruit co-researchers may be less likely to address the needs and priorities of people with intellectual and/or developmental disabilities themselves, since the research topic and questions are often determined before co-researchers are brought on board (Stack & McDonald, 2014). In these cases, power imbalances and limited co-researcher ownership may be more likely, given the role of the academic

researchers in designing the project and selecting co-researchers (Stack & McDonald, 2018). However, this approach to initiating inclusive research is common because it is perceived as most compatible with requirements of research institutions (e.g., grant application timelines, funding availability, and IRB procedures; Barnes, 2003; Schwartz, Kramer, et al., 2020).

Inclusive research projects may also be initiated by individuals or groups of people with intellectual and/or developmental disabilities who are interested in exploring a particular topic, often for the purpose of social change (Bigby et al., 2014; Kidney & McDonald, 2014). When individuals or organizations of people with intellectual and/or developmental disabilities initiate research projects, these co-researchers often have power to set research priorities and ask research questions that are more relevant and more actionable than those of academic researchers (Frankena et al., 2019; Northway et al., 2014; Walmsley et al., 2018). The significance of co-researcher initiation has been described as especially important when co-researchers have multiple identities which have been historically marginalized and misrepresented in research (e.g., Black people with intellectual and/or developmental disabilities, trans and gender-diverse Autistic youth; Johnson et al., 2021; Strang et al., 2019).

Alternatively, there are some examples of inclusive research teams consisting of academic researchers and co-researchers with intellectual and/or developmental disabilities which form independent of research funding and then collaboratively pursue funding as a team (Stack & McDonald, 2014). For example, the Inclusive Research Network in Ireland funded by the National Federation of Voluntary Service Providers,

Trinity College, and University College Cork collectively identifies research topics and subsequently pursues funding (K. Johnson et al., 2014). Similarly, in Wales, Barod is a "Human Interest Company" that conducts research the team initiates and is contracted to do (Barod, n.d.). In the United States, the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) was founded by autistic and non-autistic researchers to conduct studies desired by Autistic communities (Nicolaidis & Raymaker, 2015). In these research teams, academic researchers and co-researchers with intellectual and/or developmental disabilities typically work together.

Although there are a variety of approaches to initiating inclusive research projects, in all cases, project initiation influences how research foci are identified, the formation of the research team, and how team member roles are established. These can subsequently impact how the research is conducted and the outcomes of the project. Our two inclusive research projects were initiated quite differently, which impacted the planning of our projects. *The RISE Up Project* was initiated by an organization of people with intellectual and/or developmental disabilities, while *Developing a Peer-Delivered Mental Health Intervention* was initiated by Ariel.

Initiating The RISE Up Project. *The RISE Up Project* was initiated by Pauline Bosma, the founder and coordinator of the Rainbow Support Groups of Massachusetts, a community organization led by and for LGBTQ+ people with intellectual and/or developmental disabilities. Oscar had been working with Pauline for over a year, co-leading training and assisting with the Rainbow Support Groups. During a work meeting with Oscar, Pauline stated that she was wondering about other projects her organization

could work on to support LGBTQ+ people with intellectual and/or developmental disabilities. At that time, Oscar was a second-year PhD student. He was broadly interested in research on self-determination, had just taken a course about participatory action research, and was starting to consider what his dissertation project might be. When Pauline brought up wanting to work on more projects to support LGBTQ+ people with intellectual and/or developmental disabilities, Oscar suggested that they collaborate on a research study. Pauline was interested in the idea, thus, *The RISE Up Project* was initiated by Pauline and the mission of her organization, supported by Oscar's suggestion and position as a doctoral student. If Oscar was not a researcher who was also Pauline's assistant and friend, it seems unlikely that Pauline would have looked for an academic research partner or conducted a research project. Although Oscar was not yet at the dissertation phase of his doctoral program, he was familiar with scholarship describing how inclusive research can often take longer than other approaches (Nind et al., 2016; Stack & McDonald, 2014; Walmsley et al., 2018), and thus was eager to start his dissertation research early.

Because the project began with Pauline's interest in improving the lives of LGBTQ+ people with intellectual and/or developmental disabilities, the design of the research study was centered on developing a subsequent action research project to improve quality of life for people with those identities. In this way, *The RISE Up Project* was planned from the beginning to have two stages: first, the initial qualitative study of the experiences and perspectives of LGBTQ+ adults with intellectual and/or developmental disabilities, and second, the action research project. Oscar and Pauline

proceeded to plan the first stage of the project knowing that they could not yet know the details for the action research project. They then engaged in a second round of planning for the second stage once the action research project was chosen.

Initiating Developing a Peer-Delivered Mental Health Intervention.

Conversely, Ariel's interests drove the initiation of the *Developing a Peer-Delivered Mental Health Intervention* project. This project aimed to address a gap in mental health services for young adults with intellectual and/or developmental disabilities by developing and delivering a peer-delivered psychoeducational intervention. Through Ariel's personal and research relationships with young adults with intellectual and/or developmental disabilities, she had observed the discrepancy between mental health needs and services for this group. Further, she had recently worked with her PhD mentor on a project exploring the mental health needs of young adults, which identified inadequate social supports and a lack of trained professionals (Kramer et al., 2019). She thought a solution to these challenges may be a peer-delivered mental health intervention. As Ariel was entering the dissertation phase of her education, she applied for external funding to develop a peer mentoring intervention to address service gaps. Because she had experience with and strong commitments to inclusive research, the grant application articulated the value of and adequately budgeted for a robust inclusive research process.

Both of our inclusive research projects were initiated because we personally valued inclusive approaches to research addressing topics relevant to people with intellectual and/or developmental disabilities. However, the two projects were initiated quite differently: *The RISE Up Project* was initiated after a conversation between Oscar

and a self-advocate leader who was asking questions about future directions for her organization, whereas *Developing a Peer-Delivered Mental Health Intervention* was initiated by Ariel based on her interest in addressing a service gap. The different approaches to initiating our projects influenced how our research teams formed and the characteristics of the co-researchers on our research teams.

Team Member Characteristics and Roles

Inclusive research literature suggests that team member characteristics and role clarification are essential and interrelated components of project initiation and team formation (McDonald & Stack, 2016; O'Brien et al., 2014; Puyalto et al., 2016). Conducting research will not be inherently motivating or a good match for all individuals – with or without disabilities. In community-initiated projects, co-researchers are often members of self-advocacy organizations or other advocacy groups, have leadership skills, and are experienced in identifying issues, working in teams, and problem-solving (Bigby et al., 2014; Garcia-Iriarte et al., 2009; Schwartz, Kramer, et al., 2020). As research may be a new experience to many, teams that recruit collaborators with intellectual and/or developmental disabilities may choose to recruit based on personal or professional experience relevant to the specific research topic, or self-advocacy experience (Schwartz & Durkin, 2020; Strang et al., 2019). In addition to lived experiences and skills, scholars have described how shared values are an important foundation for inclusive research teams (McDonald & Stack, 2016; Nind & Vinha, 2014; Schwartz, Kramer, et al., 2020). Recruiting collaborators solely on the basis of an intellectual and/or developmental disability diagnosis or identity may be tokenizing, as it can assume there is a universal

‘intellectual and/or developmental disability perspective,’ discount the importance of lived expertise, and may neglect to recognize the unique skills and motivations needed for research (Bigby et al., 2014; Nicolaidis et al., 2019).

Clearly communicating team member roles often occurs at the beginning of research partnerships. Shared understanding of roles is essential for working together and establishing mutual trust and respect (Frankena et al., 2019; McDonald & Stack, 2016; Nicolaidis et al., 2019). Team member roles may be driven by multiple factors, including team member characteristics (i.e., interests, skills, availability), funding (i.e., how much time the team can work together), study design, and IRB requirements (Ham et al., 2004; Nicolaidis et al., 2011). Within any inclusive research approach, team member roles may need to be adjusted as the research project progresses (Kim et al., 2022; Nind & Vinha, 2014).

Inclusive research teams have recommended fair compensation for co-researchers with intellectual and/or developmental disabilities, and transparency about how much and for which tasks they will be compensated (Kim et al., 2022; Nicolaidis et al., 2019). Team members who pursue funding for inclusive research projects should make a concerted effort to secure compensation for co-researchers with intellectual and/or developmental disabilities (O’Brien et al., 2022). In our experiences, the characteristics of co-researchers and team member roles were largely influenced by how our projects had been initiated and contextual factors.

The RISE Up Project Team. For *The RISE Up Project*, Oscar and Pauline agreed that Pauline would be one of the co-researchers because she had initiated the

research idea and was the founder and coordinator of the Rainbow Support Groups. They then planned to invite two other self-advocates who identified as LGBTQ+ persons with an intellectual and/or developmental disability, so they could speak from their personal experiences of different identities within these intersecting communities. Pauline already had someone in mind who held a leadership position within the Rainbow Support Groups and had expressed interest in getting more involved in advocating for LGBTQ+ people. They told this potential co-researcher about the grant application and possibility of working on the project if it was funded. Oscar suggested to Pauline that they also strive to include a self-advocate who was Black, Indigenous, or a person of color, so that they did not have an all-white research team, and Oscar had a few people in mind from the Rainbow Support Groups to reach out to.

Oscar determined the roles for the first stage of the project when he applied for an internal graduate student research grant. Oscar proposed that the funding be used to compensate the co-researchers and participants. He strove to pay co-researchers a high rate to represent the value of their contributions and chose a co-researcher stipend based on the grant amount and anticipated number of hours spent working on the project. The stipend was equal to about $20 per anticipated hour of work and was paid in two parts at the middle and end of the grant period. This payment schedule was at the request of the grant administration office.

Based on his understanding of IRB requirements, Oscar believed that any co-researchers interacting with human subjects and their identifiable information would need to complete the required human subjects research training, CITI Training. Oscar had

taken the training himself and felt that it was not designed to be accessible to people with intellectual and/or developmental disabilities (e.g., the training required reading large amounts of text, which included dense academic language). The small grant to which Oscar was applying would not have allowed for enough funding to compensate the co-researchers to complete the human subjects training or to meet for a substantial number of hours. Oscar also had concerns about the amount of time that the research project would take, especially as a student striving to complete and defend his dissertation within the timeline of his fellowship funding. For these reasons, he felt that asking co-researchers to complete the human subjects training and collaboratively develop the research design would take too long and be too expensive. Thus, Oscar proposed that Pauline and the two other co-researchers not directly engage in data collection and analysis during the first stage of the project, and Oscar would conduct the interviews and an initial analysis of the data. The role of the co-researchers during the first stage would be to provide suggestions and feedback on the interview protocol, engage in a secondary analysis of the deidentified data, and then have decision-making power to choose an action project for the second stage of research.

Oscar aspired for the action research project in the second stage to be more collaborative and to shift more direct control to the co-researchers. At that time, he did not know how the action project would be funded or its potential costs. He intended to apply for additional funding if needed when they reached the second stage in the project and did eventually apply for an internal diversity and inclusion program grant. For the second grant, Oscar proposed a higher stipend of $25 per anticipated hour of work,

because the co-researchers would have more involvement at this stage. Oscar spoke with Pauline about these ideas, and she was supportive of the research approach and subsequent action project collaboration. Later, once the co-researchers decided to write a guidebook as the action project, team members' roles were decided collaboratively by Oscar and the three co-researchers. For example, the research team later agreed that they would like all decisions about the guidebook to be made by consensus between all four members of the team.

The Developing a Peer-Delivered Mental Health Intervention Team. The *Developing a Peer-Delivered Mental Health Intervention* team formed quite differently. In the grant proposal, Ariel planned for co-researchers to have an active role in co-designing the intervention and collecting and analyzing data related to social validity. After intervention development, co-researchers would then serve as peer mentors.

These planned roles influenced the selection of co-researchers. Prior to funding, through relationships developed during volunteering and her PhD mentor's work, Ariel had secured the interest and support of community-based organizations and a school-based transition program for recruitment of co-researchers. After receiving funding, Ariel identified potential co-researchers by working with these community partners. Interested co-researchers completed an interview during which they learned about research and the research topic. Ariel's main priority was to identify co-researchers who were enthusiastic about the research topic, had the communication skills to eventually serve as a peer mentor, and had an interest in and personal connection to mental health. She assumed that if these characteristics were present, she would be able to provide accommodations

needed for each co-researcher. During interviews, applicants shared why they were interested in the topic, and completed two example research activities (providing feedback on materials and categorizing quotes). The purpose of these activities was to introduce the prospective co-researchers to the type of work they would be doing and for Ariel to observe foundational skills related to articulating opinions (critical for developing the intervention) and categorizing information (a skill related to data analysis). Additionally, as she knew she was asking co-researchers for a significant time commitment – 2 hours per week while developing the intervention, and up to 5 hours per week during peer mentoring – she therefore hoped to expose applicants to tasks they would do to help them make an informed decision about their involvement. After the interview, individuals had opportunities to discuss information with people who supported them and ask additional questions.

