

“Assisted Autonomy” and Sexual Rights for Individuals
with Down Syndrome

by

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Certificate of Approval

This is to certify that the accompanying thesis by Georgia Rose Seltzer has been accepted in partial fulfillment of the requirements for graduation with Honors in Politics.

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Abstract

Individuals with Down Syndrome have too often been left out of sexual narratives and misrepresented by societal norms to be antithetical to the autonomous being. By analyzing both the autonomy and rights frameworks in tandem with the experiences of employment and housing opportunities, I argue that “assisted autonomy” increases access to sexual rights for individuals with Down Syndrome. “Assisted autonomy” refers to one’s ability to make decisions or act with the assistance, but not force, of a support system. In the case of Down Syndrome sexuality, this includes accessible sex education, facilitated consent, and sex surrogacy. This thesis hopes to begin the process of shifting the harmful perceptions of autonomy, sexuality, Down Syndrome, and their inherent connections.

Introduction

“Welcome to Holland”

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It’s like this...

When you’re going to have a baby, it’s like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It’s all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, “Welcome to Holland.” “Holland?!?” you say. “What do you mean Holland?? I signed up for Italy! I’m supposed to be in Italy. All my life I’ve dreamed of going to Italy.”

But there’s been a change in the flight plan. They’ve landed in Holland and there you must stay. The important thing is they haven’t taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It’s just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you never would have met. It’s just a different place. It’s slower-paced than Italy, less flashy than Italy. But after you’ve been there for a while and you catch your breath, you look around...and you begin to notice Holland has windmills...and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they’re all bragging about what a wonderful time they had there. And for the rest of your life, you will say, “Yes, that’s where I was supposed to go. That’s what I had planned.”

And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very, very significant loss.

But...if you spend your life mourning the fact that you didn’t get to go to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

- Emily Perl Kingsley

Individuals with Down Syndrome¹, a developmental disability affecting the “development of social maturity, emotional self control, social communication, abstract thinking and problem solving abilities,” are left out of sexual narratives and subject to norms or stereotypes that restrict their autonomy (“National Down...” 2019). Sex as a social concept is constrained to very specific norms that “other” people and actions as deviant or unnatural, creating a public discourse that ignores or ostracizes populations (Warner 2000, Garland-Thomson 2005). Similar to the way Perl Kingsley discusses the shift in perception for parents of children with disabilities in her poem *Welcome to Holland*, society must re-conceptualize sexual autonomy to be disability-inclusive and attainable even if one requires support (Perl Kingsley n.d.). Removing the bounds of what is seen as normal and respecting one’s abilities and autonomy without comparison to how others perform allows for a new conception of Down Syndrome ability where their humanity and contributions are acknowledged. This poem was read at Kyle, my dear friend’s, memorial and it has stuck with me over ten years later. Kyle had Down Syndrome and this poem said everything that I wanted to explain about being friends with him without having the words to say it. Celebrating Kyle’s strengths and ability to form important relationships lead me to ask important questions about autonomy, rights, and sexuality. In Perl Kingsley’s analogy, past expectations work as blinders to new opportunities (Perl Kingsley n.d.). In regards to Down Syndrome sexuality, societal norms and assumptions blind society to the abilities that individuals with Down

¹ There is debate in the field whether to use Down Syndrome or Down’s Syndrome. I choose to proceed with the term most often cited in my research. However, I acknowledge that both forms are valid and could be interchangeable.

Syndrome do have and the ways in which perceptions and actions can be altered to fully recognize the humanity of those with Down Syndrome.

The popular sexual narrative of individuals with Down Syndrome as asexual or of needing protection from sexuality prompts the question: why have people with Down Syndrome been left out of sexual discourse? Both sexual deviancy and disability exist as social constructs, legible in comparison to constructed norms. However, norms become seemingly natural and undeniable over time making their construct unrecognizable. As disability studies scholar, Robert McRuer, argues, "Able-bodiedness...largely masquerades as a nonidentity, as the natural order of things" (McRuer 2006, 1). When norms proclaim that those with Down Syndrome should not be having sex, its participants get labeled as deviant, exploitative, and exploitable. However, increasing visibility and introducing a counter-narrative to the sexuality of those with Down Syndrome can reject the othering of sexual bodies while providing a framework for possible ways to support the lives of those with Down Syndrome.

How can individuals with Down Syndrome practice autonomy in sexual decision making specifically? I argue that "assisted autonomy," one's ability to make decisions or act with the assistance, but not force, of a support system, increases access to sexual rights for individuals with Down Syndrome. "Assisted autonomy" offers those with Down Syndrome a new framework that can include a strong reliance on care, but this concept can and should be used for all of society as well. I begin my argument with a brief context of Down Syndrome that includes their denied humanity historically and why that contextualizes this research as an important area of study. Additionally, I use employment and housing opportunities for individuals with Down Syndrome to make

connections to sexuality and offer an image of Down Syndrome that includes autonomy. I then proceed to contextualize autonomy and its inherent inaccessibility in a socially connected world. Following this section, I situate “assisted autonomy” into a rights framework, which both rhetorically frames the sexuality of those with Down Syndrome as valid and increases access to sexual rights. Lastly, I dive into the concept of “assisted autonomy” directly and offer suggestions for how one can contribute to an “assisted autonomy” for Down Syndrome sexuality including sex education and facilitated sex.

This argument lies at the nexus of disability studies and sexuality studies. I draw from these areas of study and introduce key political concepts, autonomy and the rights framework, to construct a potential ideology to follow. While the lived reality can seem removed from this methodology, new conceptual frameworks can propel further explorations and research in the future. Disability studies scholar, Rosemarie Garland-Thomson, defines disability as "a cultural interpretation of human variation rather than an inherent inferiority, a pathology to cure, or an undesirable trait to eliminate" (Garland-Thomson 2005, 1557). Disability studies, thus, rejects the privileging of some bodies over others under the guise of supposed norms, like that of a lack in needed support, that double as a “nonidentity” (McRuer 2006, 1). Sexuality studies follows a similar framework in attempt to uncover the construction of normative sexual values and destigmatize variations to sexuality, whether that refers to attraction, forms of activity, or physical or intellectual ability (Warner 2000, Seidman et al. 2006). Sexuality studies, furthermore, works to understand how biology has influenced these normative constructions: “The new sexuality studies perspective does not deny the biological aspects of sexuality...However, it is social forces which determine which organs and

orifices become ‘sexual’...their social and moral meaning, which desires and acts become the basis of identities, and what social norms regulate behavior and intimacies” (Seidman et al. 2006, xii). Disability and sexuality studies come together under a common desire to obstruct societal norms and reimagine worlds outside that of normal. Disability and sex in the same conversation enhances both of these literatures by reaching against the norm in both respects, that of disability sexuality. Instead of trying to deconstruct one harmful societal norm, situating this thesis in the controversial landscape of Down Syndrome sexuality hopes to deconstruct the constraints of normal itself while simultaneously rejecting specific sex and ability norms.

