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Sexual Citizenship on the Autism Spectrum

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Sexual Citizenship on the Autism Spectrum

By

Jessica Penwell Barnett

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2014

Sexual Citizenship on the Autism Spectrum

by

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ABSTRACT

Work on sexual citizenship, or the imbrication of citizenship and sexuality, has traditionally focused on the role of heteronormativity in social organization and the impacts of that organization on the lives of LGBTQ persons. Little work has examined the utility of this framework for understanding the experiences and positioning of persons with cognitive (dis)abilities, though they too have a long history of sexual oppression and civic disenfranchisement. In addition, few studies have empirically investigated the sexual and gender identities or intimate lives of this population. This study sought to fill these gaps in basic and theoretical understanding through in-depth, Internet facilitated interviews with 24 adults on the autism spectrum. Autism Spectrum Disorder is characterized by differences in social communication and unusual behaviours or interests, as well as sensory differences. Two levels of thematic analysis were conducted on interview data. A semantic analysis of participants' intimate experiences and sexual-gender identities demonstrates that participants were successful at developing satisfying relationships and using intimate and genital touch for self-regulation. On the other hand, participants struggled with sensory-based barriers to sexual satisfaction, courtship difficulties, and experiences of intimate violence and betrayal. This analysis also substantiates previous research indicating a propensity toward gender and sexual non-conformity among persons on the spectrum, as well as delayed sexual milestones. A latent analysis connecting participants' everyday experiences with structural processes demonstrates that participants were positioned as marginal citizens through the workings of ability and (hetero)sexual normativity in their everyday lives. Participants' sexual citizenship was limited by the operation of these normativities evident in experiences of structural and cultural ableism, as well as heteronormativity and the primacy of monogamous sexual relationships. Participants also enacted and enhanced their sexual citizenship through the sexual economy and (hetero)sexual normalization, as well as social support, an Autistic identity, and the deployment of proactive strategies for managing (dis)ability. Finally, participants articulated new gender, sexual, and ability normativities that better facilitated their access to sexual citizenship. These analyses illustrate how normative sexuality is predicated on typical ability. Further, they show how ability and sexuality separately and in their entwined aspect mediate access to full citizenship.

ACKNOWLEDGEMENTS

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CHAPTER ONE

Introduction

The visibility of Autism Spectrum Disorder (ASD), a neurological disorder characterized by differences in social communication and unusual behaviours or interests, has grown rapidly over the last 20 years as increasing numbers of children have been diagnosed with the condition (Centers for Disease Control and Prevention, 2012; Liu, King, & Bearman, 2010). Now, increasingly large cohorts of individuals diagnosed as children are "coming of age". In the current climate of cultural visibility, undiagnosed adults are self-identifying as individuals on the autism spectrum as well. Many of these self-identified autistic adults[1] seek validation of that identity and access to services or accommodations through formal diagnosis. We have, for the first time, a culturally-recognized population of autistic adults. Concurrent with the emergence of this new social category has been the emergence of the neurodiversity movement and research in areas such as higher education, employment, and sexuality in the lives of autistic individuals.

The neurodiversity movement (NDM) is allied with the broader disability rights movement (DRM). The NDM asserts neurological difference, such as ASD, as a basis for shared identity and demands social, political, and distributive change that values and respectfully supports all citizens in their neurological difference (Bumiller, 2008). The broader DRM has given increasing attention to sexuality as a

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[1] Debates rage about the most respectful way of referring to a person's disability identity, with some preferring "people first" language and others rejecting it. In this document, I will use both disabled people and people with disabilities. When referring to people on the autism spectrum specifically, I use the terminology preferred by the participants in this study. Therefore, I will refer to persons on the spectrum or to autistic persons, but not to persons with autism.

critical aspect of human rights and citizenship over the past two decades (Carey, 2009; Carlson, 2001; Fidducia, 2000; Kempton & Kahn, 1991; Shakespeare, 2000; Siebers, 2008; Waxman, 1991). Activists and disability studies scholars point to the long history of the sexual oppression of disabled people, including such measures as state-sponsored involuntary sterilization and laws preventing their marriage, the latter of which are still in effect in many states (Carlson, 2001; Carey, 2009; Kempton & Kahn, 1991). The NDM has not focused its attention, as of yet, on the sexual oppression and disenfranchisement of those with atypical neurological functioning.

As an emergent area of research, there remains little academic work and even less empirical data about the sexuality of disabled people. The extant literature on disabled sexuality, like the DRM and disability studies more broadly, privileges the experiences, perspectives, and concerns of those with physical disabilities. There is a general dearth of theorization or data about the sexual identities and experiences of individuals with cognitive disabilities, particularly those of individuals on the autism spectrum. Available empirical studies of sexuality in the lives of autistic individuals rely primarily on the secondary reports of family members, teachers, and/or caregivers. The literature is also primarily quantitative and produced from a perspective on disability and sexuality that pathologizes variation (e.g. non-heterosexuality framed as problematic). The subjective identities, experiences, and concerns of persons on the spectrum are notably absent from the literature.

In this dissertation research, I investigate autistic sexual citizenship from the standpoint of individuals on the spectrum by learning about their everyday experiences through in-depth interviews. The purpose of this research is to build knowledge about sexuality in the lives of autistic persons, understand how that sexuality is shaped by socio-legal and relational milieu, and contribute to increased understanding of the relation between sexuality and citizenship through an examination of their interplay in this context. The setting of this research is the United States.[2] I limited participation to denizens of one nation-state due to my focus on the context of participants' lived experiences in conjunction with the expectation, based on previous Internet-based sex research with this population (Byers, Nichols, & Voyer, 2013; Gilmour, Schalomon, & Smith, 2012), that my sample would be too small to allow cross-country comparisons and that the largest pool of potential participants would be U.S. denizens.

To accomplish these goals, I use these data to answer three specific research questions. 1. What are the sexual experiences and identities of individuals on the autism spectrum? 2. How are these experiences and identities shaped by normativities (i.e. social norms and the discourses, practices, and distributive arrangements associated with them)? 3. What insights does a focus on ability as manifest in the sexual lives of autistic citizens bring to our understandings of normative sexuality and its connections with socio-political status?

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[2] Internet recruitment resulted in a sample of participants from every region of the contiguous U.S., with overrepresentation of the northeast and underrepresentation of the southwest.

In Chapter 2, I first describe the theoretical framework of sexual citizenship. I then integrate insights from other veins of citizenship theorizing to develop a particular understanding of citizenship as a framework for articulating the conditions that enable equitable participation in a public struggling to realize shared aspirations for human living. These aspirations importantly include aspirations for intimate life. This conceptualization of citizenship is explicitly normative and firmly grounded in lived experiences and the concrete social locations where they occur. I also conceptualize (dis)ability as the relationship between individual and structural factors, focusing on how the boundary delimiting the social position and identity produced by this relationship is a permeable one. Finally, I review the literature on sexual citizenship for people with disabilities and empirical research on sexuality and intimacy in the lives of autistic adults.

In Chapter 3, I describe the study method. Important aspects of study procedure, such as recruitment and collaboration with a Community Advisor, are discussed in detail. I also detail the benefits and challenges of my primary interview format, e-mail. Finally, I discuss the two thematic analyses performed on the data. The first, semantic, analysis answers my first research question: What are the sexual experiences and identities of individuals on the autism spectrum? Given the dearth of information about the sexual experiences and identities of persons on the autism spectrum, this descriptive analysis is necessary to provide the empirical foundation needed before I could seek to answer my second research question: How are these experiences and identities shaped by normativities (i.e. social norms and the discourses, practices, and distributive arrangements associated with them)? This

second question, connecting lived experience with social organization through the particular understanding of sexual citizenship developed in Chapter 2, is answered through the second, latent, analysis.

In Chapter 4, I discuss the results of my inductive, semantic thematic analysis, providing a rich thematic description of commonalities in the sexual and intimate lives of autistic adults. I organize this analysis under the umbrellas of success and struggle. The analysis demonstrates that participants in this research experienced success in the areas of relationship satisfaction and sensual equilibrium. It also demonstrates that they faced struggle in the domains of courtship, sensation, and abuse-exploitation.

In Chapter 5, I discuss the results of my deductive, latent thematic analysis, providing a nuanced account of the socio-legal and relational milieu shaping the common experiences described in Chapter 4. I organize this analysis under the umbrellas of discipline-subjectification, identifying experiences that reflect limitations on sexual citizenship, and empower-fluidity, identifying experiences that reflect the exercise of sexual citizenship. The analysis demonstrates that participants' sexual citizenship is restricted by cultural and structural ableism, heteronormativity, and the primacy of monogamous sexual relationships. It also demonstrates that they exercise sexual citizenship through the sexual economy, sexual normalization, articulation of a right to pleasure and an Autistic identity, social support, use of proactive strategies, and the articulation of alternative normativities.

In Chapter 6, I discuss the foregoing analyses in the context of previous literature, developing the implications of my findings for broader analyses of sexuality and citizenship. It is through this discussion that I answer my third research question: What insights does a focus on ability as manifest in the sexual lives of autistic citizens bring to our understandings of normative sexuality and its connections with socio-political status? I argue that participation in monogamous sexual relationships, a primary form of socio-economic organization, is dependent on ability and sexuality. Sexuality is abled. It is a particular way of experiencing and being in the world that depends on particular body-mind experiences. Access to partnered sexuality is mediated by the socio-economic value attached to the demonstration of particular abilities. The incorporation of ability as an axis of experience and social stratification demands that we reconfigure the starting point of our analyses. Rather than understanding sexuality, or gender, as universal human experiences and asking only "what" sexuality organizes society, we must also attend to the theoretical question of "why" sexuality organizes society. I suggest that it has to do with fundamental connections between sexuality and our understanding of personhood. One cannot be a citizen without personhood, nor a person without sex. How then are we to understand the lives and positioning of the asexual or abstinent?