When selecting student research assistants to be on the team, Ariel sought individuals who had a strong understanding of disability rights and would be able to promote cognitive accessibility of materials and activities by breaking down tasks and rephrasing information. She also looked for research assistants who had the social skills to develop strong rapport with young adults with a wide range of interests and personalities.

When discussing team roles at the beginning of the study, Ariel emphasized the importance of lived expertise. Co-researchers understood that their role was to provide feedback based on their experiences and their beliefs about what other young adults with intellectual and/or developmental disabilities may experience, feel, and/or perceive. Ariel

explained her role as helping to make sure the team designed the intervention. Yet, she was also their employer, responsible for selecting co-researchers, paying them, and, at the request of some co-researchers' school staff, providing feedback on job performance. Thus, while Ariel attempted to shift power to the co-researchers by actively seeking and acting on their input, trialing all co-researcher ideas, and engaging in reflective practice to foster a sense of ownership in each meeting, she remained their employer and in a clear position of higher social capital. Co-researchers were paid $20 per hour for their work and their transportation was provided. She felt that paying the co-researchers this relatively high hourly rate (higher than her student research assistants) would demonstrate her value for their time and expertise. Compensation for transportation was an important way to promote accessibility. She budgeted for a wide range of transportation, including public transportation, paratransit, family/PCA transportation and parking, and rideshare.

In both of our projects, we largely determined the roles of the co-researchers as the academically-trained researchers, but also planned for opportunities for increased decision-making power throughout the projects. *The RISE Up Project* research team started with the self-advocate who proposed the research idea, and then planned to include two other self-advocates who they already knew and whose personal identities and experiences were relevant to the research topic. Therefore, the team member's characteristics played a role in how Oscar identified their roles. In contrast, Ariel's needs and pre-planned co-researcher roles drove her to identify specific characteristics needed in co-researchers. In *The RISE Up Project*, Oscar planned to conduct many of the

research activities himself and meet periodically with the co-researchers for suggestions and feedback at specific stages of the project. He then planned for the co-researchers to have decision-making power for the second stage of the project and to shift to a more collaborative process as they conducted their action research project. While Ariel planned for her team to collaboratively engage at each step through designing the intervention and interpreting findings, her institutional power, position as an employer, and overall leadership were clearly visible makers of unequal power. In both examples, our relationships with our research team also impacted how we planned our projects.

Building and Sustaining Relationships

The inclusive research literature emphasizes the importance of relationships between team members. Many inclusive research partnerships must grapple with inherent power imbalances, as people with intellectual and/or developmental disabilities may not have previously had access to the settings in which research is conducted (and as co-researchers, their access is still limited). Trust has been consistently highlighted as underpinning successful collaborations. Trust may be built and maintained through shared goals, following through on feedback/input, transparent communication, and spending informal time together as a team (Kidney & McDonald, 2014; Nicolaidis et al., 2019; Nind & Vinha, 2014; Schwartz, Kramer, et al., 2020; Stack & McDonald, 2018).

In some cases, prior relationships can be an asset to team members. Co-researchers may feel comfortable working with individuals they know from other settings and feel that their prior relationships with academic co-researchers and other co-researchers with intellectual and/or developmental disabilities are important for

teamwork (Chalachanová et al., 2020; Loeper & Schwartz, 2023; McDonald & Stack, 2016; Myers, in press). In other cases, prior relationships between academic researchers and co-researchers with intellectual and/or developmental disabilities have the potential to be coercive, as co-researchers may perceive personal or professional risks to withholding participation (Marshall et al., 2012). While Oscar's team all had existing personal and professional relationships, Ariel's team was composed of some people who knew each other and some who did not.

Relationships on The RISE Up Project Team. Before *The RISE Up Project* started, Oscar and Pauline had known each other for over a year. They met because they had facilitated training together, and then Oscar was hired by Pauline as her supporter; following her lead and assisting with the projects she coordinated. This relationship facilitated recruitment of the additional co-researchers, who Oscar and Pauline both knew. The additional two co-researchers had also received support from Oscar through their involvement in the Rainbow Support Groups. This facilitated trust and shared power on the research team because Oscar had already demonstrated a commitment to valuing self-advocates' perspectives, following their lead, and supporting projects they directed. Also, everyone on the research team was aware of their shared identities within the LGBTQ+ community, which was often a source of bonding between team members. Oscar feels that the fact that all four of the research team members already knew each other well and had positive relationships, helped facilitate honest and equitable communication on the research team.

Relationships on the Developing a Peer-Delivered Mental Health Intervention Team. Ariel felt strongly that the team needed to foster trust to work together, especially because they were likely to share personal experiences related to mental health. While Ariel had an existing relationship with one co-researcher, she had not met the remaining four prior to their interviews. Despite her broad recruitment efforts, all the co-researchers came from the same high school transition program. While one had graduated, the other four were currently in school together, and the team members had varying current and past relationships with each other. To facilitate trust within the team, each meeting began with an icebreaker. Ariel also ensured there was time to discuss day-to-day occurrences at the beginning of meetings and during breaks. This time to socialize fostered bonds between the co-researchers with intellectual and/or developmental disabilities and the academic researchers. Ariel also aimed to be transparent regarding all decisions and openly acknowledge her own mistakes and lack of knowledge to further facilitate trust between herself and the co-researchers.

Prior relationships (or the lack thereof) influenced how we planned our research projects. Given the newness of relationships within her team, Ariel intentionally devoted project resources to developing trust and shared experiences. She also made efforts to earn the trust of co-researchers. In contrast, *The RISE Up Project* commenced within the context of longstanding, trusting relationships. Therefore, while Oscar, worked to maintain trust, he did not have to plan activities and structures to build trust within *The RISE Up Project* team.

Preparing for Accessibility in the Research Process

Inclusive research literature has emphasized how accessibility of the research process can foster power sharing and is a requirement for co-researchers with intellectual and/or developmental disabilities to have opportunities to make meaningful contributions to the research project (Herer & Schwartz, 2022; Kidney & McDonald, 2014; Kramer et al., 2011; Marshall et al., 2012; Nicolaidis et al., 2019; Schwartz, Kramer, et al., 2020). Inclusive research scholars have published guidelines and toolkits that discuss strategies to prepare for access to the research process (Kidney & McDonald, 2014; Kramer et al., 2022; Nicolaidis et al., 2019; O'Brien, 2022; Preparing Individuals with IDD for Engagement in Research During Public Health Emergencies and Disasters Research Team, 2020). Some of these recommendations include: written information in plain language, synthesizing large quantities of data into themes, breaking down tasks, and sending materials to be reviewed in advance (O'Brien et al., 2014).

Scholars have also discussed how inclusive research teams may need supporters who facilitate the meaningful engagement of co-researchers, without controlling their involvement or overstepping their role (Bigby et al., 2014; Nind & Vinha, 2014). Some co-researchers with intellectual and/or developmental disabilities have discussed the value of training and guidance from academically-trained researchers so they could feel prepared and become more skilled and independent conducting research (Herer & Schwartz, 2022; Kramer et al., 2011; St. John et al., 2018). Ultimately, the accommodations, support, and training provided to co-researchers should be based on the individual needs and wishes of the co-researchers themselves. In both of our projects, we

took similar approaches to how we prepared for access to the research process, incorporating general accessibility strategies from the beginning (e.g., sending materials in advance, use of plain language, allowing time for processing information) and making accommodations throughout our projects based on the individual needs and wishes of members of our research teams. Below we each highlight just one example of how preparing for accessibility impacted how we planned a specific component of our projects.

Accessibility and The RISE Up Project. At the start of the second stage of *The RISE Up Project*, Oscar and the co-researchers collaboratively planned the research process based on the strengths, availability, and access needs of the team. Specifically, the team collaboratively developed an iterative process for writing the guidebook chapters. First, the co-researchers would share major points for the chapter and Oscar would take notes. Then, Oscar would write a chapter draft and the team would meet to read and edit the draft aloud. Each member of the team would nominate stakeholders from whom to solicit feedback on the chapters, and finally the team would meet to decide what feedback to incorporate into the guidebook.

Accessibility and Developing a Peer-Delivered Mental Health Intervention. Based on her previous experiences, Ariel knew that a potential barrier to co-researchers taking on roles in data collection, intervention delivery, and data analysis was the requirement for all co-researchers to complete university-approved research ethics training. Ariel and her PhD mentor has already conducted inclusive research at their university and had established a relationship with the IRB. Ariel engaged in discussion

with her IRB about the roles of co-researchers and it was decided that since no co-researcher would have primary responsibility for data, consent, and/or data collection (i.e., Ariel would be present for and overseeing all activities), it was appropriate for her to deliver a modified, accessible research ethics training to the team. She subsequently developed a training specific to the roles of the co-researchers on the project and provided it to the IRB for approval; it was approved without requests for modification.

Planning for Research Outcomes

Inclusive researchers have argued that research teams should thoughtfully consider how to disseminate their research in ways that are accessible and meaningful to both academically-trained researchers and to people with intellectual and/or developmental disabilities and their supporters (Garratt et al., 2022). However, time and conflicting priorities can be significant barriers to inclusive dissemination. For example, co-writing can be time consuming and may occur after funding has ended (Riches et al., 2020; Strnadová & Walmsley, 2018) and there is often little funding available for co-researchers to present their research at academic conferences (O'Brien et al., 2022). Consequently, co-researchers may be asked to engage in laborious work without compensation; and may subsequently decline the opportunity to co-write. Regardless of who writes academic articles about the research, these articles may be inaccessible to co-researchers because they are not written in accessible language or are published behind paywalls. Additionally, while academic researchers are incentivized to publish their findings in academic journals, co-researchers may not benefit from this activity. Planning for inclusive research dissemination can help to mitigate some of these barriers so

publications can be authored and presented inclusively (Frankena et al., 2019).

In addition to the immediate benefits of the research process and the dissemination of the findings to academic audiences, inclusive research teams should plan projects which contribute to sustained efforts toward long-term social changes desired by people with intellectual and/or developmental disabilities (O'Brien et al., 2022; Stack & McDonald, 2014; Walmsley et al., 2018). For example, inclusive research teams can plan for outcomes such as plain language texts, video presentations, advocacy actions, and/or art installations (K. Johnson et al., 2014; Jurkowski, 2008; Nicolaidis et al., 2019). As with any research partnership, it is ideal to plan authorship and outcomes at the beginning of the research study. These discussions may help teams identify meaningful products and prospectively plan for mutually beneficial dissemination processes and outcomes. Our projects took different approaches to planning for the outcomes of the research.

Planning The RISE Up Project Outcomes. Oscar wrote in the initial grant application that the study findings would be shared in multiple ways, including: (1) an academic research article, (2) a conference presentation, (3) a practice-centered article in a practitioner journal, and (4) an accessible summary and/or presentation for self-advocacy groups to post online. Additionally, because the research was initiated by Pauline and her ongoing work with the Rainbow Support Groups, we began to incorporate findings from the interview study into Rainbow Support Groups webinars and presentations as soon as we began analyzing the first interviews. Thus, the research was shared with the broader community throughout the project, long before we started

writing academic manuscripts. Oscar and Pauline planned for the co-researchers to develop an action project that they hoped would have a direct impact on LGBTQ+ people with intellectual and/or developmental disabilities. Because the purpose of the action project was to impact the broader community, sharing the research beyond an academic audience was inherent to the goals of the project from the beginning. In fact, the action research project eventually selected by the co-researchers was to write a free and publicly-available guidebook for families and professionals about supporting LGBTQ+ people with intellectual and/or developmental disabilities (now available at RainbowGuidebook.com). We planned to share the guidebook with members of the Rainbow Support Groups, disability service providers, state agencies serving people with disabilities, and local family organizations. We also planned for the guidebook to include information on joining and donating to the Rainbow Support Groups and how to hire LGBTQ+ self-advocates to deliver training, thus also promoting the growth of their organization and creating employment opportunities for people with intellectual and/or developmental disabilities.