Through a disability and sexuality studies lens, an “assisted autonomy” approach breaks down these norms and addresses the fears of exploitation or personal ability. Parents and caretakers shelter the sexuality of those with Down Syndrome because they either expect an inability to tend to the responsibilities of reproduction or assume a lifestyle as “eternal children” (Murphy et al. 2004, 1347). Because people with Down Syndrome often require extra support in their daily lives and may not independently have the capacity to parent, these fears are not unfounded. As people often discuss autonomy without the presence of a support system, fears of exploitative or childbearing sex can be valid. Both partners can be put into unsafe experiences if conversations about consent or birth control are ignored or misunderstood. Studies show that people with intellectual disabilities know far less about “pregnancy, masturbation, contraception, birth control, STDs, types of sexual relationships, and the legal aspects of sex” (Murphy et al. 2004, 1354). That being said, “assisted autonomy” requires support in order to ensure complete understanding of risks and safe sex practices. With proper execution, these fears become

less valid as decisions are being made with full understanding and choice. Additionally, the analysis of other autonomous decision-making abilities in the lives of those with Down Syndrome helps to undermine the “eternal child” stereotype and acknowledge the contributions of those with Down Syndrome.

Down Syndrome sexuality provides an opportunity for a shift in perception about autonomous ability and sexuality. Instead of comparing the sexuality of someone with Down Syndrome to the constructed norms of sex and ability, one should be starting with the abilities that the individual does have and working to highlight and support those qualities. Shifting one’s perception is not an effortless proposal, but rather calls upon society to educate themselves and resituate their point of view into a new context: *“So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you never would have met. It’s just a different place”* (Perl-Kingsley n.d.). This thesis hopes to begin the process of shifting the harmful societal perceptions of autonomy, sexuality, Down Syndrome, and their inherent connections.

Down Syndrome

The historical context of Down Syndrome underscores the importance of focusing on the disability's specific needs and provides an understanding to why questions of humanity and rights, autonomy, and sexual capacity are controversial to this day. It is only then that the new-found quasi-independence of individuals with Down Syndrome can influence the evaluation of sexual opportunity in the future. Down Syndrome, signified by a third copy of the 21st chromosome, is the leading cause of intellectual and developmental delay in both the United States and the world, affecting approximately 1 in 691 births ("Updated..." 2018). While having a delay in certain communication and processing skills, individuals with Down Syndrome function higher in social and personal skills than what is noticeable from their speech and cognitive skills, creating a common misunderstanding of their abilities (Wood 2004). Moreover, the disability does not affect emotional understanding ("Jobs for..." n.d.). Recognizing the history of societal treatment toward those with Down Syndrome and the autonomous experiences that they practice today situate Down Syndrome as a necessary focus group as well as a population in which understanding and practice of sexuality is possible.

History

The U.S. eugenics movement targeted individuals with disabilities, including specific laws in 1883 that forced institutionalization and sterilization of the disabled ("Down Syndrome Human..." 2012). In 1927, *Buck v. Bell*, yet to be overturned, upheld

this notion by declaring forced sterilizations for individuals with disabilities constitutional (*Buck v. Bell*, 274 U.S. 200 (1927)). Furthermore, the U.S. eugenics movement influenced Hitler's first mass murders in the 1934 Aktion-T4 program, killing an estimated 200,000 people with intellectual and developmental disabilities under orders to kill "life unworthy of life" (Carey 2010). More recently, up until 1984, doctors in the U.S. refused, by protocol, lifesaving procedures to those with Down Syndrome (*Bowen v. American Hospital Assn*, 476 U.S. 610 (1986)). Moreover, doctors categorized "feeding" as a lifesaving procedure and starved babies to death under said protocol ("Down Syndrome Human..." 2012). Evidently, society has denied the humanity of those with Down Syndrome through physical death or isolation and torture.

The U.S. government began the process of deinstitutionalization in the 1950s, but real progress did not begin until the 1980s. In 1985, the court decided in *Burlington School Committee v. DOW* that if a child requires special education, the school must pay the expense (*Burlington School Committee v. DOW*, 471 U.S. 359 (1985)). Following suit, in 1988, the Air Carrier Access Act banned airlines from charging extra fees or refusing service to people with disabilities. Also in 1988, the U.S. government amended the Fair Housing Act prohibiting housing discrimination against individuals with disabilities ("Down Syndrome Human..." 2012). In 1990, progress continued when George Bush signed the Americans with Disabilities Act which requires local, state, and federal governments and programs to follow regulations to ensure accessibility for individuals with disabilities ("Americans with..." 1990).

While these are steps in the right direction, laws and policies are having to work towards a basic humanity that should have been presumed. Therefore, instead of creating

auxiliary benefits, laws are attempting to achieve basic necessities. Social acceptance follows the same trajectory, in which progress is still needed for society to recognize individuals with Down Syndrome as full participating humans. This brief and partial history demonstrates that up until recently, society has seen individuals with Down Syndrome as lesser individuals and lives not worth saving. They were institutionalized, killed, and excluded from basic lifestyle needs like housing and travel. Attempting to suggest sexual entitlement to individuals with Down Syndrome less than forty years later means that discussions of their humanity, the rights associated with it, and autonomy must be included. The long history of maltreatment toward those with Down Syndrome proves that society has not seen individuals with Down Syndrome as human, which is a necessity to expecting respect toward their rights and autonomy. If a universal human right allocates every human being as entitled to sexuality, history complicates whether those with Down Syndrome are included as humans. If an individual with Down Syndrome is able to be denied lifesaving procedures, including basic feeding, how can one assign universality to human rights, let alone sexual rights?