The research presented here is the first known qualitative investigation of the sexual identities or sexual and romantic relationship histories of adults on the autism spectrum. It adds uniquely to our empirical knowledge of the intimate lives of this population and the broader cognitively disabled or neuro-atypical populace

to which it belongs. The analyses also contribute to our limited understanding of how the intimate lives of autistic individuals, and those within the broader (dis)ability community of which they are a part, are regulated through policy mechanisms, social norms, and dominant discourses. Finally, these analyses provide a unique position from which to contribute to theoretical understandings of how sexuality, ability, and citizenship are intertwined and reciprocally regulated in U.S. society.

CHAPTER TWO

Literature & Theoretical Framework

Sexual Citizenship

This research project was an investigation of sexual citizenship as experienced by and expressed in the lives of people on the autism spectrum. My work was motivated by interest in the concept of sexual citizenship and its emancipatory potential. Sexual citizenship is one of the many iterations of citizenship theory that arose out of a resurgence in scholarly attention to citizenship in the 1980's. The concept has been developed in a number of disciplines, including sociology, political science, law, and geography. Sexual (or intimate) citizenship is a way of conceptualizing the sexual dimensions of citizenship, while attending to the impacts of citizenship on sexual and intimate life. Sexual citizenship is not to be read here as a special *type* of citizenship, a look at "sexual" politics or "sexual" society. The concept of sexual citizenship instead serves as a call to look at the intimate aspects and impacts of citizenship *sine qua non*, the sexual embedded in the socio-political, the socio-political embedded in the sexual. As Bell & Binnie (2000) observed, "all citizenship is sexual citizenship" (p. 10, emphasis removed).

The name of the theory, however, does point to its genesis in efforts to have the sexual aspect of citizenship recognized. Simply talking about "citizenship" was inadequate at the time the theory was developed because the way "citizenship" was conceptualized explicitly excluded "private" matters like sexuality. Though sexual citizenship should be understood, simply, as citizenship, I will continue to use the marked term as it is used in the literature. Similarly, I will be discussing "disabled

sexuality" using the marked term developed in the literature. This term also reflects

the need to make visible what had been conceptually hidden, that (dis)abled people

are sexual and contribute to the articulation of diverse sexualities. Sexuality is

conceptualized in this study according to the World Health Organization's (2006)

working definition:

> Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed.

Sexual citizenship is an explicitly normative theoretical framework. Scholars

engage with this concept to grapple with questions of ethics and justice; many seek

to connect their work with social change efforts. The current project is no different

in this regard. The idea that sexuality is central to citizenship has functioned as an

organizing concept for individual and group action, as people make claims to rights,

membership, and identities (Bell & Binnie, 2000; Richardson, 2000; Seidman, 2005;

Weeks, 1998). Sexual citizenship has been used to make rights claims and explore

membership and identity as they are produced in a number of arenas, such as

marriage (e.g. Bell & Binnie, 2000, Chapter 2; Herdt & Kertzner, 2006; Phelan, 2001,

Chapter 3), military service (e.g. Conway, 2004; Bell & Binnie, 2000, Chapter 2),

reproduction and family formation (e.g. Berlant, 1997, Chapter 3; Plummer, 2003),

and representation (e.g. Berlant, 1997, Chapter 2; Richardson, 2000).

At the same time, it has been used predominantly to explicate the

heteronormativity of citizenship and its impact on LGBT and queer people. Berlant

and Warner (2002) define heteronormativity as the "sense of rightness" that
proceeds from participation in heterosexual culture (p. 194). Heterosexual culture
includes "a constellation of practices that everywhere disperses heterosexual
privilege as a tacit but central organizing index of social membership" (Berlant &
Warner, 2002, p. 195). Recently scholars and activists have given more attention to
the utility of sexual citizenship in understanding and making rights claims for other[3]
groups, such as breastfeeding mothers (Smyth, 2008), sex workers (Sanders, 2009),
and people with disabilities (Sanders, 2007; Shildrick, 2007).

Scholars employ a sexual citizenship framework to examine the nature and
use of state power; imbrications of state power with culture, society, and economy;
as well as resistance (or the potential for resistance) to this power (e.g. Bell &
Binnie, 2000; Cooper, 1993; Phelan, 2001). They examine how socio-political life is
sexually organized and the impacts of this organization. Richardson (2000), for
example, asks, "how are various forms of citizenship status dependent upon a
person's sexuality" (p. 170)? Scholars have generally focused their inquiries around
this central question, with a dominant focus on how sexual minority status affects a
person's legal relationship with the state. One might equally ask, "how are various
forms of sexuality dependent upon a person's citizenship?" This latter question calls
our attention to how citizenship (a concept which, as developed below, extends
beyond a persons' legal relationship with the state) shapes intimate life.

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[3] Of course LGBT and queer people may equally be breastfeeding mothers,
etc. However, the work is differentiated by the organizing identity and/or practices
under study.

In this project, I seek to engage with both questions. One contribution of this project, therefore, is to expand scholarship using the sexual citizenship framework to examine the sexual organization of socio-political life and the socio-political organization of sexual life. This is accomplished, in part, through the development below of a synthetic understanding of citizenship as a framework for articulating the conditions that enable equitable participation in a public struggling to realize shared aspirations for human living. These aspirations importantly include aspirations for intimate life. This conceptualization of citizenship is explicitly normative and firmly grounded in lived experiences and the concrete social locations where they occur. As such, the conceptualization developed here emphasizes the relational nature of citizenship.

These emphases on normativity and situated social relations, explicated in *Relations in place,* are related to the second way this project expands sexual citizenship scholarship; that is its application to a social group differentiated by cognitive (dis)ability. These emphases are important to understanding the experiences of persons with (dis)abilities for two reasons. First, the emphasis on normativity assists in refocusing the sexual citizenship lens so that it may perceive *ability* as a normativity, as well as heterosexuality as a normativity. Second, persons with (dis)abilities depend on caring relationships throughout their lives. The citizenship of persons with (dis)abilities is, therefore, mediated through their relationships with those they live alongside. This is particularly true for those with more limiting and/or less socio-politically accommodated impairments. The importance of sociality for citizenship is further highlighted for the particular sub-

group of the disability community on whom this project centers, persons on the

autism spectrum, given that social difficulties are a defining aspect of their

condition. I turn now to an elaboration of this perspective.

Membership-Rights-Responsibilities.

Membership. Citizenship in liberal democracies is most broadly read as a

combination of rights and membership. Membership has traditionally meant that a

person has a legal relationship with a nation-state in which that state agrees to

provide certain resources (i.e. rights), like protection from harm, in exchange for

compliance with particular rules (i.e. responsibilities), like obeying the law.

However, membership can be conceived more broadly to mean recognition as a

moral equal and inclusion in a particular human community based on this and other

shared characteristics (e.g. location, heritage, etc.). I will call the two aspects legal

membership and social membership. Legal and social membership are interrelated.

Both are necessary for full citizenship.

Sassen (2005) usefully distinguishes between these two conditions by

referring to the former as "authorized" and the latter as "recognized." She calls

attention to the imbrication of rights with membership by distinguishing those who

are "authorized but not recognized" (for example, sex workers with legal citizenship

status) from those who are "recognized but not authorized" (for example,

undocumented immigrants who otherwise demonstrate the qualities of a "moral

equal"). The former refers to those persons who have legal but not social

membership and the latter to those persons with social but not legal membership.

Persons in either condition of incomplete membership are offered a variegated,

incomplete complement of rights that are more precarious and contingent than those offered persons with full membership.

This is because membership is necessary to activate rights, i.e. resources of membership. Legal membership will entail one constellation of rights. Social membership will entail another. Both types of membership are necessary to entail a full set of rights, many of which are only available to those with *both* types of membership. Manipulating a person's membership is one way to adjust their complement of rights. Luibheid (2008), arguing that citizenship status (or legal membership) is a contingent process rather than a fixed characteristic, points to how shifting immigration policy renders once-viable paths to authorization suddenly closed. These policy shifts are often driven by concerns over who has access to rights. Importantly, these are state-based decisions. The state is actively engaged in the process of regulating what persons constitute it.[4]

Some scholars argue that under conditions of globalization we have moved away from the primacy of national membership in organizing membership-rights-responsibilities, to a primacy of residency where global norms rhetorically embodied in human rights are manifest in local settings (e.g. Benhabib, 2007), through, for example, the European Human Rights Court or compliance of national and/or state laws with the conventions or declarations of the United Nations. I agree with this formulation to some degree. As discussed above, a person's relationship with the nation-state is a contingent process with a stratified relationship to their treatment and life chances; it is not an immutable guarantee of anything. This is due

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[4] See Arendt (1968) for a discussion of such state-led disenfranchisement as a feature of the totalitarian state.

in part to the fact that local relations between a person and those they live alongside mediate or, arguably, instantiate citizenship. This local, relational conception of citizenship is explored further in *Relations in place*.

While recognizing global-local dynamics and their effects on citizenship, I *also* keep in view the crucial "right to have rights" classically articulated by Arendt (1968). A person's relationship with a nation-state, particularly the nation-state in whose borders they currently find themselves, dictates to a large extent whether or not global (or any other) norms will, in fact, be made manifest. Though it is certainly true that globalization and securitization processes have weakened the strength and reliability of a person's contract with their state (e.g. dual citizenship and the USA Patriot Act), laws and local norms still constrain the treatment of citizens by their nation-state in ways that do not apply to those without legal membership (Krause, 2008; Maher, 2002). It is particularly important to keep the "right to have rights" in view when considering citizenship in the U.S. context, where the current study was conducted, due to the long history of U.S. exceptionalism (Somers & Roberts, 2008). Exceptionalism refers to the perception that the U.S. is somehow exceptional and therefore not subject to the norms and rules that other countries are expected to follow (e.g. UN conventions and declarations). This exceptionalism is one reason I choose to conceptualize social justice efforts through the paradigm of citizenship rather than human rights.