Planning Developing a Peer-Delivered Mental Health Intervention Outcomes. Ariel did not plan for how the research would be shared with people with disabilities. She proposed to disseminate through academic manuscripts but did not anticipate how outcomes would be meaningful to people with intellectual and/or developmental disabilities beyond the development of an intervention that she hoped would fill a service gap and be socially valid. She did eventually work with the team to determine several accessible dissemination channels, giving each individual team member the option to

participate in podcasts, conference presentations, the production of a video hosted on YouTube, and academic manuscripts. However, none of these opportunities were discussed or planned at the onset of the project; rather, they were discussed as opportunities arose. Further, nearly all dissemination channels occurred primarily within academic venues, rather than settings that directly reached people with intellectual and/or developmental disabilities (e.g., self-advocacy groups/conferences, social groups, etc.) Had Ariel developed this project with the team from the start, likely they would have mutually identified valued outcomes, including meaningful dissemination outlets.

Discussion

Thoughtful planning is especially important to conduct projects consistent with the guiding principles of inclusive research. Research projects that are authentically inclusive plan for and strive to maintain meaningful engagement and decision-making power of co-researchers with intellectual and/or developmental disabilities. Additionally, inclusive research projects should address issues that are important to communities of people with intellectual and/or developmental disabilities, and should contribute to broader social change that improves the quality of disabled people's lives (Walmsley & Johnson, 2003). The ideal inclusive research plan is not simply to include people with intellectual and/or developmental disabilities as much as possible, merely for the sake of inclusion. People with intellectual and/or developmental disabilities should be included as researchers leading or contributing to inclusive research because they bring value to the questions that are asked, the ways that research is conducted, and the impact of research outcomes (Walmsley et al., 2018). As described in this article, projects that are

planned in diverse ways can strive to uphold these principles. We note that while planning is important, researchers should remain focused on purpose over pre-planning, and be prepared to adjust or abandon initial plans so that co-researcher engagement and social change remain central (Felner, 2020; Nind & Vinha, 2014).

In both of our inclusive dissertation research projects, we strove for trust, accessibility, and decision-making processes that facilitated shared leadership and authentic contributions to the processes and outcomes of the projects. However, our approaches differed by whom they were initiated, how co-researchers became involved, the roles of co-researchers, and the relationships among members of the research team. We also prepared differently for the outcomes of the research projects. As can be seen in our examples, contextual factors, such as funding availability, dissertation timelines, and IRB requirements, can impact how inclusive research projects are planned, and may limit the contributions and decision-making power of co-researchers with intellectual and/or developmental disabilities.

In both of our projects, relationships impacted all stages of planning. The centrality of relationships to inclusive research brings needed attention to the ongoing harms of the enduring exclusion of people with intellectual and/or developmental disabilities from society more broadly (Chalachanová et al., 2020). Unfortunately, persisting segregation of disabled people in our societies, especially from universities and research institutions, means that academically-trained researchers often do not have meaningful interpersonal relationships, let alone collaborative partnerships, with people with intellectual and/or developmental disabilities in their communities. Similarly,

because people with disabilities face barriers to forming and leading organizations, there are limited opportunities for partnerships with organizations of this type. Part of the work of furthering inclusive research is breaking down the cultural and structural barriers to the full community participation of people with intellectual and/or developmental disabilities in society that make truly mutual partnerships so difficult. Our experiences, and those of others (Loeper & Schwartz, 2023; McDonald & Stack, 2016; Shogren, 2023; Walmsley et al., 2018) suggest that in some cases, the strong relationships built during research may have the potential to help break down these barriers.

As we expect many inclusive research teams will relate to, planning inclusive research and conducting and disseminating that research can be two very different stories. Institutional policies and procedures can serve as systemic barriers to authentic engagement of people with intellectual and/or developmental disabilities in the research process (McDonald et al., in press; Shogren, 2023). In our examples, we can reflect on moments where institutional factors drove decisions that were not as collaborative as we had planned for. For example, Oscar had planned to meet with the co-researchers to collaboratively develop the second-round interview protocol, however, because there were limited grant funds left to compensate the co-researchers for meeting and because it could take weeks to receive the approved IRB amendment, Oscar wrote the second-round interview questions himself. Similarly, while Ariel intended to pay co-researchers for all time worked on dissemination, there was one dissemination opportunity that occurred after funding had concluded, which meant some co-researchers chose to engage in unpaid work. We wrestle with the tension of completing meaningful work with communities

while working within time-consuming academic structures. Conducting our projects within research institutions allowed us to access grants and gave us the time to work on these projects, but we wonder if these projects would have benefitted and moved forward more quickly if they occurred outside of research institutions.

Research teams planning inclusive research should discuss the benefits and drawbacks of limiting co-researcher involvement due to systemic barriers versus challenging those barriers. For example, we hope some research teams decide, based on their timelines and funding, to engage in education and advocacy to try to improve the accessibility of human subjects training or to pursue institutional approval of alternative, accessible training. We understand that many teams may decide instead to base team member roles on the existing human subjects training requirements. With open dialogue about the research partnership goals and potential barriers to collaboration, teams can collaboratively determine if and when to direct their resources toward breaking down these barriers. We encourage academic researchers to continue to identify barriers to inclusive research and to advocate for systemic changes that could improve inclusive research planning, such as extending grant application and funding timelines, supporting faculty service in community organizations, and expanding university hiring of co-researchers with intellectual and/or developmental disabilities.

Future Research and Limitations

This manuscript describes just two inclusive research projects. Other teams will have different experiences and perspectives, given their unique context(s), team members, and goals. Furthermore, we did not empirically evaluate how our planning

processes impacted inclusive research processes or outcomes, nor did we include the voices or reflections of the co-researchers on our teams. As inclusive research becomes more common, we hope there will be sufficient resources and teams to conduct empirical research on the inclusive research planning approaches that contribute to authentic inclusive research processes and further the goals of people with intellectual and/or developmental disabilities. For example, longitudinal observational designs could help identify how different approaches to initiation–by whom (i.e., by academics or people with disabilities) and when (i.e., before or after submission of grants)–influence decision making and power as research progresses. Other studies may evaluate how teams work together when co-researchers are or are not paid and how co-researcher recruitment is impacted by the availability of hourly vs. full-time/benefited jobs. These efforts should be conducted inclusively, so the voices and experiences of co-researchers drive procedures, targeted outcomes, and resultant actions.

In our short careers to date, we have already observed a growth of inclusive research and increased capacity of academic researchers and co-researchers with intellectual and/or developmental disabilities (Jones et al., 2020; O'Brien, 2022). The literature available to our projects was more extensive than that available to inclusive researchers before us, and we expect our own work may soon appear outdated as the science and practice of inclusive research continues to grow and realize its potential to bolster the power of people with intellectual and/or developmental disabilities. While existing principles, frameworks, and guidelines have been crucial in the development of our own inclusive research projects, we have both found that there cannot exist one

universal framework for planning inclusive research, as the planning and adjusting of inclusive research projects should always reflect, by its very nature, the purposes and process of each unique research project. We found mentorship helpful in tailoring our approaches to our specific teams and projects. We encourage those new to inclusive research to connect with mentors and resources in the growing field of inclusive research, and for those with experience in inclusive research to support the emerging community of inclusive research scholars.

Conclusion

Planning inclusive research projects involves thoughtful consideration of project initiation, team member characteristics and roles, relationships, accessibility, and outcomes. There is not a one-size-fits-all approach to planning inclusive research; many paths can lead to meaningful collaborations between academic researchers and co-researchers with intellectual and/or developmental disabilities with outcomes that meaningfully impact the lives of people with disabilities. We look forward to continued growth in the scholarship of inclusive research and practices that further break down systemic barriers to research engagement. We are hopeful that commitment to the principles of inclusive research, with support from a growing field of inclusive research mentors, will continue to contribute to a more inclusive and equitable society.

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

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" and states that, "self-determined people (i.e., causal agents) act in service to freely chosen goals" (Wehmeyer, 2020). Self-determination research has confirmed what self-advocates continue to argue: that 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).

Self-determination does not require that a person with an intellectual or developmental disability is able to clearly demonstrate independent decision-making in all aspects of their life. People with disabilities who have significant support needs, including those with limited communication abilities, can be self-determined when they receive support based on their interests and preferences (Brock et al., 2020; Wehmeyer, 2005). Efforts to ensure access to self-determination are ongoing, as people with intellectual and developmental disabilities continue to encounter laws and policies, as well as individual family members and service providers, that limit their decision-making

control and prevent them from striving for their goals (Shogren et al., 2015; 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 to 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, how to style their hair) and if, how, and with whom to be in intimate relationships. Gender and sexual self-determination are especially important for people with intellectual and developmental disabilities who are LGBTQ+[9]. Unfortunately, research examining the experiences and perspectives 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, their gender and sexual identities, and their other sociocultural identities (e.g., race, class, language; McCann et al., 2016; Santinele Martino, 2017).

[9] I use the initialism "LGBTQ+" to refer to people who have diverse gender and sexual identities which transgress heterosexual and/or cisgender norms. This refers to people who identify as lesbian, gay, bisexual, transgender, and/or queer or who are questioning their gender and sexual identity. The "+" is to refer to a myriad of other gender and sexual identities, such as pansexual, asexual, intersex, and non-binary, to include people who are creating new gender and sexual identities to describe themselves, and for people who defy or transgress the identification of their gender and sexuality altogether. Additionally, because this article centers the experiences of people with intellectual and developmental disabilities, I include under the LGBTQ+ umbrella, people who may not directly communicate an LGBTQ+ identity *in those terms*, but they otherwise express their gender or sexuality outside of heterosexual or cisgender normative expectations.

Although no studies have focused on gender and sexual self-determination specifically, researchers who have examined the life experiences of LGBTQ+ adults with intellectual and developmental disabilities have highlighted some of the ways in which members of this community face restrictions and barriers to expressing their gender and sexual identities (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 instead of a valid way of being (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 people 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 sexuality education, it rarely adequately addresses the educational 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 especially 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 sexual identities, 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 because 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 gender and sexual identities under the LGBTQ+ umbrella (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 in their lives. Consequently, 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 Pauline

Bosma, the founder and coordinator of the Rainbow Support Groups of Massachusetts, to learn more about supporting LGBTQ+ people with intellectual and developmental disabilities. All research procedures were approved by the Boston 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 created a guidebook for caregivers, such as family members and disability service providers, about supporting LGBTQ+ people with intellectual and developmental disabilities (available at RainbowGuidebook.com). 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 youth and adults 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.

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 participant group, 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.

Table 1

Participant Demographic Data

Characteristic		Frequency
Age		
	18-29	8
	30-39	6
	40-49	6
	50-59	2
	60-69	1
State		
	Massachusetts	4
	New York	4
	Rhode Island	3
	Illinois	3
	Vermont	2
	Oregon	2
	California	1
	Connecticut	1
	Michigan	1
	Ohio	1
	Virginia	1

Gender Identity	
Cisgender man	11
Transgender man	2
Cisgender woman	2
Non-binary	2
“Female, I guess”	1
Demiboy	1
Transgender woman	1
Half and half	1
Genderqueer	1
(Not specified)	1
Sexual Identity	
Gay	13
Pansexual	2
Asexual	2
Bisexual	1
Queer	1
Homoflexible	1
Lesbian	1
Pansexual demisexual aromantic	1
(Not specified)	1
Disability	
Autism/Autism, with other disabilities	11
Intellectual disability	4
Cerebral palsy	4
Down syndrome	2
ADHD, with other disabilities	1
William syndrome	1
Racial and/or Ethnic Identity	
White or Caucasian	15
Black or African American	3
Biracial, Black and White	2
Hispanic/Latino and White	1
Irish and Puerto Rican	1
Pakistani Muslim American	1

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, peer debriefing, researcher reflexivity, 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. Peer debriefing 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 sexual identity due to fear of rejection, the co-researchers shared their own varying experiences of being rejected for their LGBTQ+ identity and hiding their identity from others. I also engaged in peer debriefing by soliciting critical feedback on the thematic analysis from experienced qualitative researchers in disability and gender and sexuality studies who were members of my dissertation committee. I 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). 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 (see Figure 1) and share how they could present barriers or facilitators to gender and sexual self-determination. Within each theme, the recommendations I describe come directly from the participants.