Decision-Making Capacity

Individuals with Down Syndrome already practice forms of autonomy that attempt to normalize their belonging in the public sphere, creating a possible framework for the rise of a sexual autonomy. Their increased presence in society helps bolster public perception of those with Down Syndrome, hopefully creates a larger support network, and labels those with Down Syndrome as autonomous. One of these influential realms is the employment sector. As of April of 2015, approximately 57% of Americans with

Down Syndrome are employed working in places such as restaurants, offices, cleaning companies, or grocery stores (“How Having...” n.d.).

Individuals with Down Syndrome occupy two categories of job opportunities most commonly: competitive and sheltered work. Competitive work is the most visible, in which participants work in the main workforce. This option offers equal wages and conditions, but includes less additional support (Meltzer et al. 2018). Competitive employment is the most successful when paired with a long orientation, either through hired employment supports or job coaching, and the use of a follow-up specialist that makes sure that both parties, employer and employee, are satisfied. “Fading” is a useful technique in this sector, in which hired supports help participants in their job and slowly come less until the participant can work on their own (“Employment and...” n.d.).

Sheltered employment includes workshops employed completely by those with intellectual disabilities. While often having the most services, like advocacy, case management, transportation, and counseling, segregation and lower wages limit the growth potential of these individuals (Meltzer et al. 2018). Ultimately, determining what job is best suited for an individual depends on one’s abilities. That being said, studies show that competitive employment is correlated with higher feelings of autonomy, empowerment, and self-esteem (Meltzer et al. 2018). Therefore, finding ways to better support individuals in the main workforce can help create better quality of life. One’s ability to find and maintain employment provides an example of autonomous capacity and the competence to learn and be trusted. The decision-making skills showcased in the employment sector can then be transferred to the sexual realm through similar or deviated forms of support.

Individuals with Down Syndrome also practice their autonomy in their housing opportunities with varying degrees of support. Traditionally, there are four different housing options for people with Down Syndrome: privately owned personal housing, vendor owned, shared living, and foster homes (“Housing...” n.d.). Privately owned personal housing consists of an individual living alone with no paid support. While relatively uncommon, this option fulfills those with higher-functioning abilities (“How Having...” n.d.). Vendor owned housing consists of group homes, community residences, and congregate housing. Management controls these housing units and staffs them in accordance to tenants’ needs, ranging from 24-hour total supervision to a few hours per week supervision (“Housing...” n.d., Connery 2016). While minimal supervision is similar to privately owned personal housing, management presence limits one’s autonomy and decision-making (“Housing...” n.d.). In these cases, they spend more time alone, but do not have to make many choices in that time.

Shared living arrangements are less common, but impactful. These spaces consist of people with and without disabilities, where the non-disabled roommate is financially compensated (Connery 2016). The individual with Down Syndrome in this option enjoys both the presence of a support system and the opportunity to practice decision-making. Lastly, foster homes present an opportunity for individuals with Down Syndrome to live with another family where the assistance of an unfamiliar support network can help aid one’s future growth (Connery 2016). Like employment options, the best housing choice is entirely dependent on the needs and abilities of the individual. Looking at how decision-making is practiced and supported in both housing and employment helps to form a new support framework for sexuality, as well as provide new ideas for those

sectors as well. Housing, most specifically, highlights the different formats of support created for individuals with Down Syndrome and the ways in which each person varies in their needs. Supporting one's sexuality follows the same framework, in that some will need more support than others.

The variability of each individual with Down Syndrome helps to uncover the reasons their sexuality has been ignored for so long. As showcased by housing and employment, each individual has different abilities. When questions of consent arise, different abilities make gaining and evaluating consent more difficult. There is no one way to practice consent for those with Down Syndrome, which fosters fear about sexual misconduct. However, consent does not require standardization, but rather, necessitates proper understanding and willingness. This can be gained in different ways, meaning that education must instill the value, on top of skills for gaining consent. Additionally, the history of treatment for people with Down Syndrome showcases why conversations of pleasure have yet to surface. If humanity is just starting to be recognized, mostly in ways that prevent danger, conversations of happiness and fulfillment will take time to follow suit. That being said, housing and employment opportunities for people with Down Syndrome show that decisions are being made, agency is being practiced, and sexual decision-making is possible.

Autonomy

Understanding autonomy's role in sexual rights for individuals with Down Syndrome relies on a knowledge of autonomy and its influences on dominant ideologies. Autonomy has become a norm in which its fulfillment is associated with humanity. Unfortunately, its normalization casts those needing support as less than human: "Normal is the category obscured by its own privilege - its normalcy - that casts people with disabilities into pathologized others" (Garland-Thomson 2005,1577). Because individuals with Down Syndrome rely on different forms of support seen through their experiences with employment and housing, they do not fit into the autonomous norm. Autonomy is defined as "self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice" (Le Gallez et al. 2018). The interference provided in this definition disqualifies those needing support from its attainment.

Critiques of Autonomy

Immanuel Kant popularized the concept of autonomy in the late 1700s by categorizing enlightenment, the goal of human life, as one's ability to act free from the control of others (Kant 1996). In doing so, autonomy as a concept became well-known, and in reference to its relationship to enlightenment. Centuries after this concept gained normality, a developmental psychologist, Carol Gilligan, offered an essential critique of autonomy by illuminating the ways in which the concept favors men. Carol Gilligan

found issue specifically with the patriarchal tendencies in Lawrence Kohlberg's theory of moral development and alternatively argued that women are more likely to emphasize care in their decision making, founded by her research on abortion decisions (Gilligan 1982). While both Kohlberg and Gilligan include autonomy in their moral development theories, Gilligan emphasizes an autonomy that includes care for and from others. This care creates opportunities for individuals with Down Syndrome, who rely on care, to still represent an autonomous subject.

“Relational autonomy,” a term coined by Jennifer Nedelsky, arose out of the feminist critique that autonomy is inherently masculine: individualistic and rationalistic (Nedelsky 2012). However, instead of rejecting the concept in entirety, the study of relational autonomy acknowledges autonomy's existence in order to understand female oppression and agency (Mackenzie et al. 2000). Catriona Mackenzie and Natalie Stoljar, two relational autonomy theorists, follow Jennifer Nedelsky's concept and work to resituate autonomy into a context more representative of the true experience of women and men alike. While definitions of relational autonomy differ, there is a general agreement that all of the different “perspectives are premised on a shared conviction, the conviction that persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender, and ethnicity” (Mackenzie et al. 2000, 4). According to this definition, relational autonomy relies on the assumption that humans are made beings who are influenced by others in their thoughts, actions, and identities (Mackenzie et al. 2000). While this does not offer a full suggestion for how to support

individuals with Down Syndrome's autonomy, it does help to break down the issues present in favoring autonomy.