As pointed out by Sassen (2005), however, legal membership is only one malleable component of membership. Social membership is also, and perhaps especially, open to manipulation. The histories of liberal democracies are rife with

exclusions and oppressions based on beliefs that persons with one type of difference or another (i.e. difference from the dominant group) are not the moral equal of those currently dominating resources (for example, racial/ethnic minorities, women, etc.). Sexual citizenship was first articulated to point to how *sexual* difference has historically served as a basis for the denigration of a person's moral worth and, from there, their claim on membership and rights, i.e. mapping the effects of heteronormativity. Its intellectual genealogy is different, therefore, from citizenship scholarship focusing on the regulation of access to legal membership or describing the contours of a state's relationship with its unmarked *citoyen*. Sexual citizenship developed out of the positionality[5] of those who are "authorized but not recognized", or to use Phelan's (2001) evocative terminology, strangers born *in* but not *of* a society. One effect of this genealogy on the development of the framework is careful attention to social membership and its relationship with legal rights (i.e. rights as formally articulated through law and legal institutions).

> **Rights.** Legal rights are a (somewhat contingent) "guarantee" conferred on members. Marshall (1963) classically articulated these guarantees as of three types: civil, political, and social. In this formulation, civil rights are guarantees which define our freedom to act without intervention (e.g. freedom of speech). Political rights are guarantees which define our participation in the governance of the nation-state (e.g. voting). Social rights are guarantees which define our standard of living and status within the community (e.g. provision of a minimum income). Rights are still largely understood through this tripartite framework. However, social justice scholars

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[5] A way of knowing and interacting with the world that is associated with a particular social position (adapted from Naples, 2003, p. 23).

point out that social rights are absolutely crucial to enabling the exercise of civil or political rights and are, therefore, in some sense prior to the other two (e.g. Somers & Roberts, 2008).

Rights are not simply formal guarantees, however; they are also an on-going performance of membership. As Carey (2009) points out, "the politics of rights are principally centered on attempts to create a particular pattern of relationships within society" (28). "Rights constitute a resource of citizenship, providing a tool to be used to influence others, pursue one's interests, and mark one as a respected member of the community" (Carey, 2009, 15-16). Thus, rights both reflect and help produce our standing in society.

Rights as an on-going performance of membership, or rules for relating, fixes our gaze on the context in which rights are exercised. Rights exist (or not) only in context. Correa, Petchesky, and Parker (2008) join others in arguing that we rely on immediate others for, "respecting (or not) the right to sexual pleasure by adhering (or not) to fundamental principles of social inclusion, freedom, and human dignity" (4). In other words, rights, as tangible resources that we can use to pursue desired ends or experience desired states of being, are actually provided *in situ* by the people we live alongside. This reliance on others and the context-dependency of rights is explored further in *Relations in place*.

Responsibilities. In addition to membership and rights, many scholars also keep responsibilities in view when articulating the components of citizenship. While a few scholars taking up the issue of sexual rights remind us of the importance of responsibilities and the necessary trade-off between rights and responsibilities to

create a balanced, sustaining social system (e.g. Eskridge, 2001; Maticka-Tyndale &

Smylie, 2008), the majority of scholars working toward emancipatory change see

the responsibilities component as a (perhaps) necessary evil. In contrast to their

claims on membership and rights, most scholars of sexual citizenship who engage

with responsibilities deny or decry their necessity as a component of citizenship.

They see it as citizenship's main weakness as a framework for emancipatory change.

Other scholars in this tradition fail to engage with responsibilities at all, or do so

under the guise of regulation and normativity without identifying these processes as

citizenship responsibilities.

Essentially, scholars observe (correctly) that making citizenship claims

brings subjects, and the social group by virtue of which they can be claims-makers,

under the regulatory gaze of state and society. This happens at the ideological,

group, and individual levels. At the ideological level, Phelan (2001) argues that

requests to be admitted to a community as moral equals (for example, access to

legal marriage for same-sex couples), i.e. social membership claims, shore up the

dominant normativities of that community by demonstrating that those

normativities are valid conditions for social acceptance. Rather than asserting the

value of the difference and being embraced *in* their difference, group members are

embraced *in spite* of their difference. Because the original normativities are left

unchallenged, the imperative to act in ways that align with those normativities

remains intact.

At the group level, these unchallenged normativities become demands for the

particularized performance of a particular identity. Normativities are expressed in

and through law. Legal systems rely on rigid identity categories (e.g. man, woman, child, etc.), with particular sets of rights and responsibilities entailed to individuals by virtue of their membership in an identified social group (Carey, 2009; Fabeni, 2007; Shildrick, 2007). At a very basic level, citizenship claims have normalizing limitations because they require ascription to a fixed identity. This limits, or arguably prevents, the expression of intra-group difference and stagnates the pool of social positions available for people to occupy (Alexander, 1999; Bickford, 1997). Following this line of argument, citizenship will always be flawed as a framework for emancipatory change because the very act of claims-making, while enabling persons to achieve desired ends, relies on the social reproduction of current normativities and individual subjectification to them, i.e. the fitting of the self into an available social position with its associated practices (Burchell, 1991; Cruikshank, 1999) (e.g. monogamously married adult).

Others, however, argue that citizenship claims-making does not *necessarily* entail the reproduction of the current social order. Scholars making this argument emphasize three points. First, they emphasize that identity-based politics are strategically necessary (Bernstein, 2005, Carey, 2009). Carey (2009), for example, describes how claims on community resources (for community based care for people with intellectual disabilities, for example) in the U.S. are structured by the rhetorical necessity of the rights framework. Second, they argue that identity-based politics are not necessarily totalizing. Claims, once fulfilled, provide resources for the renegotiation of the normativities on which terms they were articulated (Bell & Binnie, Chapter 1, 2000; Bernstein, 2002 & 2005; Correa et al., 2008; Rosenblum,

2009). For example, workplace accommodations, provided on the basis of claims reinforcing the normativity of ability, provide resources that can enable the challenge of that normativity when competence becomes redefined. As Stychin (2003) observes, citizenship both disciplines and empowers. In other words, it both constrains and enables the pursuit of desired ends. Third, scholars promote the pursuit of claims-making based on open identities and/or common concerns shared by a coalition of identity-based groups (Bernstein, 2002 & 2005; Bickford, 1997; Correa et al., 2008; Phelan, 2001; Stychin, 2003). For example, rather than making claims on the basis of a disability identity or diagnosis, it is preferable to engage a coalition of people who experience limitations (e.g. people with various disabilities, those experiencing mental illness, the elderly, the gestating, etc.).

  Relations in place. This discussion of the normative limits of citizenship points to tension in the conception and purpose of citizenship. Sassen (2005) identifies this tension as one between citizenship as a status and citizenship as a normative project. Sexual citizenship scholars typically situate themselves within the community of scholars who see citizenship's purpose - and function - as a normative one. The articulation of citizenship answers questions about who we are as a human community and how that is expressed by, and constructed through, how we treat one another. Integrating these insights with an understanding of institutions, such as citizenship, as "the social relations enacted in the setting that rule what can happen" (Campbell, 2008, p. 270), I understand rights as rules of relation, rules structuring how we treat others. Citizenship is conceptualized in the

current research as a framework for realizing a shared normative aspiration for human collectivities and individualities.

Feminist and queer scholars have been developing this vein of citizenship theorizing for some time. Understanding rights as rules for relating instantiated in concrete social locations, they have articulated "relational rights" (e.g. Carey, 2009; Lister, 2003). Scholars working in this tradition emphasize, against the common interpretation of rights as individual legal entitlements, that rights exist *only* in relationship with others. Under this understanding, rights are not *granted* by the "state". State power, though foundational to the security of rights as argued above (see p. 14), is only one aspect of how rights become manifest through relations with those we live alongside. Scholars developing this vein of citizenship theorizing also sometimes challenge the interpretation of rights as rules regulating the performance of specific *acts*. Seidman (2001), for example, calls for us to focus instead on the social exchange. Rather than evaluating the moral meaning of the *act*, we should evaluate the moral meaning of the act *in its communicative context*. Does the social exchange in question align with our shared normative aspiration? Does it respect the humanity of each person involved with or affected by the exchange?

From this perspective, questions about how citizenship is dependent on sexuality and sexuality upon citizenship are best answered through an examination of social relations as manifest in the everyday realities of individuals (Plummer, 2003). These realities are space and resource bound. They are dependent on the particular socio-legal and relational context in which an individual finds themselves. This approach allows us to look at "concrete interactions within institutions to show

how people negotiate or succumb to hierarchical relations and how these relations

of power shape what kind of person it is possible to be within these institutions"

(Moon, 2008, p. 191).

Examining the local production of legality through municipal rulings on birth

certificates, Sterett (2009) shows how the recognition of parenthood is not only or

primarily produced through state law, but through the everyday experiences of

families with pediatricians, school officials, etc. Families able to obtain state-based

"proof" (i.e. birth certificate) of parenthood, even when this status is denied by state

law, are effectively granted access to social membership when that document is

accepted by those in their everyday life. These local others actually produce

parental rights by behaving as if the parental relationship and entailed rights exist.

As illustrated by Sterett's (2009) analysis, the legal consciousness of local others,

particularly gatekeepers, is critical to the production of rights *in situ*. In the case of

people on the autism spectrum, important gatekeepers include parents, school

administration and staff, doctors, and mental health or social welfare providers.

This relational conception of citizenship makes clear that citizenship is

defined by a person's participation in a *public*. This may seem like an obvious point,

since the concept of citizenship developed out of attempts to articulate the

relationship between people and the body governing their collectivity. It is,

therefore, inherently a conceptualization of a person's place within a particular

public. However, citizenship in the U.S. has largely become understood as an

individual property identifying the legal relationship between a specific person and

their abstract, reified, national government (i.e. legal membership). Against this

popular understanding, I join other scholars in emphasizing that citizenship is defined by participation in public life (Lister, 2007; Phelan 2001).[6] Under this definition, citizenship as a normative aspiration is clarified as a framework for articulating the conditions that enable people to participate equitably in public life - or the co-construction of our shared aspiration for human living and its associated distributive arrangements. Our shared aspirations for human living in a particular space-bound collectivity are expressed by and created, in part, through culture. Therefore, I argue that cultural change *is* citizenship practice. Our shared aspirations for human living importantly include sexuality and intimacy. For example, shared aspirations may include reproduction, monogamous marriage, or the opportunity for positive desired sexual experiences.