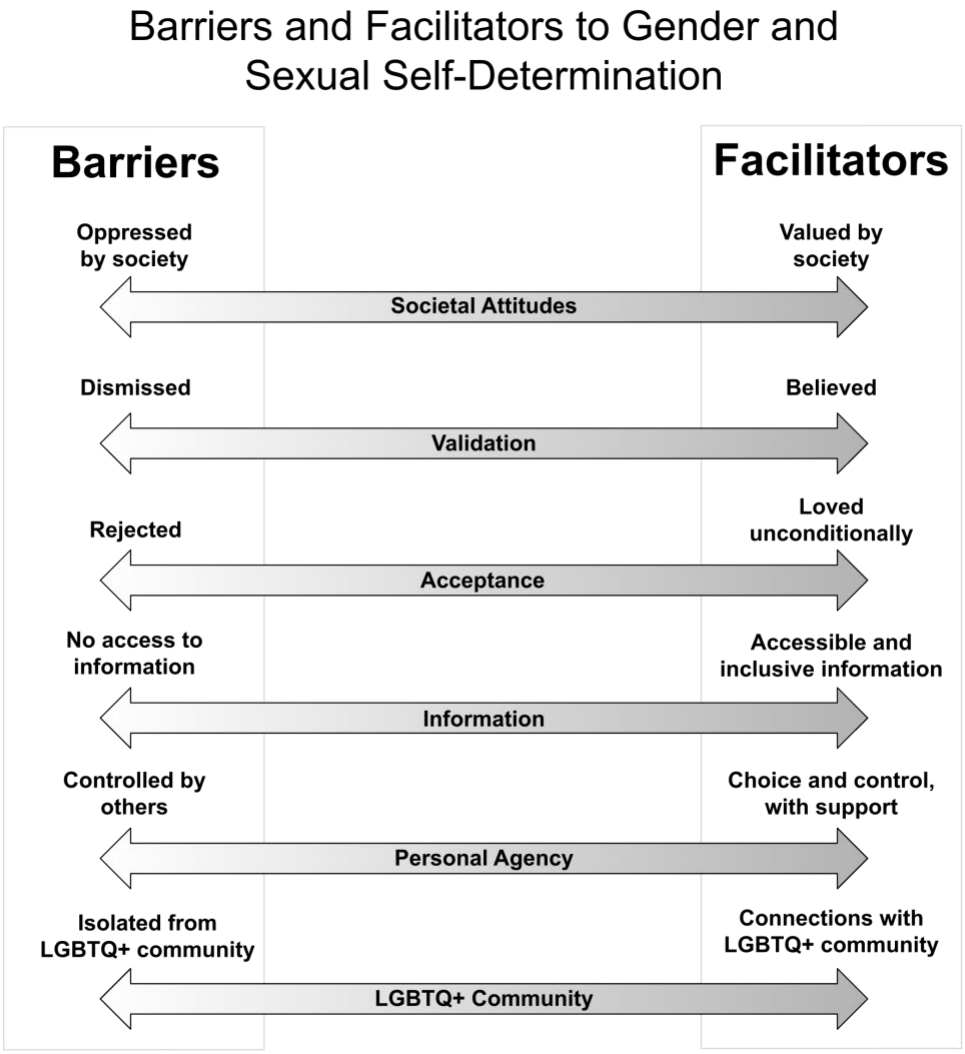
Societal Attitudes

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.

Figure 1

Continuums of Barriers and Facilitators to Gender and Sexual Self-Determination



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 sexual identity 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. You can help and support in ways that are age appropriate for them to be able to express their sexuality.

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.

Alex and Andy, who had been in a relationship with each other since high school, described one teacher who knew they were in a relationship. They described the teacher's

reaction to their relationship as, “fantastic, always super supportive. Made her classroom really safe.” Because of this teacher’s reaction, Alex shared, “[This teacher] was the second person I ever came out to as trans.” 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 sexual identities. 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 sexual identities. 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 a gay friend who helped him have fun gay experiences,

> He took me to a bathhouse[10] and I experienced what a bathhouse is all about…And then him and his good friends took me to P-town[11], 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 their 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

[10] Gay bathhouses are public baths frequented by gay and bisexual men, commonly visited for sexual activity (Bérubé, 2003).
[11] Provincetown, MA, often referred to as P-town, is known for its gay residents and LGBTQ+ tourism (Krahulik, 2007).

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).

Inclusive research scholars have argued that inclusive research approaches have the potential to prevent researcher misinterpretation and lead to meaningful outcomes shared beyond academic audiences which promote the needs and priorities of people with disabilities (Bigby et al., 2014; 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 and perspectives, 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

Unfortunately, research about the lives of LGBTQ+ people with intellectual and developmental disabilities has failed to include diverse perspectives, often including all or mostly white participants who do not have significant support needs. The current study is the largest study to-date which has described the lived experiences of LGBTQ+ adults with intellectual and developmental disabilities in the United States and 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. The participants were from specific regions of the United States which are generally more accepting of

LGBTQ+ identities (e.g., the Northeast) and all participants were out as LGBTQ+ to at least 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 approaches and stories of lived experience can promote gender and sexual self-determination in the lives of LGBTQ+ people with intellectual and developmental disabilities. 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 leads to meaningful outcomes which can improve quality of life for disabled people.

Conclusion

In examining the experiences of gender and sexual self-determination in the lives of LGBTQ+ adults with intellectual and developmental disabilities, information accessibility, personal agency, and connection with the LGBTQ+ community played pivotal roles in the participants' journeys of gender and sexual self-determination. Many

participants described the impact of knowledge, 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 practical supports, which emphasizes the influence of caregivers and support systems in the self-expression of people with intellectual and developmental disabilities. Moreover, participants' shared narratives underscore the importance of validation and connection, suggesting that fostering inclusivity within the LGBTQ+ community can improve their lives. As these stories emphasize, 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.

CHAPTER FOUR – Community-Based Participatory Gender and Sexualities Research with LGBTQ+ People with Intellectual and/or Developmental Disabilities

Oscar E. Hughes

Department of Teaching and Learning, Wheelock College of Education & Human Development, Boston University, Boston, MA, United States

https://orcid.org/0000-0003-4722-5832

ohughes@bu.edu

26 Andrew Street

Cambridge, MA 02139

631-487-4571

Alan Santinele Martino

Assistant Professor, Department of Community Health Sciences, University of Calgary, Calgary, AB, Canada

https://orcid.org/0000-0002-2270-3482

alan.martino@ucalgary.ca

3330 Hospital Dr NW

Calgary, AB T2N 4N1

403-220-6484

Abstract: In this article, we discuss practical lessons for promoting meaningful collaboration in inclusive and community-based participatory gender and sexualities research with LGBTQ+ people with intellectual and/or developmental disabilities. First, we describe the historical and ongoing exclusion from research engagement of people with intellectual and/or developmental disabilities and the importance of including LGBTQ+ people with intellectual and/or developmental disabilities in inclusive and community-based research projects that address gender and sexuality. Then, we provide reflections on how we are striving to embrace core principles of community-based participatory research in our current gender and sexualities research projects. Finally, we end with a call to action for future meaningful and collaborative research that addresses gender and sexuality in the lives of people with intellectual and/or developmental disabilities.

Keywords: gender; sexuality; intellectual disability; developmental disability; inclusive research; participatory action research; qualitative methods

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Introduction

People with intellectual and/or developmental disabilities[12] continue to be excluded from meaningful engagement and participation in all stages of research (Howell & Shogren, 2019; McDonald et al., 2013; Santinele Martino & Fudge Schormans, 2018). This exclusion is magnified when research endeavors seek to address gender and sexuality, and to understand the experiences and perspectives of LGBTQ+[13] people with disabilities (Santinele Martino & Fudge Schormans, 2018). Qualitative gender and sexualities research in collaboration with co-researchers and advisors with intellectual and/or developmental disabilities has the potential to recognize gender and sexual diversity and improve supports and services, thus promoting gender and sexual self-determination in the lives of people with intellectual and/or developmental disabilities (McCann et al., 2016; Smith et al., 2022; Strang et al., 2019). Drawing from core principles of community-based participatory research (Israel et al., 2011), we strive to provide practical guidance on engaging in accessible and collaborative gender and

[12] We understand that there is no one agreed-upon term to describe people with and people who have been labeled with intellectual and/or developmental disabilities and that language preference can vary greatly based on geographical location and self-advocacy networks. For the purposes of this article, we use the term "people with intellectual and/or developmental disabilities" to refer to people who identify as or who have been labeled with an intellectual disability, developmental disability, or both. We use the term "people labeled/with intellectual and/or developmental disabilities" when specifically discussing the second author's *Queering Disability Project* because this is the terminology used by his research team. Ultimately, we believe that everyone should have opportunities to define and describe their own individual identities and experiences for themselves.

[13] We use the initialism "LGBTQ+" to refer to people who have diverse gender and sexual identities which transgress heterosexual and/or cisgender norms. This refers to people who identify as lesbian, gay, bisexual, transgender, and/or queer or who are questioning their gender and sexual identity. The "+" is to refer to a myriad of other gender and sexual identities, such as two-spirit, pansexual, asexual, intersex, and non-binary, to include people who are creating new gender and sexual identities to describe themselves, and to refer to people who defy or transgress the identification of their gender and sexuality altogether.

sexualities research with LGBTQ+ people with intellectual and/or developmental disabilities. Specifically, we describe finding shared community, building on strengths, facilitating collaborative partnership, and promoting empowerment. We hope the perspectives shared in this article can support future inclusive and community-based participatory research projects that address topics of gender and sexuality, and support gender and sexual expression in the lives of people with intellectual and/or developmental disabilities.

Historical and Ongoing Exclusion

Traditional research approaches have denied self-determination to people with intellectual and/or developmental disabilities. Historically, people with disabilities have been the target of exploitation and dehumanization in research, often treated as experimental 'subjects' (McDonald et al., 2013; Santinele Martino & Fudge Schormans, 2018; Wehmeyer, 2013). The perspectives of people with intellectual and/or developmental disabilities have been commonly excluded from the literature based on the ableist notions that they are incapable of providing meaningful narratives, unable to make informed decisions of their own and provide consent, or simply too vulnerable to participate in research (Howell & Shogren, 2019; McDonald et al., 2013). These ableist notions have led to institutionalized forms of gatekeeping, such as barriers to research participation codified by Institutional Review Boards (IRB; McDonald et al., 2015; Santinele Martino & Fudge Schormans, 2018). For example, IRBs may label people with intellectual and/or developmental disabilities as "lacking capacity to consent" and require the consent of court-appointed guardians, while failing to ask for information about

accessibility and community involvement of people with disabilities throughout the research process (Flicker et al., 2007; Howell & Shogren, 2019). Subsequently, researchers often seek other people, such as family members, teachers, and direct care workers, to speak for disabled people (Kelly et al., 2009).

The issue around gatekeeping is further accentuated by the fact that many adults with intellectual and/or developmental disabilities have court-appointed guardians (approximately 40% in the U.S.; National Council on Disability, 2018). When an adult with an intellectual and/or developmental disability has a court-appointed guardian, IRBs often require the consent of the court-appointed guardian for the adult to participate in research (Howell & Shogren, 2019). Although this process is intended to protect the rights of research participants, it also has the potential to deny agency to people with disabilities, introduce additional risk, and prevent people with disabilities from sharing their perspectives on stigmatized topics that guardians may feel uncomfortable with (Santinele Martino & Fudge Schormans, 2018). There are widespread ongoing advocacy efforts of people with intellectual and/or developmental disabilities to remove unjustified guardianships and create more agentic alternatives to guardianship (Howell & Shogren, 2019; Jameson et al., 2015). Thus, requiring guardianship consent in all research projects does not reflect this advocacy and instead denies agency to disabled people.

When people with intellectual and/or developmental disabilities are considered eligible for research participation, the accommodations available to them may be insufficient for them to meaningfully share their perspectives and experiences (e.g., written surveys may not be accessible to some people with intellectual and/or

developmental disabilities who do not read or write independently; Kidney & McDonald, 2014; McDonald et al., 2013). Also, people with intellectual and/or developmental disabilities have often been excluded from accessing research findings, as research is often published in academic journals and written in academic jargon, which is inaccessible to many people with intellectual and/or developmental disabilities.