“Assisted Autonomy”

Relational autonomy provides a framework for the ways in which people are shaped by the communities, institutions, and ideologies that surround them, while leaving out opportunities to assist in one's autonomy. In order to access one's sexual rights, a person with Down Syndrome might need assistance and, thus, relational autonomy does not provide all of the answers. Subsequently, “assisted autonomy”² attempts to reconcile this disparity. In this new framework, caretakers, family members, friends, acquaintances, could all be involved in providing accessible information for those with Down Syndrome, facilitating conversations, and participating in shared action. Sexual autonomy, specifically, demands that everyone has full knowledge of the topic, which includes a universal teaching and accessibility to that information (Warner 2000). Addressing “assisted autonomy” for those with Down Syndrome, thus, includes offering information about sexuality in a way that is accessible to their learning.

Independence-based autonomy ignores society's inevitable dependencies and rejects notions of support, casting populations who require extra support as inferior. Individuals with Down Syndrome tend to require additional support, putting their autonomy into question. Autonomy's historical context highlights how radical the

² I chose the identifier of “assisted” because I want to center the individual actor instead of putting the assister on equal footing with the assisted, as terms like “collaborative” would do. I also veered away from “supported” because I did not want to portray a blind support to what one autonomously chooses.

concept of “assisted autonomy” is. The value is so rooted in traditional beliefs that those who do not fit into its tight constraints are cast as other and less than. Therefore, a radical shift in how society conceptualizes ability and worth is essential to an “assisted autonomy.” By acknowledging the need for support in decision-making, “assisted autonomy” should be implemented in order to promote sexual rights for individuals with Down Syndrome.

Rights Framework

The rights framework situates Down Syndrome sexuality as an entitlement to which one's access can be supported. That being said, it is limited by a lack of access and assumption of equity. By pairing "assisted autonomy" with the rights framework, these limitations are addressed as access becomes more attainable and the use of rights provides a rhetorical benefit. In a basic definition, "To have a right to x is to be entitled to x. It is owed to you, belongs to you in particular" (Donnelly 2013, 7). Rights as entitlement provide individuals with Down Syndrome a foundation of humanity that they are able to assert through their actions. In this way, rights both increase personal self-esteem for individuals with Down Syndrome and direct society as a whole to respect their humanity. The term "rights" helps to dissuade those who may believe that sex is mutually exclusive with Down Syndrome, and promotes and persuades society that individuals with Down Syndrome should be assisted with their sexuality. This assistance then becomes the directive to increase access to current and further rights in the future for those with Down Syndrome. The critique of the rights framework helps to develop this perspective on rights that benefits Down Syndrome sexuality.

Critiques

Human rights are supposed to be based on equality and universality: "Human rights are *equal* rights: one either is or is not a human being, and therefore has the same human rights as everyone else (or none at all)...And they are *universal* rights, in the

sense that today we consider all members of the species *Homo sapiens* ‘human beings’ and thus holders of human rights” (Donnelly 2013, 10). If the allocation of rights is based on humanity, society must determine what the basis for humanity is and why those lines have been drawn. Humans deem themselves more advanced than other animals because of our capacity for intellectual, moral, and spiritual development (Donnelly 2013). This is a dangerous qualification, however, because purposive agency is not universal for humans and some people are unaware of their surroundings, incapable of rational thought, or unable to distinguish right from wrong (Donnelly 2013). If this is the case, human rights are easily infringed upon for those who struggle with purposive agency, which could include those with Down Syndrome. The history of maltreatment for individuals with Down Syndrome reinforces this idea, as their humanity has been put into question previously.

Rights implementation further exposes exclusivity as one’s access to a right determines its utility. Many rights, according to Damon Young and Ruth Quibell, unfortunately, come into play after a right has been breached or never do the preemptory work to allow one to enjoy said rights (Young et al. 2000). For Down Syndrome sexuality, this could occur by never teaching individuals with Down Syndrome about sexuality or distancing them from potential sexual partners. Furthermore, a lack of structure and resources mean that one’s rights do not have to be infringed upon for them to not be able to access services. An individual with Down Syndrome could be on a waiting list for five years for services that they have a right to, but its inaccessibility does not count as an infringement. As Martha Fineman suggests, the rights framework does

not provide a challenge to how resources and power have been distributed and who has access to them (Fineman 2008).

Instead of focusing on rights, Young and Quibell propose a narrative approach, which involves attempting to understand one another on a personal level to truly get to know who people are and what they need. While understanding that there are inequalities that need to be addressed, Young and Quibell explain that the only way to fix inequality is with true understanding: “this is an acknowledgement that material, legal, and social injustices can only be redressed by people who understand each other, and thus understand what it is for this individual or that group to *be* in an unequal situation” (Young et al. 2000, 758-9). While mutual understanding is imperative to fighting inequality, there is a larger learning curve to promoting this understanding than they let on. Individuals with Down Syndrome are not currently in the public eye enough to create mutual understanding, meaning that rights must be implemented in ways that bring them into the social sphere. Additionally, these rights add a rhetorical benefit in that their assertion directs society to shift their ideology. While understanding that rights will not be a complete fix to the legal issues that surround individuals with Down Syndrome’s access to sexuality, the rhetorical potential of rights can be helpful in highlighting humanity for those with Down Syndrome. Additionally, because they start as an oppressed group, rights can begin to address the inequalities even if they do not promote full accessibility.

Rights as Rhetoric

The language of rights creates a notion of authority, in which mere perspective or opinion is deemed null: "It is a presupposition of the discourse that there is a crucial distinction between 'value judgements' - which are a matter of preference, subjectivity, the arbitrary, the 'philosophical' - and 'factual judgements,' or scientific, objective, or empirical judgements" (Kennedy 2002, 184). Accordingly, rights prove to a society that a specific treatment or accommodation is beyond subjectivity, that one is merely entitled. Furthermore, the rights discourse also creates a notion of personhood for the one able to claim the right. Instead of solely accepting that one is entitled to a certain right, the discourse reinforces the humanity in that who can claim a right: "In particular, the very ability to claim rights establishes that the person or group making the claims is entitled to be taken into account" (Tushnet 1988, 53). Furthermore, "the concept of rights...is the marker of our citizenship, our participatoriness, our relation to others" (Williams 1988, 65). While rights implementation is certainly important in offering resources and attempting to bridge the gap in accessibility, the pure rhetoric of rights takes the first step in creating social change, because it asserts personhood and agency to a certain group.