The take-away. This articulation of citizenship as equitable participation in a public striving to realize shared aspirations for human living is critical to my understanding of citizenship as a theoretical framework to conceptualize emancipatory social change. The emphasis on the relational nature of citizenship is critical to its utility in conceptualizing such change for persons with (dis)abilities, who depend on caring relationships throughout their lives. This is particularly true for those whose impairments are more limiting and/or less socio-politically accommodated. While I am myself deeply wary of the normalizing limitations of citizenship claims, I also find citizenship to be the most actionable framework for

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[6] Public is not meant here to be understood as singular. Following Warner (2005), I recognize the existence of multiple publics and the importance of this heterogeneity for social progress. However, some equitability of participation in the hegemonic public sphere is necessary to substantively affect shared norms and resource distribution.

emancipatory social change currently available. Thus, while affirming the critiques of those who warn against citizenship claims as inherently limited and normalizing, I situate myself, and this project, within efforts to make the best of an imperfect framework. While citizenship may have "developed as elaborate tariffs of partial or complete exclusion according to adjudicated standards of status conformity" (Evans, 1993, p.55), one responsibility of citizenship understood as participation in a public striving to realize shared aspirations for human living is working to change and expand those standards. As Shotwell (2012) argues, "shaping new ways of knowing and being with altered criteria for what will count as successfully meeting relevant norms—creating new norma-tivities—opens the possibility for finding our bearings even in the process of working to change the world" (p. 1003).

Consonant with the understanding of citizenship developed here, and in response to the valid critiques reviewed in *Responsibilities*, I keep two related dynamics in view in the current study, 1) the tension between discipline and empowerment and 2) the tension between subjectification and the contestable entity of an "open identity". Following the insights of Foucault (1995) and Cruikshank (1999), I do not conceptualize discipline and empowerment as opposed power dynamics. Rather, these terms are used in this research to identify "moments" in which persons experience limitation or support in the pursuit of socially pre-figured ends. In other words, the concepts are used to sensitize us to how participants experience their efforts to participate in dominant visions of the common good.

As will become clear in Chapter 5, substantial evidence of "open identities" was not found in this research. However, the data provide evidence of robust efforts to articulate alternative (i.e. outside the framework of dominant normativities) identities and associated social positions. Subjectification and "fluidity" as I refer to these latter efforts, therefore both refer to the process of fitting oneself into a social position, with subjectification requiring fit into an existing social position in the hegemonic public sphere and fluidity requiring negotiation of a nascent social position, often in an alternative public. Finally, this project responds directly to the call for coalition-based citizenship claims by explicating the common ground of difference centered in sexuality and ability and seeking to draw into conversation two social movements that may benefit from shared struggle.

Disability Model

The two social movements that I seek to bring into conversation are the disability rights movement (DRM) and the LGBTQ rights movement.[7] There are many parallels between the experiences, concerns, and theoretical insights of these two social and intellectual movements (Kafer, 2003; McRuer, 2002, 2003; Rembis, 2010; Sherry, 2004; Shuttleworth, 2007). McRuer (2002), in fact, argues that the normative goals of these movements are fundamentally intertwined, as, "compulsory heterosexuality is contingent on compulsory able-bodiedness and vice versa" (p. 89). The disability and LGBTQ rights movements therefore share a

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[7] Each of these "movements" is itself made up of several strains of advocacy that are often in tension with each other (Alexander, 1999; Caruso, 2010). However, each is here used to designate broad movements for social change intended to benefit those whose identities and ways of life are (more or less) represented by these broad categories.

common enemy in these entwined normativities. Scholars have also drawn parallels

between the persistent imperative for the always incomplete performance of

gender, as articulated by Judith Butler (1999), and the performance of ability (e.g.

McRuer, 2002). Both movements seek to understand and dismantle an oppressive

system in which a particular normativity for the expression of human life, one

rooted in the relationship between the self and the experience and uses of the body,

becomes the taken-for-granted basis of fundamental social structures (e.g. all bodies

are either male or female with corresponding masculine or feminine gender

identities and social roles).

      Like feminist and queer studies, disability studies emerged out of the critical

insights of a social movement that had begun to problematize the taken-for-granted.

Common concerns addressed by these movements and related scholarship will be

explicated as we turn from feminist and queer studies to examine theoretical

models of disability and the fruitfulness of applying the sexual citizenship

framework first articulated by LGBTQ and feminist scholars to the intimate

concerns of people with disabilities.

      Disability activism became more organized and visible in the West in the

1970's. Activist groups, like the Union of the Physically Impaired Against

Segregation, began to redefine the problem of disability as social rather than

individual (Union of the Physically Impaired Against Segregation, 1976). This was a

path-breaking shift in how (dis)ability was experienced, understood, and studied. A

decade or so later, this radical shift in thinking made its way into the academy. What

was to become disability studies began to germinate and take root as scholars

explored the possibilities for rethinking social structures, relations, and norms through an ableist lens.

This shift to understanding personal troubles as public issues was first articulated through the social model of disability. The social model posits that "disability is an emergent property of social relationships" (Williams, 1998, p. 238) that is defined by shared experiences of oppression rather than the existence of a physical or intellectual impairment (Shakespeare, 2006). This model divorces impairment, a physical or cognitive limitation, from disability, a social identity and condition (Oliver, 1990). Thus, like scholarship on sexual and gender identities, early disability studies work sought to illuminate the socially-dependent nature of a characteristic previously thought biological and universal. This theoretical maneuver has been critical to strides in disability activism and scholarship. Contemporary disability studies scholarship has largely moved past this initial conceptualiztion, however, offering a variety of post-social disability models.

Evolving models of disability emphasize how impairment categories are themselves socially constructed, a point clearly illustrated by how the labeling of non-normative cognitive functioning has shifted meaning and shifted *in* meaning over time so that any demarcation between "norm" and "not norm" is constructed (Carey, 2009, p. 14). This point is particularly salient when considering autism spectrum disorder, a (dis)ability defined by social deviation. In addition, the impairment/disability distinction as originally conceptualized through the social model has not been best able to account for empirical research on the lives of people living with disabilities, where the effects of each are important for quality of life and

may be entwined (see Shakespeare, 2006, Chapter 3 for a review). Shakespeare

(2006) observes that "even in the absence of social barriers or oppression, it would

still be problematic to have an impairment, because many impairments are limiting

or difficult, not neutral" (p. 41). Importantly, many of the studies where this

imbrication and indivisibility are highlighted focus on people with neurological

conditions. The distinction between impairment and disability is more difficult to

sustain when the brain is involved. For those for whom impairment is not neutral,

regardless of social conditions, research and policy decisions guided by an

unmodified social model prove suboptimal.

Scholars developing new (dis)ability models typically affirm the fundamental

insights of the social model and the positive impact it has had on identity, esteem,

and activism for people with disabilities. They seek to integrate these insights with

those from subsequent work emphasizing the failure to adequately theorize or

make analytic room for the embodied experience of impairment-disability and,

linked with this, the historical marginalization of people with cognitive disabilities

from research and activism (Chappell, 1998; Clifford, 2012; Meekosha, 1998;

Overboe, 1999; Rembis, 2010; Tremain, 2001). In parallel with similar schisms in

feminist and LGBTQ studies, there is tension in contemporary disability studies

between those who call for a radical or queer approach to social change efforts and

those who call for a pragmatic and gradual approach. Those in the first camp tend to

be theorists who imagine radically emancipatory possibilities for human living and

do not want to settle for less. Those in the second camp are more likely to be

involved in practical social change efforts and/or research and exhibit heightened

concern about everyday realities in the here and now. Scholars in the first camp

often label the position as "critical disability studies". They call for a move beyond

the extension and solidification of rights to an examination of impediments to the

"evolution of equitable conditions of possibility" (Shildrick, 2009, p. 2) and "access

to a newly imagined and newly configured public sphere where full participation is

not contingent on an able body" (McRuer, 2002, p. 96).

In contradistinction to these queer positions, other scholars call for rights-

based claims for inclusion. Among these approaches, Shakespeare's (2006)

interactional model of disability provides the best union of theoretical precision and

pragmatics (Chapter 4). He recognizes the context-dependency of impairment-

disability as well as the need to draw boundaries to effectively pursue redistributive

goals. Shakespeare (2006) defines disability as the relationship between individual

(e.g. impairment) and structural (e.g. accessibility) factors (p. 55). Shakespeare

(2006) argues that the inclusion of the body as a contributing causal factor for

disability is necessary because "[t]he problems associated with disability cannot be

entirely eliminated by any imaginable form of social arrangements" (p. 56). In this

model people are disabled by their bodies *and* society. This model aligns with the

World Health Organization International Classification of Functioning, Disability,

and Health, under which "the label of disability becomes a designation of the

outcome of the interaction of the individual and the environment and not merely a

label applied to a person" (Bornman, 2004, p. 186).

Shakespeare (2006) argues that impairment should be understood as a

"predicament", something that makes life harder but which we cannot ultimately

avoid (p. 63). He likens it to menstruation, childbirth, and the inevitability of death for all humans. In this formulation, impairment is a universal experience. This is not a unique insight, as disability scholars regularly point out that disabled is one of the few social categories every person occupies at some point or another in their lifespan. The difference is that the focus on "impairment" rather than "disability" as a universal experience moves it out of the category of identity. While every human experiences impairment at some point in their life,[8] not everyone will *identify* as disabled. Shakespeare (2006) argues that this maneuver will focus distributive efforts on creating structures capable of supporting people, generally, with their various capabilities and needs rather than meeting the "extra" demands of a special population.