This ongoing exclusion from research participation is often magnified when projects focus on topics considered to be sensitive, such as sexuality, intimacy, and pleasure (Santinele Martino & Fudge Schormans, 2018). People with intellectual and/or developmental disabilities are often mischaracterized as "perpetual children" and infantilized, and thus misperceived as requiring protection from research which includes discussions of sexuality (Azzopardi-Lane & Callus, 2015). Guardianship barriers to conducting or participating in research are especially relevant for gender and sexualities research, which includes topics that may be considered taboo or concerning by some court-appointed guardians (Kammes et al., 2020; Sinclair et al., 2015). Historically, caregivers have had more space to discuss experiences of gender and sexuality compared to people with intellectual and/or developmental disabilities themselves (Santinele Martino & Fudge Schormans, 2018).

Despite this exploitation and exclusion, people with intellectual and/or developmental disabilities have expressed that, if there is trust and accessibility, they are interested in participating in and conducting research that could improve quality of life for people in their communities (Kramer et al., 2011; Nind & Vinha, 2014; Schwartz, Kramer, et al., 2020; St. John et al., 2018), including research about gender and sexuality

(Santinele Martino & Fudge Schormans, 2018; Strang et al., 2019). Inclusive and community-based participatory research approaches, specifically, have the potential to recognize gender and sexual expression in the lives of people with intellectual and/or developmental disabilities, promote relevant and valued supports and services, and ultimately improve quality of life through gender and sexual self-determination (McCann et al., 2016; Smith et al., 2022; Strang et al., 2019).

Inclusive and Community-Based Participatory Research Approaches

Inclusive research is an umbrella term to describe a range of research approaches in which people with intellectual and/or developmental disabilities collaborate with researchers with academic training as advisors or co-researchers on projects that impact their communities (Walmsley & Johnson, 2003). *Participatory research*, one such inclusive research approach, is premised on 1) centering issues that matter to historically marginalized communities; 2) including and acknowledging their contributions; and 3) respectfully engaging with these communities throughout the research process (Baum et al., 2006; Walmsley & Johnson, 2003). Similarly, community-based participatory research is premised on engaging in research collaboration, with an emphasis on engaging with communities to address their research questions and promote meaningful social change within their communities (Minkler & Wallerstein, 2011). The core principles of community-based participatory research include (1) recognizing community as an aspect of identity, (2) building on the strengths of communities, (3) engaging in collaborative partnerships, and (4) promoting empowerment, among others (Israel et al., 2011). Inclusive and community-based participatory research approaches are consistent

with the advocacy efforts of people with intellectual and/or developmental disabilities to serve as "decision makers and planners" in issues that impact their lives (Self Advocates Becoming Empowered, 1996-1997).

Inclusive and community-based participatory research approaches can make "research more collaborative and relevant" (Nind, 2014, p. 525) and bring the skills of academic researchers and people with intellectual and/or developmental disabilities together, "to generate new knowledge that neither group could do alone" (Bigby et al., 2014, p. 8). Inclusive and community-based participatory research approaches also emphasize the necessity of research that leads to concrete and meaningful action that can improve material conditions for the community engaged in the collaboration (Bradbury-Huang, 2010). Community-based participatory research projects emphasize action to promote social change in both the process and outcomes of the research project, and build capacity and empowerment in communities, while addressing relevant and valued research questions. (Fine et al., 2021; Kincheloe et al., 2011; Stack & McDonald, 2018). Additionally, community-based participatory research approaches create the potential for research collaborations in which collaborators with multiple historically marginalized identities, such as LGBTQ+ disabled people who are Black, Indigenous, or people of color, can bring unique insights that recognize complex contributors to structural racism and oppression (Chmielewski et al., 2016; Yull et al., 2018). Knowledge and action resulting from the research collaboration can then be shared in accessible and practical ways within local communities in addition to circulation within academic communities.

Inclusive and Community-Based Participatory Gender and Sexualities Research

Inclusive and community-based participatory research approaches are especially important for research endeavors that seek to address lived experiences related to gender and sexuality. Due to the enduring misperception that people with intellectual and/or developmental disabilities are uninterested or unable to have sexual lives, little extant research examines their experiences or perspectives on this topic (Brown & McCann, 2018; Ditchman et al., 2016; Friedman et al., 2014). Consequently, there continues to be a lack of relevant and accessible resources and supports that promote gender and sexual expression for people with intellectual and/or developmental disabilities (Atkinson et al., 2022; Brown & McCann, 2018; McDaniels & Fleming, 2016).

Recognizing Gender and Sexual Diversity. As Santinele Martino (2017) has noted, the "pervasive heteronormativity in most of the literature, coupled with the assumption that disabled people cannot identify as queer, has obscured the rich array of sexualities among individuals with disabilities" (p. 1). It is crucial for research to center the experiences and perspectives of LGBTQ+ people with intellectual and/or developmental disabilities themselves. This can facilitate our understanding of the unique and complex experiences of individuals with intersecting LGBTQ+ and disability identities, and to develop better supports and resources that promote gender and sexual self-determination (Blanchett, 2002; Santinele Martino, 2017; Strang et al., 2019). In their discussion of community-based participatory design research that impacts autistic gender-diverse people, Strang et al. (2019) noted the importance of the perspectives of autistic gender-diverse people in research projects related to their lives. The authors, many of whom were autistic co-researchers, describe the potential for non-autistic and

non-gender-diverse researchers to misinterpret the complex identities and experiences of their community. Collaboration with LGBTQ+ adults with intellectual and/or developmental disabilities throughout the research process is more likely to prevent misinterpretation and address the priorities of their community. For example, while most studies on autism and gender diversity have focused on rates of co-occurrence, research collaboration with community members has led to projects that emphasize their experiences and meeting their support needs.

Addressing the Lack of Supports and Services. People with intellectual and/or developmental disabilities, including those with LGBTQ+ identities, commonly face a lack of services and resources that appropriately address their needs and experiences (McCann et al., 2016; Santinele Martino, 2017; Sinclair et al., 2015; Smith et al., 2022; Wilson et al., 2018). They rarely have an opportunity to access spaces that are queer and sex-positive and that are accessible, and thus, many have reported feeling socially isolated and having to negotiate their identities with limited community support (Lewis et al., 2021; Santinele Martino, 2017; Wilson et al., 2018). In addition, caregivers, including family members and disability service providers, may struggle to support people with disabilities when it comes to sexuality due to discomfort and lack of resources (Atkinson et al., 2022; McCann et al., 2016; Smith et al., 2022). Many LGBTQ+ people with intellectual and/or developmental disabilities rely on supports and services from caregivers who hold heteronormative and cisnormative assumptions, express negative attitudes toward LGBTQ+ identities, or place limits on their gender and sexual expression (Kafer, 2003; McCann et al., 2016; Smith et al., 2022). We hope the following

insights from our ongoing inclusive gender and sexuality research projects can contribute to efforts to address this lack of supports and services by providing practical guidance that promotes inclusive and community-based participatory gender and sexualities research.

The Rainbow Inclusion Speaking Up (RISE Up) Project

The first author, Oscar, is a former high school special education teacher of students with intellectual and/or developmental disabilities, who is currently pursuing a PhD in special education. As a gay transgender teacher, he is especially passionate about promoting access to gender and sexual expression for youth and adults with disabilities. In this article, he shares lessons learned based on his ongoing qualitative dissertation project examining the experiences and desired supports of LGBTQ+ adults with intellectual and/or developmental disabilities in the United States. His research occurs in collaboration with a team of three LGBTQ+ co-researchers with intellectual and/or developmental disabilities, whom he knew from previous work with a local self-advocacy organization. The research project began when one of the co-researchers voiced interest in learning more about supporting LGBTQ+ people with intellectual and/or developmental disabilities. Oscar then completed an IRB application to form *The Rainbow Inclusion Speaking Up (RISE Up) Project* and received two small graduate student grants from his university to compensate the co-researchers and participants. The co-researchers then began meeting monthly in September 2021, where they developed the interview protocols. Oscar conducted the interviews and organized the findings into major themes with representative quotes and vignettes and presented these to the co-

researchers. Based on the interview findings, the co-researchers decided they wanted to create a training manual for caregivers, such as family members and disability service providers, about supporting LGBTQ+ people with intellectual and/or developmental disabilities. The research team continues to meet monthly to collaboratively write the chapters to be included in the training manual, which will then be made publicly available and distributed online for free. (The training manual is expected to be available beginning in May 2023 at WeAreMASS.org/rainbow.) Oscar and the co-researchers regularly co-lead training and presentations to share the research findings.

The Queering Disability Project

The second author, Alan, is currently an assistant professor in a disability studies program. He is openly queer and disabled and, as a community member and a community-based researcher, he has built long-standing relationships with community organizations supporting disabled and LGBTQ+ people. He is currently leading a qualitative research project focused on the intimate lives of 2SLGBTQ+ people labeled/with intellectual and/or developmental disabilities in Canada. Prior to that, based on discussions with self-advocates and service providers, he conducted an exploratory, qualitative study to gain preliminary insights into the sexual experiences of gay, lesbian, and bisexual people labeled/with intellectual disabilities. The research team for his current project includes the principal researcher, two service providers (one from the disability services sector and another that provides services to queer and trans youth), two queer people labeled/with intellectual disabilities who serve as advisors, and two research assistants. Honoraria for the two advisors on the team was included in the project budget

from the start. This is both in recognition of the contributions of disabled people to the research project and the fact that people with disabilities in Canada are more likely to be living under poverty lines compared to nondisabled people (Crawford, 2013). The team has worked collaboratively in all aspects of the research process, from conceptualizing the aims and scope of the project, to co-producing an interview guide that is written in plain language and addresses everyone's questions. The team meets on a regular basis, sometimes all together at the same time, sometimes in smaller groups. The deliverables from this project will include traditional material (e.g., publications, conference presentations), as well as more wide-reaching ones (e.g., free-of-cost webinar, infographics, resource lists).

Practical Reflections for Conducting Inclusive Gender and Sexualities Research

Below we discuss how we strive to embrace core principles of community-based participatory research in our ongoing inclusive gender and sexualities research projects. We focus our reflections on details which we feel are unique to gender and sexualities research projects in collaboration with people with intellectual and/or developmental disabilities. We discuss specifically: (1) finding community through shared identities, values, and trust (2) building on community strengths and resources, (3) maintaining collaborative partnerships, and (4) promoting empowerment. We believe these reflections provide practical lessons to support collaborative and impactful future studies in this area.

Shared Community

Shared values and identities provide the necessary foundation for trust and collaboration in our inclusive research projects with LGBTQ+ people with intellectual

and/or developmental disabilities. Throughout *The RISE Up Project*, familiarity, enduring relationships, and shared LGBTQ+ identity have promoted Oscar's trusting connections with his research team and participants. Oscar feels that he was better able to establish a sense of trust and equality with the research team because of his demonstrated commitments to providing support and following their lead on past projects, and his enthusiasm for a project guided by their perspectives (Schwartz, Kramer, et al., 2020). In the preparation of this article, the co-researchers shared that because professionals in their lives have come and gone so frequently, they find it especially difficult to trust new people who claim to be supporters. *The RISE Up Project* co-researchers appear more comfortable participating on the research team and sharing their perspectives honestly because Oscar had already demonstrated a level of trustworthiness. Oscar has also been open about his own gay and transgender identities, which has been a source of solidarity and understanding between the members of the team. Similarly, many of the interview participants knew Oscar was LGBTQ+ or asked if he was and expressed feeling more comfortable because they shared identity within the LGBTQ+ community. That said, Oscar does not have an intellectual and/or developmental disability, which may have limited trust and understanding with his co-researchers and participants. Inclusive research projects in which co-researchers with intellectual and/or developmental disabilities conduct data collection have the potential to further promote trust and solidarity between researchers and participants.

As Alan has consistently noticed throughout his work, it is also important to build a sense of shared community with other social actors who often can act as gatekeepers in

the lives of disabled people, such as family members, legal guardians, and service providers. At times, researchers seeking to conduct research focused on disability and sexuality are confronted with hesitation and even suspicion from caregivers and service providers (see, for example, Santinele Martino, 2022a). The research participation of disabled people can be highly influenced by the views, and sometimes even court-appointed decision-making power, of caregivers. Gaining the trust of gatekeepers, especially gatekeepers of a social group that is often considered to be vulnerable, can be essential to ensure collaboration with and participation of disabled people in research. Disabled people themselves may sometimes rely on these other social actors to understand recruitment material, facilitate communication with researchers, support with transportation, and provide a space for research engagement. In his research practice, Alan has, at times, met with parents and siblings, for example, to clarify the purpose of the study and offer them an opportunity to ask questions. Due to protectionism from family members and other caregivers, the recruitment of people with intellectual and/or developmental disabilities can be challenging (Santinele Martino & Fudge Schormans, 2018); however, having relationships with service providers and family-led groups can be crucial in facilitating access to potential participants. In fact, many participants in *The RISE Up Project* had heard about the study from supportive service providers to whom they had disclosed their LGBTQ+ identity. Of course, ultimately, it is important that people with intellectual and/or developmental disabilities and are not pressured or forced to participate and make their own decisions about whether to conduct and participate in research.