Because the rights framework can also subjugate certain subordinated groups, the history of Down Syndrome is imperative. The specification of a certain group in the creation of a right reinforces the difference between said group and the so-called norm. Wendy Brown explains this paradox in regards to women by saying, "And the paradox within this problem is this: the more highly specified rights are as rights for women, the more likely they are to build that fence insofar as they are more likely to encode a definition of women premised on our subordination" (Brown 2002, 422). Accordingly,

individuals with Down Syndrome claiming rights simultaneously emphasize the fact that there is a difference between the abled and the disabled. However, ignoring population specificity in laws or policies benefits the dominant population the most (Brown 2002). A population's reality influences how this paradox should be addressed because even though rights could highlight the differences between those with and without Down Syndrome, the contrast is already accentuated in daily life. Society views people with Down Syndrome so far from normal that highlighting this relationship will have less of an effect than to populations who have a closer social standing to the norm. Therefore, the claim to personhood has an important effect as people with Down Syndrome, up until very recently, have not been seen as fully human.

Individuals with Down Syndrome are vulnerable to lacking access to rights because society has not acknowledged their personhood and abilities. In regards to sexual rights, a cultural shift around sex for those with Down Syndrome is necessary, that calls for the acknowledgement that people with Down Syndrome desire sex, are entitled to have sex, and should be offered assistance in pursuing sex. While the hope would be that society would accept this notion without intervention, current stereotypes and oppression point otherwise. Therefore, the rights framework reinforces both the State's support in engaging with the sexuality of those with Down Syndrome and that individuals can claim their own identity as sexual beings.

Sexual Rights

According to the International Women's Health Coalition, sexual rights "rest on the recognition that all individuals have the right – free of coercion, violence, and

discrimination of any kind – to the highest attainable standard of sexual health; to pursue a satisfying, safe, and pleasurable sex life; to have control over and decide freely, and with due regard for the rights of others, on matters related to their sexuality, reproduction, sexual orientation, bodily integrity, choice of partner, and gender identity; and to the services, education, and information...necessary to do so” (“Sexual Rights...” n.d.). Sexual rights locate themselves in universal rights through a grouping of treaties called the International Bill of Rights: The Universal Declaration of Human Rights (UDHR), International Covenant on Civil and Political Rights (ICCPR), and the International Covenant on Economic, Social, and Cultural Rights (ICESCR) (Thukral et al. 2012). The universal rights given by these treaties, including, but not limited to, liberty, self-determination, the best available healthcare, and education, make up the defense of sexual rights more broadly (“UN General...” 1948, “UN General...Civil and Political Rights” 1976, “UN General...Economic, Social and Cultural Rights” 1976). The ICESCR specifically states that “these rights derive from the inherent dignity of the human person” (“UN General...Economic, Social and Cultural Rights” 1976). Therefore, the basis of the rights afforded by the treaty are dependent on humanity, which while being questioned in the past for those with Down Syndrome, is solidified in the UNCRPD (UN Convention on the Rights of Persons with Disabilities).

The UNCRPD is the first disability-specific international treaty using a human rights approach. According to the UNCRPD, the purpose of the convention is to “protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (“UN General...” 2008). As sexual rights are protected by universal human rights through the

International Bill of Rights, those with Down Syndrome are protected by the same rights (Thukral et al. 2012). While the humanity-based argument of the ICESR should signal full rights for individuals with Down Syndrome on its own, the UNCRPD poses an intentional granting of rights to those often overlooked in rights-bearing conversations. These rights help to both reject the conception of those with Down Syndrome as less than human and flag their entitlement.

The one caveat of this treaty is that article 8(2) of the European Convention on Human Rights “allows a public authority to interfere with a right if it is... necessary in a democratic society in the interests of...public safety...for the prevention of disorder or crime, for the protection of health or morals or for the protection of the rights and freedoms of others” (Le Gallez et al. 2018, 335). This article affects individuals with intellectual disabilities because they can misunderstand sexual interactions or consent leading to sexual assault³. Without the right education on sex, individuals with intellectual disabilities are vulnerable to losing their sexual rights due to a misunderstanding. By misreading interactions to be sexual or unknowingly disregarding consent, individuals with Down Syndrome who have not been properly educated could sexually assault another person without understanding why what they did was wrong.

Rights provide a framework in which individuals with Down Syndrome can assert their humanity and mark those with Down Syndrome as a deserving population of entitlements and assistance. While the rights framework includes many holes in its implementation, it also posits a specific group as needing extra support which can be

³ I chose to steer away from the sexual assault conversations in this thesis because its gravity did not align with the small section it would have to fit in. That being said, I acknowledge the real effects of sexual assault for those with and without intellectual disabilities and that it is a topic that should be brought up when discussing increased access to sexual opportunity for those with intellectual disabilities.

advantageous for those with Down Syndrome. The rights framework specifically addresses the stereotype of individuals with Down Syndrome as asexual or unable to have sexual relations by creating a new narrative. Individuals with Down Syndrome have explicit sexual rights offered through the International Bill of Rights and UNCRPD, showcasing that there must be a reason for these rights (Thukral et al. 2012, “UN General...” 2008). While rights to protect Down Syndrome sexuality are already in place, “assisted autonomy” reinforces sexual rights because the increase in access to sexual rights enhances visibility and engages outsiders to join the support systems for those with Down Syndrome.

“Assisted Autonomy”

“Assisted autonomy” supplements the abilities of those with Down Syndrome to best access their sexual rights. Because individuals with Down Syndrome often struggle with communication and processing skills, “assisted autonomy” works to both educate accordingly and offer opportunities that may be lacking (“National Down...” 2019).