Acknowledging the insights of Shildrick (2009) regarding the need to rhetorically interrogate attempts to reify disability, I incorporate the use of *(dis)ability* to signal the permeability of the boundary between ability and disability. Thus, when (dis)ability is used rather than disability, the intent is to focus the reader on the spectrum of human ability and functioning. Thus, when I point to the importance of relationships with those we live alongside for the exercise of citizenship for persons with (dis)abilities, I am pointing to how sociality mediates citizenship for *all* persons. Consistent with the interactional model of disability adopted here, I also acknowledge that a relational conception of sexual citizenship is

[8] Aside from the vicissitudes of unpredictable life experiences and the physical limitations inherent in aging, infancy is arguably a stage of life characterized by impairment that all humans experience perforce. In addition, postmodern understandings of impairment emphasize that it is a spectrum, like gender or sexuality. Impairment simply points to natural variations in types and degrees of abilities.

of particular import for persons whose impairments-disabilities are more limiting

and/or less socio-politically accommodated. Shakespeare (2006) correctly identifies

that some sort of 'cutoff' or temporary solidification of identity categories will be

necessary in the foreseeable future for the purposes of policy, planning, and service

delivery. With (dis)ability, I seek to emphasize that this solidification need only be

temporary. As argued by scholars working toward sexual rights (see p. 18 above),

the conditions on which current identity-policing and related provisioning occur

may be open to rearrangement once a base of rights and resources have been

achieved.

Theoretically, the use of this term signals my focus on ability rather than

disability. Ability as a normativity becomes visible through the practice of ableism.

Simply put, ableism is the preference for ability. Carlson (2001) defines cognitive

ableism as "a prejudice or attitude of bias in favor of the interests of individuals who

possess certain cognitive abilities (or the *potential* for them) against those who are

believed not to actually or potentially possess them" (p. 140). Ability is the ideology

driving social relations that marginalize and oppress people with impairments. It is

also a normativity that disempowers a range of people, as identified by Shakespeare

(2006) when he likens menstruation and childbirth as impairments, and is therefore

a broader platform for the development of a broad-based coalition for emancipatory

social change.[9]

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[9] This understanding is indebted to hooks' (2000) argument regarding the
preference for coalition-building to end sexist oppression rather than identification
as a feminist.

Emergence of the Neurodiversity Movement

As outlined above, one limitation of the social model of disability as originally articulated is the difficulty empirically separating impairment and disability the lives of people living with disabilities. This slippage is readily available for many people with disabilities who are "but-for" abled (Rosenblum, 2009). That is, many people with disabilities that have stable, physical limitations can imagine themselves without such limitations. They can imagine themselves participating fully in society and fulfilling normative social roles (e.g. paid labour, marriage, etc.) once those limitations are accommodated. They can access normative citizenship with the theoretical insight of the social model and its associated policy outcomes.

This slippage is less available, however, to those with chronic and/or degenerative physical conditions, as well as those with cognitive disabilities. The articulation and dominance of the social model in the disability rights movement (DRM) was made possible by the fact that people with these conditions were not meaningfully included in the early disability rights movement. In a parallel with their exclusion from disability studies research and theorization, people with cognitive disabilities, in particular, were marginalized within the DRM. In the early decades of the DRM, the needs and rights of people with cognitive disabilities were represented primarily by their parents and the healthcare professionals who worked with them. Adults in the DRM did not want to be associated with what became known as the "parents movement", presumably because of the taint of infantalization (Carey, 2009), but also did not make serious efforts to include people with cognitive disabilities in their own organizations.

The parents movement, however, began to do just that, slowly including people with cognitive disabilities themselves in their organizations and advocacy efforts. Eventually, people with cognitive disabilities formed their own advocacy groups, which became collectively known as the self-advocacy movement (SAM). The SAM is an umbrella term that incorporates activists with a wide variety of cognitive differences that have historically disqualified them, due to ableist norms and structures, from effective self-representation. It is most commonly associated, however, with those who have mild intellectual disabilities.

Carey (2009) argues that the SAM, like other social movements, has been pivotal in creating opportunities for historically disenfranchised people to assert their value and demand social change. However, like other social movements, it is also limited by failure to be fully representative and an associated failure to challenge a key aspect of ability as a normativity- autonomy (i.e. independent, rational pursuit of one's self-interest) (Carey, 2009, Chapter 10; see also Smith, 2001). While the very name of the movement speaks to its emphasis on autonomy and participatory citizenship, Carey (2009) argues that this goal is not realistic for those most affected by intellectual limitations. Many people will, simply, never be autonomous. In addition, efforts to be seen as autonomous and extended citizenship on this basis fail to interrogate this normativity and its role in creating the structures that have historically excluded people with intellectual disabilities - along with a host of other social groups (e.g. women, children, people of color, etc). These insights affirm the normative as well as practical rationale for emphasizing a relational conception of citizenship in seeking to understand citizenship for persons

with disabilities or conceptualize a framework in which ability does not stratify participation in a public struggling to realize shared aspirations.

People on the autism spectrum are included under the SAM umbrella, as are those with mental illnesses and other neurological differences that have historically disqualified them from effective self-representation. However, people with neurological differences that do not necessarily impact their intellect also began organizing separately from the main SAM. This separate strand of organizing is known as the neurodiversity movement (NDM). Sinclair (1993) provided one of the first public articulations of this perspective and Singer (1999) one of the first scholarly ones. After a decade of growth, Bumiller (2008) outlines the contours of this largely web-based movement, identifying the key positions of the NDM as: a) autistic differences are the result of healthy genetic variation in the human population, b) heritable autistic differences result in a sub-culture of Autistic people, c) objection to the medicalization of autism, d) related objection to treatments for autism as assaults on the dignity and being of Autistic persons, and e) vehement critique of portrayals of autism as a pathology, tragedy, etc. Neurodiversity advocates, in their rejection of medicalization, adopt an identity model of autism. Self-identification as a person on the spectrum, rather than diagnosis, is the arbiter of group membership.

Like the SAM, the NDM suffers from the concentration of elites in leadership positions. The NDM's demands, however, are more radical than those of the SAM. The NDM actively challenges fundamental normativities, including autonomy, that have historically served as the basis for citizenship. Neurodiversity activists focus

on the inseperability of self from autism and subsequent demands for inclusion in difference rather than being "fixed" (i.e. treated or taught to imitate typical behaviours and preferences). These insights and demands echo scholarly arguments about the nature of full citizenship. For example, Phelan (2001) argues that "[f]ull citizenship requires that one be recognized [i.e. social membership] not in spite of one's unusual or minority characteristics, but with those characteristics understood as part of a valid possibility for the conduct of life" (p. 16). Similarly, Bauman (2001) argues that recognition politics are about asserting the ethical value of different ways of living and their attached distributive arrangements. This, essentially, is the mission of the NDM. Activists assert the intrinsic value of neurodiversity, damn efforts at normalization (including in many cases any efforts to cure or treat autism), and demand distributive arrangements that include them fully in their difference.

In examining the sexual citizenship of people on the autism spectrum, I purposefully sought to engage with the voices of NDM activists. Their strong articulation of the right to difference serves as a particular challenge to dominant normativities and attached distributive arrangements. They are actively engaged in debating questions of citizenship for Autistic people. They are also among the most organized, accessible, and least-affected sub-groups of people on the autism spectrum. Before turning to issues of sexual citizenship for people on the autism spectrum specifically, I will first discuss sexual citizenship as it pertains to people with disabilities more broadly.

Disabled Sexual Citizenship

> The challenge of sexual citizenship for people with disabilities is great
> because they remain one of the largest unrecognized minority populations,
> little awareness exists about the manner of their oppression, sex is a taboo
> subject for everyone in general and for disabled people in particular, and the
> unquestioning embrace in most societies of ability as an ideology denies
> participation in the public sphere to those not deemed quality human beings.
> (Siebers, 2008, p. 154)

Siebers (2008) argues that "disabled people experience sexual repression,
possess little or no sexual autonomy, and tolerate institutional and legal restrictions
on their intimate conduct" (p. 136). He likens these experiences to those had by
sexual minorities and explicitly links them with the concept of sexual citizenship.
These issues are matters of citizenship because they deal with control over the
body, access to public space, and political agency (Siebers, 2008, Chapter 7). As with
other social groups, the sexual and intimate lives of people with ASD and other
(dis)abilities are not, or not only, "private" matters, but reflect the cultural and
political position of disabled people in society. People with disabilities are not
extended social membership. This is evidenced in the partial and particularized
complement of rights offered them.

Rights. Scholars and activists have pointed out a number of sexual rights
concerns for people with disabilities. This is the component of citizenship most
frequently discussed in the context of sexual justice and citizenship for people with
disabilities. Siebers (2008) sets out an agenda for sexual citizenship efforts that
includes: "access to sexuality information, freedom of association in care facilities,
demedicalization of disability sexuality, sexual needs/desires as healthcare, and

training professionals to recognize sexuality and provide privacy on demand" (p. 148). Most of these agenda items can be conceptualized as rights, rights to privacy and association for example. These are rights ideally held by citizens in most liberal democracies. These rights are withheld from people with disabilities in two mutually-reinforcing ways: formally through the law and informally through the context in which rights are deployed. This context includes family and social relationships, institutions, and service agencies (Carey, 2009; Correa et al., 2008, Chaper 1).

The most salient legal barrier to the exercise of full sexual rights for people with disabilities, especially those with cognitive disabilities, is the legal concept of competency. This concept acts as a method for formal disenfranchisement. People with disabilities can be declared completely incompetent, in which case a family member or state representative is usually appointed to decide on the best interests of the person in all areas of life, including their sexuality. Alternatively, many U.S. states have "graduated guardianship", which allows people with disabilities to be declared incompetent in specific areas. Finally, people with disabilities can be declared incompetent in the context of specific situations/decisions, without requiring the establishment of guardianship. This formal disenfranchisement means that people with disabilities have *no legal right* to make fundamental decisions about their own lives (Sheehan, 2002). Though more rights have been granted to people with disabilities in the last 20-30 years as the result of social change efforts, sexual rights have lagged behind. Carey (2009) argues that this is due to a fundamental difference between sexual rights and the type of rights being granted.