Building on Strengths and Resources

Building on the strengths and resources of community partners in inclusive research means seeing people with intellectual and/or developmental disabilities as capable and insightful people who can make meaningful contributions to knowledge and action as researchers and research participants. Unfortunately, barriers to engagement and participation in research persist. For instance, in one of his previous projects on disability and sexuality, Alan was asked during a full ethics committee board meeting if people labeled/with intellectual disabilities would be "able to give [you] any good data at all." Instead, this board member suggested he was "highly encouraged to speak with the parents or support workers" of disabled people instead. At multiple occasions, it took Alan months to gain ethics approval, requiring pages and pages of written responses and cited literature, endless emails, phone calls, one-on-one meetings, and full board meetings.

Adults with intellectual and/or developmental disabilities with court-appointed guardians may wish to share their perspectives on gender and sexuality, and improve gender and sexuality supports and services, but may not feel comfortable or safe disclosing this research topic to their court-appointed guardians. Thus, mandating guardian consent may introduce unnecessary additional risks or limitations for research projects addressing the gender and sexual lives of people with intellectual and/or developmental disabilities. In fact, Oscar has worked with LGBTQ+ adults with intellectual and/or developmental disabilities whose court-appointed guardians did not know they were LGBTQ+ or who were unsupportive or antagonistic toward their

LGBTQ+ identity. Thus, requiring guardian consent could mean that some participants are either forced to disclose their LGBTQ+ identity to obtain consent to participate, or denied the opportunity to participate by unsupportive guardians. Arguably, it is especially important that we understand the struggles and support needs of LGBTQ+ adults whose decision-making is controlled by guardians who are unaware or unaccepting of their gender or sexual identity.

***The RISE Up Project* IRB Process.** In the case of *The RISE Up Project*, through discussion of these issues, Oscar and the IRB were able to develop a research protocol that we feel presumed competence and honored agency and privacy, while reducing risks and safeguarding well-being, and ultimately allowed for the waiver of court-appointed guardian consent in particular circumstances. First, the IRB determined that if the person can demonstrate the ability to consent to participate in a specific research activity, the consent of the participant's court-appointed guardian is not required. Then, Oscar developed a consent process that was designed to be accessible to potential participants and attuned to possible misunderstanding or hesitancy about the project. If Oscar observed any of the specified signs that the participant did not or could not provide informed consent, then the participant could include their guardian in the informed consent process. If the participant did not have a court-appointed guardian or felt that informing their guardian about the study could jeopardize their well-being, then informed consent was waived and the participant could give assent with an assent monitor they designated (e.g., a familiar supporter or a local disability advocate). The role of the participant's chosen assent monitor was to attend during the assent process, monitor for

any signs of confusion or coercion, help clarify the study description, and provide advice to the participant. Study participation was then ultimately decided by participant assent. This was based on an important resource from the self-advocacy movement, Supported Decision-Making, an alternative to guardianship where adults with intellectual and/or developmental disabilities can designate trusted supporters when making their own decisions (Howell & Shogren, 2019; Jameson et al., 2015). We feel that this process provides a useful model for future collaborative partnerships, to prevent unnecessary risk and safeguard co-researcher and participant well-being, while adapting to individuals' support needs and promoting agency and privacy. (See Figure 2 for a detailed graphical representation of the approved consent/assent process; contact the first author with additional questions about this process).

Collaborative Partnership

Empowerment for truly collaborative partnership is facilitated by shared leadership and accessibility (Schwartz, Kramer, et al., 2020; Stack & McDonald, 2018). Inclusive research teams have published guides and toolkits on engaging in collaborative partnerships with people with intellectual and/or developmental disabilities, with recommendations on sharing power and accessibility (see Kidney & McDonald, 2014; Nicolaidis et al. 2019; O'Brien, 2022; Preparing Individuals with IDD for Engagement in Research During Public Health Emergencies and Disasters Research Team, 2020). Use of accessible language is important to inclusive gender and sexualities research with collaborators with intellectual and/or developmental disabilities. Research materials should use language access strategies when necessary, such as plain language and easy-

read text, pre-meetings to prepare for research team collaboration, reading materials aloud, and/or including visual supports (see the Supplementary Material for example plain language and visual materials from *The RISE Up Project*).

In addition to general language access strategies, we recommend that research teams expand their use of language to describe gender and sexuality as to not marginalize people who may have unanticipated ways of discussing their gender and sexual identities and experiences. To illustrate how one can never take meanings for granted, in a previous study conducted by Alan focused on the romantic and sexual lives of adults labeled/with intellectual disabilities, when a participant was asked if he had ever had sex, he quickly replied, "no." Yet, as the interview continued, the participant shared that he had previously "made love" with someone. This was a reminder to the researcher of the importance of understanding how participants make sense of sex and sexuality from their own standpoint.

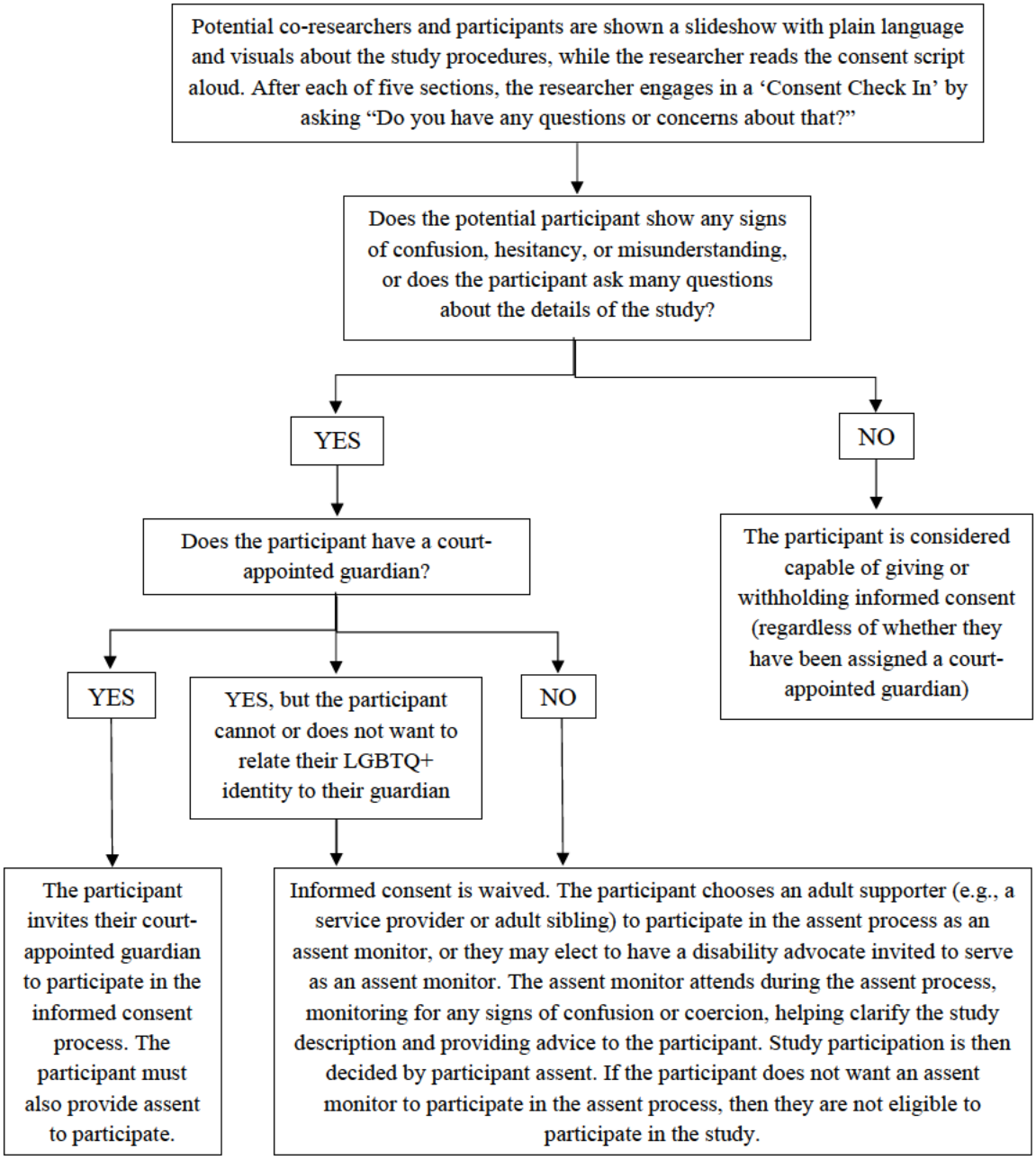
We also know that the ways communities discuss gender and sexuality can vary, and that this can be influenced by social identities and experiences, such as race, class, and access to formal education. There is much variation in language use within the LGBTQ+ community (e.g., there continue to be class and generational differences in perceptions and usage of terms such as 'gay', 'queer', 'transgender', 'transsexual', and 'non-binary'; Bragg et al., 2018; Robertson, 2019; Valentine, 2007). Valentine (2007), for example, documented the ways in which the experiences of gay-identified poor people of color have been erased by white scholars and public health officials who labeled them as "transgender." People with intellectual and/or developmental disabilities

may not communicate about gender and sexuality using terminology that academic researchers or social movements use.

Both authors have consistently seen how people with intellectual and/or developmental disabilities frequently face a "limited menu of possibilities that rarely includes LGBT[Q]+ identities," which means that some people may not have the vocabulary or may not use expected vocabulary to articulate their queer desires or trans identities (Santinele Martino, 2021, p. 15). For example, when Oscar asked participants, "What is your gender identity?", one participant replied, "I never think about that, gender identity. Like male or female?" Oscar responded, "Yeah, some people say male or man or female or woman." The participant then described herself as, "I could be half and half, I could say that" and explained, "I feel like a woman inside of me. I know I look like a guy. I know I was a guy. Now I feel like a woman." This participant did not identity as transgender or non-binary, and did not appear familiar with the terms, even though her identity could be perceived as meeting definitions of those identity terms. Instead, she had her own way of putting her gender into words. To provide another example, a few transgender participants, when describing their gender identity, stated that they *were* a certain sex or were *born* a certain sex, rather than using the terminology of *sex assigned at birth*, which is common among academics engaged in gender and sexualities research (Cahill et al., 2014; GenIUSS Group, 2014).

Figure 2

The RISE Up Project **IRB-approved consent/assent process**



Promoting language access within gender and sexualities research means avoiding assumptions or expectations about the words that people use or understand, and instead learning the ways in which people describe and define themselves. As is arguably the case in gender and sexualities research more broadly, inclusive researchers should be careful not to expect or enforce specific ways of describing or understanding gender and sexuality, which could limit the self-expression of co-researchers and participants with intellectual and/or developmental disabilities. Using multiple-choice surveys or questions with limited options, for example, can restrict the possibilities of how people can define who they are. Instead, we suggest that researchers strive to understand how individuals and communities describe themselves and to use this vocabulary to communicate effectively with collaborators, without judgment.

Co-Learning and Empowering

Most often, studies addressing gender and sexuality in the lives of people with intellectual and/or developmental disabilities focus on deficits and disparities and offer little acknowledgment or celebration of the strengths and joy in their gender and sexual lives. For example, recent research in sexuality education has documented vulnerability to abuse and lack of sexual knowledge experienced by adults with intellectual and/or developmental disabilities (Brown & McCann, 2018; Sinclair et al., 2015). Similarly, research which has examined the lives of LGBTQ+ adults with intellectual and/or developmental disabilities has detailed the restriction, isolation, and violence they have experienced (McCann et al., 2016; Smith et al., 2022). While we do not doubt the accuracy or importance of these findings, we know that these stories of limitations and

struggle do not fully represent the gender and sexual lives of people with intellectual and/or developmental disabilities. The centrality of lack and strife in current research contributes to the ongoing dominance of deficit-based perspectives of people with intellectual and/or developmental disabilities and reinforces assumptions of dependence and perceptions of pity. More importantly, these negative understandings of gender and sexualities can become internalized by people with intellectual and/or developmental disabilities. For example, in an interview with a young man with an intellectual disability, Alan heard from the participant: "Well, we talked [in sex education class] about the parts, the different parts of the male and the female. About what STDs, what STIs, what transmitted diseases are. I think we talked about everything. *What sexuality is all about*" (Santinele Martino, 2022b, p. 463, emphasis added).