“Assisted autonomy” refers to one’s personal decision-making capacity or the ability to perform an action with the assistance, lacking force, of a support system. Seeking help is normalized as a form of dependence incompatible with an independence-based model of autonomy. Conversely, “assisted autonomy” recognizes assistance as a useful strategy to best practice autonomy. The abilities and functionality of each individual varies, meaning that “assisted autonomy” also varies based on an individual’s capabilities and desire for sexual assistance. While specific sex education may be all that one needs in assisting their autonomy, others may need extra assistance, including but not limited to offering contraceptive options, facilitating consent conversations, positioning partners, and participating as a sexual surrogate. Using the examples of how one’s autonomy is supported in housing and employment, sexual “assisted autonomy” constructs opportunities for individuals with Down Syndrome to make their own choices and participate in sexual actions if they desire them.

Education

A foundational method for supporting the sexuality of those with Down Syndrome is to educate them on their bodies, relationships, and sexual encounters. Many individuals with Down Syndrome participate in sex education in schools, but fail to understand the material because lessons are not targeting their learning styles. This also assumes schools are teaching sex education, which is far from universal. Part of understanding how to teach sex education to people with Down Syndrome is recognizing the ways in which they learn differently. The Down's Syndrome Association (DSA) provides a sex education curriculum specifically for individuals with Down Syndrome, highlighting the importance of visual graphics, repetition, and storytelling ("Let's Talk..." 2019). Carol Boys, the Chief Executive of DSA, explains their mission by saying, "People with [Down Syndrome] and other learning disabilities have a right to exist as sexual beings, to receive accessible information to enable them to enjoy sex and, crucially, to be protected from sexual abuse. As practitioners, parents, and teachers, we have a responsibility to ensure that the people we support are able to live with these rights firmly in place" ("Let's Talk..." 2019, 4). By creating a Down Syndrome specific curriculum, DSA directly combats the norm that individuals with Down Syndrome are asexual or need to be protected from sex. Rather, they take the approach that proper education protects them from the risks that come with sex. DSA's reference to other intellectual disabilities is important to sex education practices because people with other disabilities will have different individual learning styles. Lessons, thus, must be approached with that in mind, rather than grouping all students with disabilities into one special education classroom. An "assisted autonomy" approach to sex education relies on

understanding the needs of each individual and targeting specific learning styles. DSA's curriculum is just a baseline to understanding certain strategies that might be the most fruitful for those with Down Syndrome.

In their "Let's Talk about Relationships and Sex" curriculum, DSA explains that it is important for trainers to fully understand how each individual with Down Syndrome learns the best (Let's Talk... 2019). Therefore, in addition to offering specific learning guides, the curriculum also offers helpful information about how individuals with Down Syndrome learn differently. DSA suggests that those with Down Syndrome are often interactive and visual learners, so strategies should include images, videos, and material objects ("Let's Talk..." 2019, Wood 2004). Other teaching suggestions for individuals with Down Syndrome include limiting the amount of points on a slide, reviewing material often, clarifying slang terms, using teaching strategies the student has previously enjoyed, making up hypothetical stories with known characters, and being patient, so not to rescue people before they can figure things out on their own ("Let's Talk..." 2019, Wood 2004). Specifically, in regards to sexual education, students should practice reading facial expressions and nonverbal communication in hopes that one is more attune to how a partner feels in a sexual interaction ("Let's Talk..." 2019).

While these lessons often come up in school, sex education can and should also be practiced at home. Individuals with Down Syndrome are especially perceptive and will mimic behaviors that they encounter, so lessons or learned behavior taught at home can include topics of privacy, body positivity, and self-worth (Wood 2004). Outsiders often intrude on the privacy of those with Down Syndrome, making the concept difficult to grasp when projected onto others.

Therefore, allowing those with Down Syndrome to have forms of privacy can be beneficial in their future relationships (“Let’s Talk…” 2019). Treating those with Down Syndrome with respect will, thus, influence how they treat themselves and others.

Sex education is a controversial topic nationally, as people debate the use of abstinence-only and comprehensive sex education. However, an extensive and honest sex education is vital to the sexual health and rights of individuals. This education must include consent to ensure participants understand that they cannot continue an action just because they desire it and they are also permitted to say no to any action they do not desire. Unfortunately, consent is difficult to teach because the qualifications for the ability to consent are vague (Lyden 2007). One must understand that they need to stop if they do not get consent, can say no to a situation they do not want to engage in, but also need to make sure that their partner understands their intentions. While different definitions vary, a common set of evaluations for consent capacity relies on voluntariness, safety, lack of exploitation and abuse, appropriate time and place, and the ability to weigh pros and cons, say no, and communicate the decision (Warner 2000, Murphy et al. 2004). Instead of disregarding an individual with Down Syndrome’s ability to understand or practice consent, one should work to teach helpful tools to ensure that consent will be practiced in the future. Because of the vague tendencies of consent, interactive activities can be useful to test one’s ability to decipher what is and what is not consent. This can include examples of conversations, facial expressions, and/or experiences (“Let’s Talk…” 2019). In the workforce, just because an individual with Down Syndrome might need extra training support, seen in the use of employment supports, does not mean that they cannot be successful in the job thereafter. Similarly,

teaching consent more thoroughly and in potentially new ways can be enough to ensure that individuals with Down Syndrome practice consent in the future.

People with Down Syndrome vary in ability and, therefore, education could be all that one needs in “assisted autonomy” to proceed in a safe and pleasurable way in the future. However, oftentimes, extra support will be necessary to ensure that sexuality is being practiced safely and that people have the opportunity to practice it. Additional support comes in different forms of facilitated sex, which all rely on a baseline of previous or continued sex education.

Facilitated Sex

Facilitated sex, actions that a second or third party without Down Syndrome can engage in to assist the preparation for or substantive act of sex, is another essential option for “assisted autonomy.” This practice is primarily used for people with physical disabilities, but has been neglected as a suitable option for individuals with intellectual disabilities. The general discomfort in facilitated sex for those with intellectual disabilities, or Down Syndrome more specifically, comes from the stereotypes that they are asexual, should not be having sex, or that forcing sex would be a form of exploitation. If society instead understood individuals with Down Syndrome to be sexual beings with the capacity to make decisions for themselves, facilitated sex would be no different than respecting their ability to engage without assistance.