Rights are often understood as a resource ensuring the freedom of individuals to pursue their interests. However, rather than consistently conferring freedom of choice to people with disabilities, the rights granted to them often situate them within environments that impose supervision and demand conformity ... Access to other rights that do not provide similar opportunities for supervision and are perceived as having greater potential negative consequences for others, such as the right to privacy in decision making regarding one's sexuality and reproduction, is often still discouraged for this population. (Carey, 2009, p. 219)

The attribution of incompetency has acted as rationale for forcible

sterilization and pregnancy termination, removal of children and termination of

parental rights, barring access to marriage, preventing the formation of intimate

relationships or forcing their termination, and denying ability to consent to sexual

relations, thus forcing unwanted celibacy on people with disabilities and

criminalizing their lovers (Carey, 2009; Carlson, 2001; Fidducia, 2000; Kempton &

Kahn, 1991; Waxman, 1991). These acts are often committed in the name of

protecting people with disabilities from exploitation or negative consequences

beyond their understanding, protecting children from incompetent parenting,

and/or protecting society from shouldering the costs of reproduction or "special"

accommodations. They are also inconsistent with respect for the humanity of people

with (dis)abilities.

There are also legal barriers to the exercise of sexual rights in the form of

public benefits and programs. Fiduccia (2000) argues that for progress to be made

in the area of sexual rights for people with disabilities "[r]esearchers must begin

asking questions about life areas such as marital status, privacy, and birth control in

the context of public benefits and programs" (p. 169). These programs are often

structured in such a way that sexual autonomy for people with disabilities is either

explicitly precluded as a condition for benefits or functionally so, for example,

excluding married couples from services (Carey, 2009, pp. 172-174) or structuring

funding such that people are forced to get services in institutional rather than

community settings (Carey, 2009, p. 185). In addition, social provisioning is

generally provided for "needs" but not 'desires". Sexuality has largely been

interpreted as a desire and social supports for its expression (e.g. physical or social

facilitation, commercial sex workers, etc.) correspondingly withheld (Earle, 1999;

Sanders, 2007; Shildrick, 2007).

Private sector institutions and service agencies are also critical sites for the

sexual rights of people with disabilities. This will be discussed further in the specific

context of people on the autism spectrum (see pp. 52-53). Institutions and service

agencies are often the empirical, relational context in which people with disabilities

sexual rights are respected, ignored, or denied. Finally, Shuttleworth (2007) calls for

us to broaden our understanding of accessibility, a standard disability rights

concept, to include sexuality. He argues that "[a]ny movement for sexual rights that

includes disabled people must at a minimum address the barriers to accessing the

options for people who may not be able to achieve sexual expression and/or sexual

intimacy with others through normative cultural avenues" (Shuttleworth, 2007, p.

194). Shuttleworth (2007) calls for a focus on "the construction of

access/obstruction to the sociocultural contexts in which desire is evoked and

sexual negotiations become possible" (Shuttleworth, 2007, p. 174). Green (2008)

theorizes such sociocultural contexts as the *sites*, or spaces and places, which anchor

a "socially stratified, institutionalized matrix of relations" in which sexuality occurs,

referred to as a *sexual field* (p. 28). Taken together, these scholars point to the need

to look at the accessibility of the sites that compose a sexual field.

   In addition to the legal and institutional barriers previously discussed,

Shuttleworth (2007) lists common socio-cultural barriers experienced by (dis)abled

people, such as "sociosexual isolation during their adolescent years, parents'

negative or protective attitudes, a lack of sexual negotiation models for disabled

people, unattainable ideals of desirability, social expectations of normative

functioning, poor body image, and ... gender role expectations" (p. 178). He asks,

"how accessible for disabled people are these [gender and sexual] identity formative

processes and contexts?" (p. 193). These observations direct our attention to the

types of erotic capital that are required for status in various sexual fields (Green,

2008) and how the accumulation of this capital is stratified by ability through,

among other processes, limitations on rights and membership.

   The disrespect shown to people with disabilities through the failure to confer

on them the rights available to other citizens stems from ableism. People with

disabilities, particularly those with cognitive disabilities, lack the illusion of

autonomy and unfettered rational pursuit of self-interest that undergirds the

provision of rights in liberal democracies (Carey, 2009). As pointed out above, the

guarantees that *are* granted to people with disabilities are fundamentally different

from those offered to other citizens. "[N]ormal citizens [are offered] a host of civil

rights and abnormal citizens protection and care instead" (Carey, 2009, p. 16). Many

argue that this protection and care is an obligation that society has toward its

vulnerable members, like people with cognitive disabilities, but that it should be balanced with the obligation to provide access to full human rights as well (e.g. Gougeon, 2010). This balancing act is difficult to achieve (Kalyva, 2010). From my perspective, the rationale to guide a just and humane balance has yet to be properly articulated.

Whether or not (or to what degree) one finds protection and care necessary, this different set of guarantees, or guidelines for social relations, is a mark of the liminal status of people with disabilities. They are not fully excluded from community membership, but neither are they welcomed as full and respected members. Disability scholars point out that the extension of rights to people with disabilities usually comes at the price of conformity (Carey, 2009, pp. 31-34; Tremain, 2001), the performance of ability. Those who view (dis)ability as a flourishing of human diversity that is fundamental to the understanding of self understandably decry this rights-for-assimilation deal and instead demand full inclusion in the community as themselves (Shakespeare, 2000; Shildrick, 2007; Shuttleworth, 2007; Siebers, 2008). Shakespeare (2000), making an explicit claim to sexual citizenship for people with disabilities, argues that control (over bodies and relationships), access (to spaces, relationships, and representations), and choice (in identity, lifestyle, and gender) are requisite for true belonging.

Responsibilities. These demands for full inclusion are often accompanied by calls to celebrate and value the diversity that (dis)abled sexuality has to offer. Scholars point out that (dis)abled sexuality tends to foster a focus on sensation rather than orgasm, touch rather than penetration, and intimacy rather than

performance (Kafer, 2003; Siebers, 2008, Chapter 7). There is also a trend toward

non-traditional understandings and performances of gender and sexuality (Kafer,

2003; Shakespeare, 2000; Shuttleworth, 2007). Though it is not framed in the

language of citizenship responsibilities, this is the one place in the disability sexual

rights and citizenship literature that the contributions of people with disabilities are

addressed.

Responsibilities are typically not addressed in this literature. An exception is

Carey (2009), who discusses the importance of recognizing common vulnerabilities

and interdependency. Essentially, Carey (2009) argues that vulnerability and

interdependency are defining characteristics of human life. Therefore, all people

receive care and contribute as they are able. Carey (2009) explicitly stops short,

however, of enumerating the required contributions or costs of citizenship rights

and membership for people with disabilities. She relies instead on the ethic of care.

Disability scholars recognize that the responsibility component of citizenship is

inherently problematic for people with disabilities, as it is based explicitly on the

ideology of ability.

Autism

As discussed in *Emergence of the Neurodiversity Movement*, many NDM

activists argue that autism should not be medicalized. They also acknowledge both

common and diverse ways in which autistic people are different from neurotypical

(NT) people, i.e. those with typical neurological functioning. These acknowledged

differences are rooted in those defined by the psychiatric diagnosis. Autism

spectrum disorder used to refer to a group of psychiatric diagnoses primarily

characterized by social difficulties, including Asperger's Disorder, Pervasive

Developmental Disorder-Not Otherwise Specified (PDD-NOS), and Autistic Disorder.

Recently, the American Psychiatric Association collapsed these diagnostic categories

to create one official Autism Spectrum Disorder (ASD) diagnosis due to concern

about the validity of diagnostic distinctions among the previous categories. The

diagnostic criteria for an ASD are impaired social communication and repetitive or

unusual behaviours and interests (American Psychiatric Association, 2013). The

new specification of these diagnostic criteria in the fifth edition of the Diagnostic

and Statistical Manual of Mental Health Conditions addresses sensory sensitivities

and/or desensitization, a salient part of the experience of being autistic, as an aspect

of unusual behaviour/interests. They are addressed in terms of a person's reactions

to sensory input. The particularities of body-mind experience to which these criteria

point are of particular relevance to the current study of citizenship and sexuality.

Autism is primarily diagnosed in young children. The most recent estimate of

prevalence by the Centers for Disease Control (CDC) indicates that 14.7 per 1,000 (1

in 68) children aged 8 years qualify for an ASD diagnosis. This estimate is based on a

secondary review of the health care, and sometimes educational, records of children

living in one of 11 non-representative sampling sites across the U.S. Prevalence

estimates vary widely among sites (5.7-21.9 per 1,000). Among children identified

through case review, roughly 20% did not have an ASD diagnosis or eligibility for

autism special education services on file. This means that roughly 20% of children

who meet criteria for an ASD diagnosis have not received one and are not receiving

services. Males identified through case review were significantly more likely to have

an ASD classification on file (OR = 1.3, p<0.01), indicating that female children on the spectrum are less likely to be diagnosed or receive services than males. Males are also significantly more likely to be assigned an ASD diagnosis through case review than females (rate ratio 4.5). In addition, racialized groups are significantly less likely to be assigned an ASD diagnosis than whites. The racial disparity is greatest for Hispanics, with 10.8 in 1,000 being attributed an ASD in comparison with 12.3 non-Hispanic Black children and 15.8 non-Hispanic white children (Centers for Disease Control and Prevention, 2014).

Overall, 31% of cases assigned an ASD diagnosis in 2010 were classified as intellectually disabled (IQ ≤ 70), with another 23% classified as borderline (IQ 71-85), and the remaining 46% classified as having average or above-average intellect. Female and racialized children identified as having an ASD are more likely to be identified as intellectually disabled as well. Females assigned an ASD diagnosis are significantly more likely to receive a co-occurring intellectual disability diagnosis than males (36% females vs. 30% males), as are Black (48%) and Hispanic (38%) children in comparison with white children (25%). (Centers for Disease Control and Prevention, 2014). These findings indicate that members of minoritized groups, in comparison with white males, are more often assigned an ASD diagnosis in conjunction with co-occurring intellectual limitations that may render their level of impairment more pronounced.