What often remains missing in these current discussions is attention to positive aspects of gender and sexuality in the lives of disabled people, including conversations about sex, pleasure, and desires, and the creative strategies disabled people employ that demonstrate their agency. We have both been fortunate to witness the strength, creativity, and joys of people with intellectual and/or developmental disabilities within our own work, and we have caught glimpses of this represented sporadically within existing literature. For example, studies have made mention of the resourcefulness of youth with intellectual and/or developmental disabilities whose sexual expression was restricted (McClelland et al., 2012) and the resilience and self-love that LGBTQ+ adults with intellectual and/or developmental disabilities have created for themselves despite harassment and violence (Dinwoodie et al., 2020; Tallentire et al., 2020). Unfortunately,

these positive expressions of gender and sexuality have rarely been centered in the design or analysis of research related to the gender and sexual lives of people with intellectual and/or developmental disabilities. We argue that engaging in gender and sexuality research should highlight strengths and joy in the lives of people with intellectual and/or developmental disabilities, and that collaboration with people with intellectual and/or developmental disabilities has the potential to acknowledge and celebrate those experiences more authentically.

In *The RISE Up Project*, for example, in addition to understanding the ongoing struggles within their community, the co-researchers were interested in learning about the positive support that LGBTQ+ people with intellectual and/or developmental disabilities have already received. This led to the inclusion of interview questions such as, “Is there anyone in your life who accepts you? How do you know they accept you?” In response, participants shared successes and celebrations from their lives. For example, one interview participant explained, "My mom is very supportive. She buys me everything rainbow whenever she gets the chance.” and another described, “My parents were very, very, very accepting. And they said to me, they said, ‘We don't care what you are, as long as you're healthy. And you're happy.” Our findings in this area have been especially meaningful, as they provide specific and compelling models of what an accepting supporter looks like, which have practical implications for improving the lives of LGBTQ+ people with intellectual and/or developmental disabilities, and thus will be included throughout our training manual project. Another interview question which helped us to celebrate queer joy in our work was, “What makes you feel happy or proud

to be LGBTQ+?" Many participants detailed reasons they felt happy and proud as a LGBTQ+ person with intellectual and/or developmental disability, such as feeling free to be their true selves, practicing self-love, and making a difference for others. For example, one Autistic participant stated about what makes him happy to be gay, "Many different things. Just a lot more freedom and kissing lots of men." The co-researchers suggested we include these messages in accessible resources for people with intellectual and/or developmental disabilities so they can see that being an LGBTQ+ person is not only full of struggles, and that many people are happy to be out and live their truth.

We feel that centering these perspectives is not just more authentic and valuable, but also necessary for the empowerment of inclusive research teams. When *The RISE Up Project* team began to analyze the themes in our research findings, the co-researchers experienced much despair and hopelessness when discussing the many struggles that participants had recounted. In fact, at one point during a research meeting the discussion of struggles became so upsetting that we decided to pivot to an analysis of themes of strengths and joy for the remainder of that meeting. Centering themes of positive support and pride meant that our team felt revitalized and motivated to continue the work of improving the lives of LGBTQ+ people with intellectual and/or developmental disabilities.

The impact of this co-learning on the researchers with university affiliation cannot be overlooked either. As the second author has articulated in a previous publication (Santinele Martino, 2022a), research at the intersections of disability, gender, and sexualities can be a transformative process:

> Doing this type of work has challenged me, in positive ways, to interrogate my own (dis)comfort with talking openly about sexuality. It has (thankfully) forced me to learn about evidence-based information related to sexuality, to build a refined vocabulary, and get to a position where I could say the word "sex" with the same tone as when I say "food." This work has undoubtedly enriched my own life as a sexual being and sexualities scholar (p. 7).

Our hope is to see more qualitative research that examines strengths and joy in the gender and sexual lives of people with intellectual and/or developmental disabilities. Some examples of this could be studies of sexual expression which include stories of participants' pleasure and fulfillment in their sexual lives, narratives that highlight how people with intellectual and/or developmental disabilities have creatively navigated expression of their gender despite the restrictions that have been placed on them, and examples of how disabled people are "cripping" sexualities by challenging and transforming normative understandings of gender and sexuality (McRuer & Mollow, 2012; Santinele Martino & Fudge Schormans, 2021).

Conclusion

Engaging in inclusive and community-based participatory research about gender and sexualities in collaboration with people with intellectual and/or developmental disabilities creates possibilities for disrupting misunderstandings of disabled people's sexualities and instead recognizing their ability to contribute to knowledge production. By working together with advisors and co-researchers with intellectual and/or developmental disabilities, we have found that our work has been significantly enriched,

that dominant assumptions about language, ability, consent, and voice have been challenged, and that, mostly importantly, our research projects have been made more relevant and accessible to those whose lives are most affected by the issues we are exploring in our projects.

We have described how some of the core principles of community-based participatory research are reflected in our ongoing inclusive gender and sexualities research projects. In addition to future inclusive and community-based participatory gender and sexualities research, we hope to see scholarship which adds to and/or critiques the work we have presented here. For example, the perspectives of researchers with intellectual and/or developmental disabilities themselves bring great value to discussions of inclusive research approaches, and we hope to see more literature which reflects their experiences and perspectives engaging in gender and sexualities research specifically. Additionally, we have discussed the value of inclusive research approaches, but were not able to adequately address potential unintended consequences of inclusive research approaches, such as tokenism or the appropriation of inclusive approaches to maintain inequitable power structures (Bigby et al., 2014; Jordan, 2009). The potential for inclusive gender and sexualities research to reinforce dominant oppressive narratives of gender, sexuality, and disability is a necessary area of critical discussion in the pursuit of the intended purposes of inclusive and community-based participatory research.

Self-advocates have long advocated for "nothing about us, without us" in research endeavors (Charlton, 1998), and people with intellectual and/or developmental disabilities have emphasized the importance of being seen as knowers and having an

opportunity to speak for themselves (McDonald et al., 2015). Having the opportunity to represent oneself and be an active partner in research, as well as being able to speak on one's own behalf, are important aspects of intimate citizenship, which as Plummer (1995) explains, refers to our "rights to choose what we do with our bodies, our feelings, our identities, our relationships, our genders, our eroticisms and our representations" (p. 17). Inclusive and community-based participatory research can be one of the many ways in which we create space for intimate citizenship in the lives of people with intellectual and/or developmental disabilities. Our hope is that our work and others' future inclusive research projects can help shed light on the unique experiences, challenges, and triumphs in the gender and sexual lives of disabled people, and lead to meaningful social change.

CHAPTER FIVE – Conclusion

Inclusive research projects should promote meaningful engagement of people with intellectual and developmental disabilities throughout the research process for the purpose of social change that can improve their lives (Garratt et al., 2022; Walmsley & Johnson, 2003). Through thoughtful planning, built on trust and shared decision-making, The RISE Up Project centered the lived experiences of LGBTQ+ people with intellectual and developmental disabilities to design an actionable project to share beyond academic audiences. By striving to honor the principles of inclusive research, our project had a direct impact on positive social change in the lives of LGBTQ+ people with intellectual and developmental disabilities. We were able to create a valued resource that brings visibility to the co-researchers' and participants' complex identities and experiences to improve understanding and support for their communities.

However, we also encountered structural barriers to conducting meaningful inclusive research. For example, the IRB required that researchers interacting with human subjects complete mandated research ethics training that did not have accessibility features for researchers with intellectual and developmental disabilities. Additionally, the available grant funding to compensate the research team was small and had a short timeline. In response to these factors, I decided to conduct all interviews myself, instead of collaborating with the research team to collect interview data. Co-conducting interviews with co-researchers could have led to more authentic and relevant research data and provided an opportunity for the co-researchers to hone skills valuable to their work outside of this project (Nind et al., 2016; St. John et al., 2018). Inclusive research

scholars should continue to challenge structural barriers so that meaningful inclusive research partnership is possible. This includes sustaining partnerships between academically-trained researchers and people with intellectual and developmental disabilities, creating accessible research ethics training, and providing grant funding and grant timelines compatible with conducting inclusive research and sharing the outcomes (McDonald & Schwartz, 2023; Riches et al., 2020; Shogren, 2023).

Based on interviews with LGBTQ+ adults with intellectual and developmental disabilities and feedback from supporters and educators, the research team created The Rainbow Guidebook, which is now publicly available online for people with intellectual and developmental disabilities and their supporters to access. Since its release, The Rainbow Guidebook has been sent to disability professional and special education mailing lists, shared in state and national disability services newsletters, and posted to various social media platforms. The resource is viewed frequently, having received over 23,000 page views during the first six months it was available, from May to November 2023. We have received messages from direct service providers, disability professionals, educators, family members, and self-advocates from across the United States and Canada who have read the resource and used the information to promote gender and sexual self-determination for people with intellectual and developmental disabilities. For example, we recently heard from a school psychologist in New York who looks at the guidebook stories with her students with intellectual disabilities to show that joyful LGBTQ+ adult lives are possible, an LGBTQ+ support group in Minnesota that read and discussed The Rainbow Guidebook together, and a professor of special education in Florida who assigns

The Rainbow Guidebook for pre-service teachers to read so they can better work with LGBTQ+ students with disabilities. The co-researchers on the team have also been invited by disability service provider agencies, universities, and LGBTQ+ organizations to present on The Rainbow Guidebook. We are enthusiastic to write more chapters, post more self-advocate stories, and further share The Rainbow Guidebook so it can continue to spread understanding and support for LGBTQ+ people with intellectual and developmental disabilities.

Our interview findings also led to the qualitative study where I report barriers and facilitators to gender and sexual self-determination in the participants' lives. These findings provide specific, practical information about barriers to gender and sexual self-determination that must be challenged. By resisting traditional rigid beliefs about gender and sexuality and valuing and accepting gender and sexual diversity, LGBTQ+ people with intellectual and developmental disabilities will have more opportunities to express their authentic selves. Additionally, the participants described how we must improve access to information about gender and sexuality, respect personal agency, and facilitate connections and accessibility within the LGBTQ+ community. This study highlights important implications for improving direct supports, laws, and policies to promote gender and sexual self-determination.

Upon reflection, I identified practical methodological lessons which I hope give valuable insight for future inclusive gender and sexualities research projects with LGBTQ+ adults with intellectual and developmental disabilities. I reflect on how shared values and identities created a foundation for trust and collaboration and how creative

approaches to consent and the IRB process allowed me to presume competence and honor co-researchers' and participants' agency and privacy. Additionally, I believe that inclusive gender and sexualities research endeavors are strengthened when research teams recognize expansive use of language to describe gender and sexual diversity and celebrate the joy of co-researchers and participants to empower their teams to take action. Ultimately, The RISE Up Project informed future inclusive research, challenged dominant assumptions about language, ability, and identity, and, mostly importantly, was accessible, relevant, and impactful to the lives of LGBTQ+ people with intellectual and developmental disabilities.

APPENDIX A – Round One Interview Protocol

Hello! Thank you for agreeing to do this interview with me. I have some questions to ask you about being an LGBTQ+ person with a disability. You get to decide what you want to talk about. If something feels too personal or private, you can decide not to talk to me about it; it's up to you. You can skip any of the questions if you want to. Remember, your answers are confidential. I will share with other people what we talked about, but I won't tell them that it was you.

The plan is to talk for about 1 hour. I will record your voice but not video. If you decide you want to stop the interview, just let me know and we can stop any time. Does that sound okay with you? Is it okay for me to start the voice recording?

Demographic questions

These questions are about who you are. It's up to you if you want to give your personal information. You can skip the questions if you want.

1. What state do you live in?
2. Do you live in a big city or do you live in a small town?
3. How old are you?
4. What is your race or nationality?
5. Can you tell me a little bit about your disability?
6. What is your gender?
7. When I write an article later on about the interviews, what pronouns would you like me to use to refer to you?
8. What is your LGBTQ+ identity?