Facilitated sex occurs at many different levels and can be practiced by varying individuals. On the institutional level, the healthcare system can practice versions of facilitated sex by providing their patients with Down Syndrome proper explanations of

and access to contraception and reproductive health options. Physicians often assume that women with Down Syndrome are asexual and do not understand contraception, therefore refusing to offer proper explanations of use. Instead, physicians tend to provide invasive forms of contraception without giving the patient any autonomy in the decision (Pebdani 2016). The physician acting in accordance with “assisted autonomy” would, rather, include a provision of all necessary information for the patient to make a decision *and* respect the wishes of said patient. Even though reproduction can increase the amount of care a certain individual may need, physicians should only interfere if the patient is in medical danger. More importantly, if care is normalized through “assisted autonomy,” reproduction should be less of a danger⁴.

Facilitated sex also offers members of society the option to be a third party helping the interaction between one or two other individuals with Down Syndrome go smoothly. This concept is already used for individuals with physical disabilities, where third party assistance “could include positioning them for masturbation or for sex with a partner, helping them undress, helping with stimulation, or physically moving the person” (Shuttleworth 2007, 5). These interactions allow the individual(s) to proceed with the action they have chosen to the safest extent. While these actions are possible for individuals with Down Syndrome as well, many of the fears for Down Syndrome sexuality come from the ability to understand the situation/risks and gain consent. Therefore, facilitated sex for those with Down Syndrome can include helping an individual access birth control, find social spaces for individuals to meet each other, and

⁴ An entire thesis could be written about Down Syndrome and parenting, but I choose to focus specifically on sexual rights. Therefore, I only use it to describe the effects of contraception. However, I do understand that more research on this topic is necessary to create safe and attainable parenting environments for those with Down Syndrome.

facilitate consent between two people (Shuttleworth 2007). In its current use for individuals with physical disabilities, the facilitation occurs only in respect to physical positioning and maneuvering. Therefore, extending the concept to include intellectual and social supports remarkably advances this approach. This advancement, however, relies specifically on the belief that one's autonomy can be supported as much as one's physical disabilities can.

One of the most critical forms of facilitated sex is facilitated consent. While still fitting under the definition of facilitated sex, as it includes a third party assisting in the preparation for sex, its importance calls for a separate feature. A third party can supplement one's consent education by assessing its validity and ensuring clarity in expectations and circumstances. While there is little research on sexual consent for people with Down Syndrome, researchers have suggested ways to obtain their research consent. The ability to consent for these researchers is assumed unless determined otherwise (Taua et al. 2014). The sexual assister is also assuming an ability to consent, but reinforces clear understanding of what one is consenting to. In gaining consent, researchers suggest that one communicates slowly and quietly, introduces concepts and questions one point at a time, uses an appropriate level of language, and asks for the information to be repeated back to them (Taua et al. 2014). Once the consent facilitator provides each sexual participant with the information necessary to proceed with clear understanding, they can leave and allow for actions to proceed. This practice should be continued with subsequent sexual interactions, even with the same person. However, if sexual actions continue in the same partnership, a practice of "fading," discussed in employment options, could be utilized, in which an assistant slowly phases themselves

out of the process. Depending on the individual and their abilities, they may even no longer need a consent facilitator in future relationships.

The option of sex surrogacy becomes available through discussions of facilitated sex, as it locates itself in supporting one's ability to have sex. Anthony Skelton describes the aim of the sex surrogate as one to "nurture a person's sexuality and to help them gain self esteem, sexual health, and confidence. This may involve everything from touching to sexual intercourse" (Skelton 2013). Therefore, the act of engaging in sexual relations with an individual with Down Syndrome for a sexual surrogate would be a form of facilitated sex – supporting a person with Down Syndrome's ability to have sex by being the one that they have sex with. Sex therapists partner with certified surrogates who have "received formal training on how to ethically, medically, intellectually, cathartically, and empathically care for persons who are socially, culturally, emotionally, psychologically and physiologically apprehensive" (Skelton 2013, "Sexual Surrogacy..." n.d.). This concept is highly controversial and often associated with prostitution and sex work. Society holds a stigma toward both of these activities because of their association with exploitation and criminality. However, the International Professional Surrogates Association (IPSA) asserts important differences between a sex surrogate and a prostitute or sex worker. Sex surrogates, also referred to as partner surrogates, receive specific training and focus on long-term healing and education. As Vena Blanchard, the president of the IPSA explains, "People go to sex workers for an immediate experience—the agenda is sexual and about right now, not therapeutic and about the future" (Savage 2018). In contrast, individuals engage with sex surrogates in order to work through dysfunction, fears, or physical barriers.

This argument holds if, and only if, the point of sex surrogacy is to heal or direct someone to a future in which a sex surrogate will no longer be needed. Steven Firth includes this notion in his definition, by explaining part of the responsibility of the surrogate to be “the development of personal (working) relationships” (Firth 2019, 364). This conception of sex surrogacy assumes a sense of progress. Instead, individuals with Down Syndrome use sex surrogacy as a way to access their sexual rights. This does not have to include a fear, dysfunction, or physical barrier. Instead, the barriers imposed on people with Down Syndrome stem from stigma and discrimination, decreasing their options for partners. If one assumes that people with Down Syndrome are sexual beings possessing sexual rights, it follows that those rights may necessitate the use of a paid surrogate to be able to practice that right. Therefore, the only reason to distinguish sex surrogates from the generalized term of prostitute or sex worker is that sex surrogates are trained to better assist the autonomy of those with Down Syndrome. The distinction is not to establish legitimacy of one over the other, but rather suggest the relative advantage of surrogacy in a specific circumstance.

Sex surrogacy follows a similar framework to the shared living spaces that housing options offer. Shared living spaces include a compensated roommate to provide support, without curtailing the autonomy of the individuals with Down Syndrome. In sex surrogacy, the individual without Down Syndrome is paid to provide a service, while allowing the practice of autonomy to flourish. Employment options provide another framework for sex surrogacy to follow. Depending on what characteristic is prioritized, both sheltered and competitive employment rationalize the use of sex surrogacy. For those who care most about interacting with individuals without Down Syndrome, sex

surrogacy shares a similarity to competitive employment, participating in the normal workforce and interacting with society. In sex surrogacy, the individual interacts with someone who does not have Down Syndrome and may seem more representative of all of society. Conversely, for those who care most about the choice of who to have sex with, sex surrogacy shares a similarity to sheltered employment, where the available options are limited but more regulated.