Analyzing comparable data across time, the 2010 CDC estimate of 14.7 children with an ASD in 1,000 represents a 123% increase in the prevalence of ASD cases from 2002-2010 (Centers for Disease Control and Prevention, 2014). It is

generally accepted that the prevalence of autism spectrum disorders has increased

rapidly since the 1990's (Liu, King, & Bearman, 2010). However, there is

considerable debate as to whether this increase is better attributed to increased

occurrence or improved recognition and service navigation (Centers for Disease

Control and Prevention, 2014). Liu et al. (2010), for example, provide evidence that

the social diffusion of knowledge about autism may be one factor driving increased

incidence. Certainly, there has been a marked upswing in public discourse around

autism and both governmental and non-governmental funding for related research

and services over the past two decades, with the passage of the Children's Health

Act in 2000 marking a milestone in awareness and activism (Caruso, 2010; Liu et al.,

2010).[10]

Public and governmental attention to this condition has coincided with

increasing recognition of its impact on those with average or above average

intelligence (sometimes referred to as "high-functioning"). Autism was added to the

American psychiatric lexicon in the 1940's. It was typically used to describe children

who were significantly impaired. Asperger's Disorder did not become popularized in

the U.S. until the 1990's.[11] In contrast to autism, Asperger's Disorder was typically

used to describe youth who were less significantly impaired and of average intellect

(Caruso, 2010). Incidence rates and prevalence estimates of ASD also began to rise

rapidly in the 1990's (Liu et al., 2010). The 2014 CDC report on estimated

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[10] The funding for the CDC research program providing 'official' prevalence estimates, the Autism and Developmental Disabilities Monitoring network, actually stems from mandates in this Act.

[11] Asperger's disorder was originally coined in the 1940's as well, but the original German writings were not translated into English for many decades.

prevalence indicates that "the most notable change in characteristics of children identified with ASD through the ADDM Network [over the last decade] is the growing number who have average or above average intellectual ability" (Centers for Disease Control and Prevention, 2014, p. 11). The proportion of children assigned dual diagnoses through CDC review has rapidly shrunk from 47% in 2002 to 31% in 2010. The 2014 CDC report observes that "a large proportion of the observed ASD prevalence increase can be attributed to children with average or above average intellectual ability" (Centers for Disease Control and Prevention, 2012, p. 11). I do not think the coincidence of Asperger's Disorder popularization, increasing rates of ASD diagnosis among those who are not intellectually disabled, and the emergence of the NDM movement in the 1990's was chance. As discussed above, the NDM is led by elites; one of the most pronounced aspects of leaders' elitism is their relative ability.

The timing of the coincidence of the emergence of the NDM and increased prevalence of ASD diagnoses is significant to the present study. The broadening of the diagnosis, paired with increased public and self-awareness, resulted in a distinct cohort of youth with an ASD in the 1990's. These youth are now in their 20's. They are the first distinct cohort of young *adults* with an ASD. The emergence of an identifiable young adult cohort has led to increased interest in how autistic youth transition into and fulfill adult roles, such as paid employment, higher education, and romantic relationships (Aylott, 2000; Barnhill, 2007; Billstedt, Gillberg, & Gillberg, 2011; Cederlund, et al., 2008; Howlin, 2000; Marriage, Wolverton, & Marriage, 2009). These studies generally assess adult "functioning" or "outcomes"

based on criteria that are rooted in normative assumptions about what it means to live a life of value, including post-secondary education, paid employment, independent living arrangements, close friendships, and long-term romantic partnership (e.g. Cederlund, et al., 2008; Howlin, 2000; Marriage et al., 2009). Based on these criteria, roughly one quarter of adults with an ASD diagnosis and an IQ > 70 are judged to have "Good" or "Very Good" outcomes (Cederlund, et al., 2008; Howlin, 2000).

The increased cultural visibility of ASD over the last 20 years, despite its overwhelming emphasis on *childhood* ASD, has coincided with increased clinical observation of *adults* seeking ASD diagnoses as well (Marriage et al., 2009). Marriage et al. (2009) compared levels of adult "functioning" between a group of individuals diagnosed as children and a group diagnosed as adults. They found no significant differences in adult functioning among patients whose functional assessment occurred at age 20, regardless of age of ASD diagnosis. They also found that those whose functional assessment occurred a decade later (mean age of 31) had achieved significantly more in the areas of education and independent living. Differences in employment, friendship, and intimate relationships were non-significant. This finding suggests that the ability to achieve normative standards for education and independent living may simply be delayed in individuals with ASD, regardless of age of diagnosis. It also suggests that adults on the spectrum, regardless of age of diagnosis, continue to experience "deficits" in employment and relationships well into adulthood. In addition to individuals diagnosed as children who are now adults and individuals who have successfully sought an ASD diagnosis

as an adult, there are also adults who self-identify as a person on the spectrum, but do not seek diagnosis for a variety of reasons (e.g. cost) (Byers et al., 2013b). In NDM spaces, later-in-life diagnosis-identification is particularly visible among females, who have begun to mobilize as a distinct, doubly-marginalized group (see for example www.autismwomensnetwork.org). The NDM, and the current study, is composed of individuals who *self-identify* as a person on the spectrum, though the majority of participants in this study report obtaining an official ASD diagnosis as an adult.

Autistic Sexuality

There is a paucity of research on sexuality in the lives of people on the autism spectrum. The relatively high rate of co-occurrence between autism and intellectual disability, along with the perceived impacts of ASD on self-awareness and communication, have led many researchers to use secondary sources such as parents and professional caregivers for information on sexuality in the lives of autistic people (see for example Hellemans et al., 2007, p. 262). Though there is literature on caregiver/public perceptions of autistic sexuality, sexuality education programs, and parents' experiences, I was able to locate only 18 published studies that assess sexuality or intimate relationships in the lives of adults on the spectrum. Only one third of these rely on data gathered from autistic people themselves, two of which were published after the commencement of the current study. All published studies that include first-hand data were quantitative in nature.

Previous studies, particularly those using secondary sources, tend to focus on "problem behaviours". Gougeon (2010) observed that "much research continues to

pathologize sexuality and disempower the individual by focusing on the sexual

behaviors as being issues of problems reported by a third party and in need of

management [while the identified 'problematic autistic behaviors'] themselves in

many instances fell within the range of 'normal' particularities found within the rest

of the population" (p. 349). Behaviours identified as problematic include: public

masturbation, non-normative expression of arousal or sexual interest (e.g.

persistent courting), masturbation with objects (e.g. pillows) or in response to non-

normative stimuli (e.g. feet), and non-heteronormative arousal and behaviour (e.g.

same-sex) (e.g. Dozier, Iwata, & Worsdell, 2011; Haracopos & Pederson, 1992;

Hellemans et al., 2007; Ruble & Dalrymple, 1993; Tissot, 2009). Realmuto & Ruble

(1999) point out that while autistic people face a number of obstacles in learning

and expressing normative socio-sexual behavior, social perceptions exacerbate this

problematization. In particular, they observe that many behaviours labeled as

problematic are part of normal sexual development and common in children.

Children "grow out" of these behaviours as they learn socio-sexual norms through

peer interaction and formal education. Persons on the spectrum are often excluded

from these educational opportunities, particularly the social learning opportunities

that are key to gaining knowledge about norms for sexualized or intimate

interactions (Koller, 2000; Mehzabin & Stokes, 2011; Stokes, Newton, & Kaur, 2007;

Realmuto & Ruble, 1999; Tissot, 2009).

　　　The research focus on sexual "problems" also reflects the discomfort of many

parents, staff, and community members with autistic people being sexual,

particularly those who are more affected by their condition. Parents and caregivers

affirm this concern directly (Kalyva, 2010; Nichols & Blakeley-Smith, 2009; Ruble &

Dalrymple, 1993). It is also reflected in the delay of or failure to provide sexuality

education and concerns that its provision will introduce or increase sexual interest

(Ballan, 2012; Tissot, 2009). Concern regarding the "introduction" of sexual interest

reflects the asexualization that is often committed against autistic people, and

people with disabilities generally (Ballan, 2012; Byers et al., 2013b; Gougeon, 2010;

Shakespeare, 2000, 2006). There is almost no mention of sexual pleasure in the

literature, with two notable exceptions (i.e. Byers et al., 2013a; 2013b).

Masturbation is overwhelmingly addressed in the context of male sexuality,

demonstrating heterosexist bias as well as the focus on how autistic sexuality affects

others (see for example Ruble & Dalrymple, 1993). In addition, authors and parents

sometimes discount the potential existence of reciprocal intimate relationships for

autistic people (Ballan, 2012; Koller, 2000), though this is not uniform across

studies (Nichols & Blakeley-Smith, 2009). Nichols & Blakeley-Smith (2009) found

that parents with autistic adolescent children who were less affected by their

condition commonly expected, and hoped for, intimate relationships to develop in

their child's future. Parents of autistic adolescents who were more affected,

however, were likely to discount the possibility of intimate relationships and

express greater concern about sexual exploitation and abuse. Parental expectations

of celibacy stand in contrast with findings that degree of ASD symptomology is not

associated with relationship experience among autistic adults (Byers et al., 2013b).

In addition, the one published study assessing the prevalence of sexual abuse

among autistic individuals found that 16% of children and adolescents referred to a

community health clinic had experienced abuse according to parental report (Mandell et al., 2005). It is estimated that from 6.7-26.5% of North Americans in the general population experience childhood sexual abuse (Andrews et al., 2004). It is worthy of note that, because it relied on parental report, Mandell et al. (2005) may have underestimated the prevalence of sexual abuse among autistic adolescents. In addition, this study assessed individual's experiences of sexual abuse prior to the onset of dating and would not capture unwanted sexual experiences that occur in the context of adult sexuality. Finally, Mandell et al. (2005) analyzed data regarding children in clinical settings, rather than in the general population. Children from the same clinical sample with diagnoses other than ASD experienced significantly higher rates of sexual abuse according to parental report.