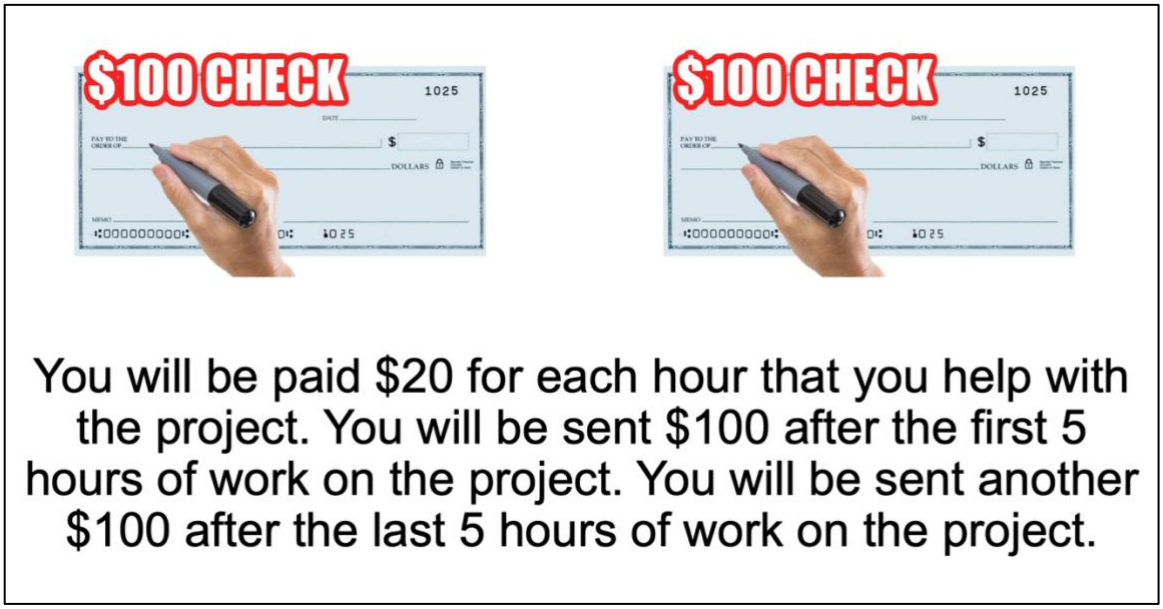
LGBTQ+ and IDD Questions

1. What was it like for you coming out as an LGBTQ+ person?
    - Tell me a story about someone who supported you when you came out.
    - What did they do to show their support?
2. Is there anyone in your life who accepts you? How do you know they accept you?
3. Is there anyone in your life who does not accept you? How do you know they do not accept you?
4. What were your experiences like in school?
    - Was it difficult to be an LGBTQ+ person with a disability when you were in school?

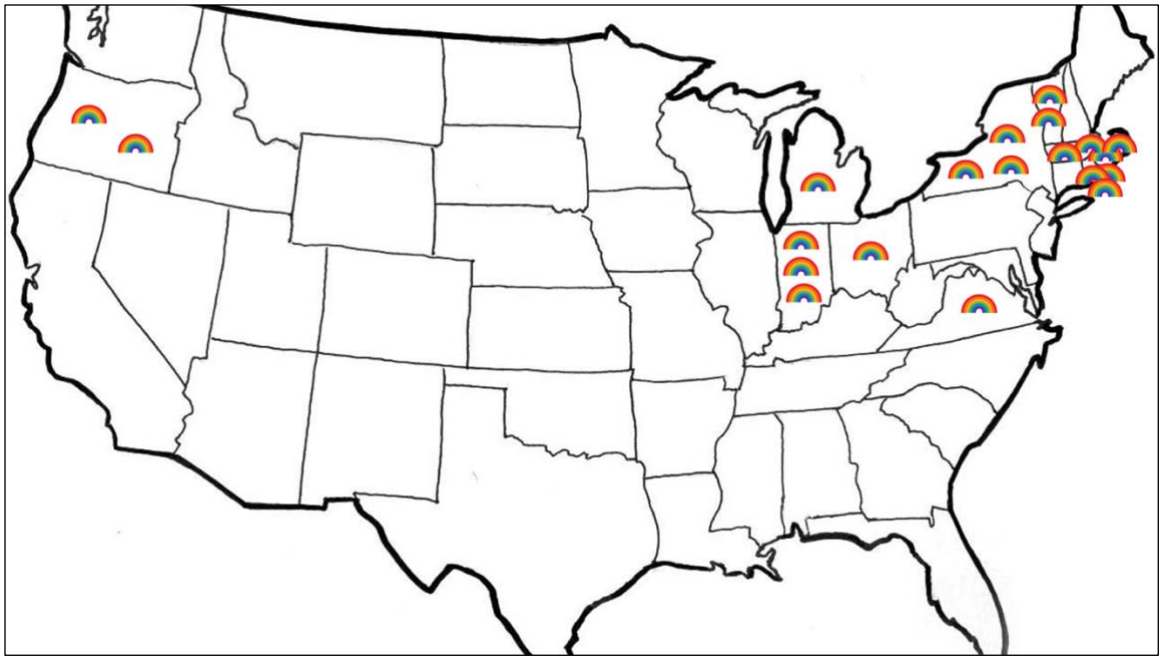
5. Are you dating or interested in dating? How have your experiences with dating been?
    - Has anyone tried to stop you from dating?
    - Has anyone supported you with dating?
6. Is there anything that is hard about being an LGBTQ+ person with a disability? What is hard?
7. Have you been to a Rainbow Support Group? What was your experience like?
8. Do you go places to meet other LGBTQ+ people (online or in person)? Where do you meet other LGBTQ+ people? How do you feel there?
9. Who supports you in your life?
    - Do you have the support and resources you need?
    - How do you get support when you need it?
    - Is there any support you wish you had that you are not getting?
    - What supports do you need that you don't have?
10. How is your health and well-being?
    - When you feel down or upset, what do you do to feel better?
    - Is there anyone who supports you when are feeling down or upset?
11. Has anyone ever treated you unfairly for being an LGBTQ+ person with a disability?
    - What happened?
    - Have you been treated poorly by a professional because you are an LGBTQ+ person with a disability?
12. We are trying to design a project that will help LGBTQ+ people with disabilities to have better lives. What do you think would help LGBTQ+ people with disabilities to have better lives?
13. Tell me a memory when you felt happy or proud to be LGBTQ+?
    - What else do you like about being LGBTQ+?
14. Is there anything else you would like to add?

APPENDIX B – Chapter Four Supplementary Material

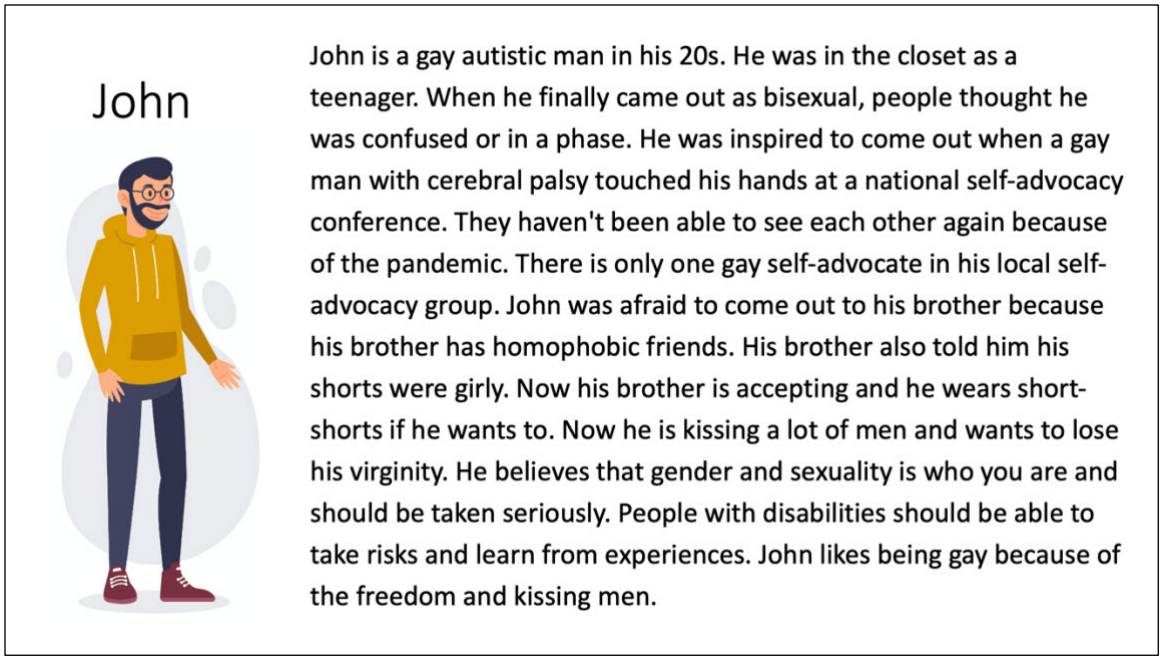
Examples of plain language and visual materials used in *The RISE Up Project*



Example 1: The image above shows one slide about co-researcher compensation from the visual slideshow shown to *The RISE Up Project* co-researchers during the consent/assent process. For the consent/assent process, Oscar read a consent/assent script aloud while showing slides consisting of plain language and visuals. The script and slides contained phrasing that was simple and direct, complex ideas broken down into short sentences, and images to promote understanding.



Example 2: The image above was presented in a slideshow to *The RISE Up Project* co-researchers during the data collection phase to visually represent the interview participants' home state demographic data. Each rainbow icon represents one participant and the state where that participant was from. The purpose of this slide was to provide an accessible summary of the location demographics to the co-researchers and discuss recruitment.



Example 3: *The RISE Up Project* interviews resulted in 253 pages of typed transcripts, which was not an accessible format to present the research data to the co-researchers. Oscar created a slideshow of shortened, plain-language vignettes based on individual participant stories and experiences. The image above shows one of the vignettes which was shown and read aloud during a team meeting for *The RISE Up Project*. The purpose of these vignettes was to support data analysis. Specifically, the co-researchers reviewed multiple vignettes to discuss common themes and individual differences between participants' stories and experiences. Image by pikisuperstar on Freepik.

APPENDIX C – Round Two Interview Protocol

Thank you for your interest in doing a second interview. Remember, you get to decide if you want to do this interview. It is okay if you change your mind and decide not to be interviewed. You can skip questions if you do not want to answer. I will record your answers so I can I write down what we talked about. I will use your answers to work on our project, but I will not tell anyone that it was you. After the interview I will send you another $25 gift card. Does that still sound okay?

Based on the 20 interviews we did with you and other people last year, we decided we are going to write a guidebook to teach parents and professionals about how to support LGBTQ+ people with I/DD. The guidebook will have information about gender, sexuality, and disability. We will include stories from LGBTQ+ people with disabilities.

1. What topics should someone learn about if their job is to support LGBTQ+ people with I/DD? What topics should we include in our guidebook?
2. If someone's job is to support people with I/DD, what should they do if someone comes out to them as LGBTQ+?
3. What are some things that LGBTQ+ people with I/DD might need help with?
4. What should a parent do to show they support their LGBTQ+ child?
5. What do you think sex ed classes should teach for LGBTQ+ people with I/DD?
6. Can you tell us about a time that you had to speak up for yourself about your gender or sexuality? For example, a time when you needed to advocate for yourself to a family member, teacher, or coworker?
7. Is there anything else you want to say?

Would you want to write a short personal story about being an LGBTQ+ person with a disability to put into our guidebook? (Yes or No)

In a few months we are hoping to record some YouTube videos of LGBTQ+ people with disabilities sharing their stories. Do you want me to email you later with more information about possibly being in a YouTube video? (Yes or No)

APPENDIX D – Rainbow Guidebook Flyer

The Rainbow Guidebook

for LGBTQ+ and Intellectual and Developmental Disabilities

Written by LGBTQ+ self-advocate leaders based on interviews with LGBTQ+ adults with intellectual and developmental disabilities from across the United States.

- Information about gender and sexuality
- Quotes and personal stories
- Advice on how to support us
- A statement of our human rights
- Tips for sex educators
- A letter to families and friends
- Resources and handouts

Available for free online

Rainbow Guidebook.com

Our Lives, Our Choices, Our Rights!

MASS

Massachusetts Advocates Standing Strong

Rainbow Groups

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