Jacob Appel supports the concept of sex surrogacy for individuals with intellectual disabilities and offers a helpful perspective on why the State should be involved in the process. For him, sexual rights are universal and should only be curtailed when impeding other rights, which paid sexual assistance does not do (Appel 2010). Instead, the State should take an active role in assisting people with intellectual disabilities to access these rights, manifested in the form of financial assistance. Because the State already financially assists people in social services (breast reconstruction after mastectomy, plastic surgery for cleft lips, etc.), funding for the pleasure of the disabled should also be an option. He cites healthcare's coverage of birth control, erectile dysfunction, abortion services, and assisted suicide to further evidence that the State is involved in financially supporting social services. While this could seem like an argument for sex surrogacy for all, he rather argues for support of those who have a disadvantage or a need. In the case of breast reconstruction, the State offers funding to those who have had a mastectomy, but not for those who merely want an enhancement or reduction (Appel 2010). While there are many factors to consider in suggesting sex surrogacy and questions not answered here, the idea warrants further discussion.

Overall well-being is the ultimate goal for those who care about individuals with Down Syndrome. Those who do not care about the humanity of those with Down Syndrome will most likely not be swayed by this argument, as it is entirely founded on a sense of humanity. Instead, the hope is that “assisted autonomy” will create societal shifts that eventually trickle down to those individuals. That being said, even disability activists find controversy in how one frames well-being and what action should be taken for protection. Sex invokes fear because participants are vulnerable to physical and emotional exploitation, pregnancy, and STIs (Warner 2000). Incorporating individuals with Down Syndrome into an already precarious situation is cause for serious concern. However, instead of excluding those with Down Syndrome from the practice, there is a call for “assisted autonomy” to disrupt these concerns. Society must work together to teach individuals with Down Syndrome about consent, safe sex, and contraception in accessible ways and provide support for them to practice these actions in order to protect those with Down Syndrome, while maximizing their well-being.

Similar to the way that there are people with Down Syndrome who can live alone, drive, and participate in competitive employment, there are people who can practice their sexuality with little assistance other than education. On the other hand, similar to those who live with 24-hour supervision, need escorts for transportation, and either do not participate in the workforce or engage in sheltered employment, there are people who will not be able to engage in sexual actions or need variant levels of facilitated sex support. Additionally, as competitive employment offers a visibility of people with Down Syndrome that can shift perspectives about their ability and autonomy, society will hopefully then ask, if we can teach people how to feed, clothe, and bathe themselves, let

alone live and work, why would we not be able to teach/support someone to have sex safely and in a pleasurable way? (Taylor Gomez 2012).

Conclusion

“Assisted autonomy” advances the possibilities of the rights framework, as the right to sexuality for people with Down Syndrome is enhanced when people can access it. Because a weakness of the rights framework is its inaccessibility, “assisted autonomy” has the responsibility to increase access to individual rights and allow for personal sexual decision-making. If people can genuinely access these rights, they not only benefit from the state-provided assistance, but also highlight to the rest of society that these rights exist. The advertisement and promotion of sexual rights, aided by access to them, signals a population as entitled to said rights. Otherwise, certain populations, that may be seen as nonnormative, can be ignored in the access of sexual rights. By assisting the practice of sexuality for those with Down Syndrome, sexual rights for said population are broadcasted to society and have a better chance of becoming legitimized. Therefore, “assisted autonomy” works in tandem with sexual rights to increase the best lifestyle for those with Down Syndrome.

Additionally, increased visibility of people with Down Syndrome making autonomous decisions corresponds to the public’s willingness to support future autonomy. Because sex often happens behind closed doors, hopefully bringing the conversation of Down Syndrome sexuality to the public sphere will increase the understanding of what is possible and recruit people into the “assisted autonomy” support systems. Better education in schools, households, and healthcare facilities also helps to emphasize the sexual rights of those with Down Syndrome.

All of this together can hopefully begin to deconstruct what is seen as normal and recognize that norms are misguided concepts: “You learn that everyone deviates from the norm in some context or other, and that the statistical norm has no moral value” (Warner 2000, 70-71). Bringing sex and disability into the public sphere demands an address to the ways in which these topics have been ignored, and further, the ways that this privileges some groups over others. The practice of “assisted autonomy” challenges the norm that sex is a private affair to universalize access to sexual rights.

“Assisted autonomy” is founded on a general respect and understanding of one’s humanity. Individuals with Down Syndrome are abled beings and labeling them as disabled only disqualifies their differences. However, the speech I wrote at ten years old for my friend Kyle’s memorial speaks to how these differences should be celebrated rather than chastised: “He made me realize how even though he was a little different, it was also us that were different. It was such a privilege to know Kyle. He made my life so much better.” The practice of sexuality for those with Down Syndrome may look different than sexual norms, but that is no reason to limit their autonomy and desires. Certainly more research should be done to address sexual assault and the ways in which those with intellectual disabilities are especially vulnerable to both being assaulted and unknowingly assaulting. Nevertheless, “assisted autonomy” can be used in these circumstances: how can “assisted autonomy” help to intervene in processes of assault or the aftermath of said assault?

Individuals with Down Syndrome vary in ability as much as those without. “Assisted autonomy” celebrates one’s abilities while supporting the skills that might be challenging. Even though this variation could include individuals who are not capable of

understanding the stakes of sexual interaction, sexual activity should not be ruled out. Instead, further conversations about how “assisted autonomy” could support these individuals should be had. Individuals with Down Syndrome are entitled to sexual rights and it is through “assisted autonomy” that they can practice these freedoms. Because individuals with Down Syndrome are initially under the care of guardians or caretakers, promoting and instilling a sense of autonomy comes from the actions of “assisted autonomy” of those who care. If, instead, caretakers overprotect the individual or limit their decision-making, they may never be able to understand what they want or that they can desire more.

Practicing “assisted autonomy” for Down Syndrome sexuality asserts confidence in their humanity, ability, and potential. Sexual rights, themselves, reinforce this concept. However, it is in the practice of these sexual rights, gained through “assisted autonomy,” that the rhetorical significance of rights influences society’s perception. Sex education and facilitated sex provide a unique opportunity to increase one’s access to sexual rights and provide individuals with Down Syndrome opportunities for autonomy. “Assisted autonomy” is just one framework to understand this process, but it has the power to influence the way society understands autonomy and the necessary ties people have to those around them, as well as deconstruct the normative framework of individuality.

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