Comparisons with neurotypical peers. Contrary to stereotypes, autistic individuals demonstrate sexual arousal, interest in sexuality and romantic relationships, and participation in sexual behaviours and relationships (Byers et al., 2013a, 2013b; Dozier et al., 2011; Gilmour et al., 2012; Hellemans et al., 2007; Hellemans et al., 2010; Kalyva, 2010; Konstantareas & Lunsky, 1997; Lau & Peterson, 2011; Mehzabin & Stokes, 2011; Ousley & Mesibov, 1991; Realmuto & Ruble, 1999; Ruble & Dalrymple, 1993; Stokes & Kaur, 2005; Stokes, Newton, & Kaur, 2007; Tissot, 2009; Van Bourgondien et al., 1997). In comparison with neurotypical (NT) peers, two studies found that "high functioning" autistic individuals demonstrate no significant differences in sexual experience or interest (Gilmour et al., 2012; Stokes & Kaur, 2005). Three studies found no significant differences in formal sexual knowledge (e.g. anatomy identification, behaviour

description, etc.)[12] (Gilmour et al., 2012; Stokes & Kaur, 2005; Stokes et al., 2007). Marital satisfaction was found to be similar in one study (Lau & Peterson, 2011) and romantic functioning in another (Stokes et al., 2007). In contrast, Mehzabin & Stokes (2011) report that "high functioning" autistic individuals scored significantly lower on both amount of sexual experience and sexual knowledge in comparison with NT controls. However, the type of sexual knowledge measured in this study was social (i.e. privacy rules), rather than mechanical, in nature. Based on survey data from larger samples of individuals living in the community, Byers et al. (2013a, 2013b) suggest that lower levels of sexual activity for adults on the spectrum are best attributed to the (lack of) partner availability. This suggestion is based on findings that, while autistic adults report a moderate level of desire for dyadic sexual experience, the majority of single adults report no sexual activity (not even kissing) in the last month (Byers et al., 2013b) whereas those who are partnered report dyadic non-genital sexual behaviours once a week and dyadic genital activity at least once a month (Byers et al., 2013a).

In contrast with these similarities between groups, significant differences have been found in sexual orientation (Byers et al., 2013a, 2013b; Gilmour et al., 2012). On a multidimensional measure of sexual orientation, autistic individuals scored lower on heterosexuality and higher on homosexuality, bisexuality, and asexuality than an NT comparison group (Gilmour et al., 2012). In addition, Byers et al. (2013a) report that 32% of their sample identified as a sexual minority in one

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[12] The types of knowledge measured in these studies is arguably "reproductive" rather than "sexual". However, it represents the type of knowledge most often taught "sex education" and was taken as a measure of "sexual" knowledge in previous studies.

study and 42% identified as such in another study with a partially overlapping

sample (Byers et al., 2013b). These rates are significantly higher than in the general

population (Mosher, Chandra, & Jones, 2005).

Autistic individuals also score lower on knowledge of social aspects of

sexuality (e.g. how to initiate a romantic relationship) (Sperry & Mesibov, 2005) and

correspondingly exhibit lower levels of normative courtship behaviours and higher

levels of non-normative courtship behaviours than NT comparison groups (Stokes

et al., 2007). In addition, rates of marriage and intimate relationship formation are

lower in samples of autistic individuals than in the general population. In a review of

the literature, Howlin (2000) found that the highest rate of intimate partnership

reported in any single study was 25%. In more recent studies, Renty & Royers

(2006) found that 33% of their "high-functioning" sample had ever been in a

heterosexual relationship, and Byers et al. (2013b) found that 59% of single autistic

adults had been in at least one relationship lasting 3 months or longer. In

comparison, a nationally representative study found that 65% of adult women and

68% of adult men in the U.S. are *currently* in a romantic relationship (Herbenick et

al., 2010; Reece et al., 2010). Lower rates of partnership are a concern among

autistic people; finding a life partner and being misunderstood or knowing how to

behave in sexual situations are common concerns among people on the spectrum

(Mehzabin & Stokes, 2011; Sperry & Mesibov, 2005). These concerns about the

future occur at a higher rate among autistic individuals than their neurotypical

peers (Mehzabin & Stokes, 2011).

It should be noted that the sample sizes in most previous studies are rather small. Most studies have a sample size in the 20-30 range. These small samples are not unexpected given the population. However, it does compromise the ability to detect group differences in comparison studies.

Relationship experiences. I was unable to locate any published studies examining the relationship experiences of people on the autism spectrum. However, I did find two unpublished Master's Theses that provide windows into these experiences. Based on interviews with five adults on the spectrum and the guardians of three other adults, Wedmore (2011) found that compatibility (e.g. shared interests), hard work (e.g. intentional communication), and external supports (e.g. parental involvement) were important for making relationships work. Autism characteristics (i.e. sensory/processing and social/communication issues), living situation (usually related to limited socio-economic independence), and external pressures (e.g. social norms) were identified as relationship challenges. Finally, Wedmore (2011) found that intimacy was articulated as a combination of admiration, intimate exchanges, affection, and companionship. Wedmore' s (2011) work demonstrates that relationships for adults on the autism spectrum are similar to those between NT people in important ways.

Whitham (2013) interviewed seven young adults about their dating experiences. Identified themes included: being pursued rather than initiating relationships, a slow process of getting to know each other, declaration of serious feelings and intents soon after relationship establishment, intentional practice of courtship skills, partnering with individuals who have a developmental disability,

partnering with anyone who expresses interest, limited genital-focused sexual activity, use of social supports, self-awareness about the learning curve for relationship skills, and lack of clarity on relationship beginnings and endings. Whitham (2013) also reported that participants displayed immature emotional intimacy and an inappropriate level of concern over minor partner behaviours. In contrast with Wedmore's (2011) findings, Whitham's (2013) work emphasizes particularities of autistic relationships, such as relative passivity, atypical progression and displays of intimacy, and awareness of difference. Taken together, these initial examinations of relationship experiences show that body-mind differences, such as sensory sensitivities, as well as structural ableism, such as a devalued status as a relationship partner, uniquely shape the relationships of adults on the autism spectrum.

Sexual satisfaction. Two published studies have assessed autistic individuals' sexual health in a comprehensive manner that includes sexual satisfaction. Byers et al. (2013a) found that community-living, relationship-experienced, autistic individuals reported moderate sexual satisfaction, infrequent sexual problems, and low sexual anxiety. Those currently in romantic relationships reported higher sexual satisfaction than those who were single (Byers et al., 2013a). In a related study comparing the sexual functioning of currently single adults who did and did not have relationship experience, Byers et al. (2013b) found that those with no relationship experience reported significantly higher sexual anxiety along with lower levels of arousability, dyadic desire, and positive sexual thoughts.

They interpret this as a lower level of sexual functioning, however, participants with no relationship experience had equivalent levels of solitary sexual activity and sexual problems in comparison with their experienced peers. As the authors themselves note "individuals who had no relationship experience were not less sexual per se, just less interested in engaging in sexual activity with a partner" (Byers et al., 2013b, 2624). In the context of previous survey research (Gilmour et al., 2012) and clinical observations (Marriage et al., 2009) that asexuality is more common among individuals on the spectrum than those in the general population, we should consider that lower levels of other-oriented sexuality may represent different, rather than lower, sexual functioning. While it is clear that the majority of autistic individuals desire and have sexual experiences with other people, there is also a minority that are content not to have these experiences. This is consistent with research on asexuality in the general population (Bogaert, 2004). It is also worthy of note that autistic adults were significantly less likely to have relationship experience if they were male, younger, or heterosexual (Byers et al., 2013b). Theoretically this may related to delayed socio-sexual development and/or social norms regulating courtship behaviours that dictate that men seeking women partners shoulder a greater proportion of assertiveness and social skill.

Social context. Previous research supports the impact of sociality and social context on sexuality. Two studies found that social behaviour mediates differences between autistic and NT participants in formal and informal sexual knowledge and sexual experience (Stokes & Kaur, 2005; Stokes et al., 2007). In other words, autistic individuals who exhibit high levels of socially normative behaviour do not differ

from their neurotypical peers in sexual knowledge or experiences, while those who exhibit lower levels of sociality also demonstrate lower levels of sexual knowledge and experience. In addition, Byers et al. (2013a) found that greater social and communication skills, as measured by the Autism Spectrum Quotient, were associated with higher dyadic sexual well-being, lower sexual anxiety, and fewer sexual problems. No other symptoms were correlated with sexual well-being. These findings demonstrate how social integration impacts sexuality. Researchers have noted that people with disabilities have trouble accessing the social spaces that enable sexual expression and relationship building due to physical and social barriers (Sanders, 2007; Shuttleworth, 2007). Shakespeare (2000), for example, points out that disabled people are often excluded from key sexual resources such as work and other venues for meeting partners, money for image and activities, and self-esteem/confidence.

It is also important to note the salient role of institutions[13] in the sexual lives of people on the autism spectrum. Most people on the spectrum rely on one or more institutions or service provision agencies in their routine lives. The intensity of institutionalization varies widely from living in a total institution (i.e. an institution which you may not leave of your own volition) to relying on state disability benefits or job training and placement programs. These institutions require autistic people to submit to a level of surveillance and compliance in order to receive services. Carey (2009) documents how "the rise of the service industry ... subjected

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[13] I am using institution in its mundane rather than sociological sense here, i.e. physical buildings and coordinated services in the private and/or public sectors, such as mental health institutions and state-funded vocational rehabilitation programs.

consumers to constant monitoring and evaluation, segregation, rights restrictions, and control over their daily lives" (p. 181). Many service agencies do not have a sexuality policy, leaving decisions about what is allowed or provided to the personal judgment of front-line workers. Workers without training or guidance can impose their personal beliefs, judgments, and comfort level on clients (Earle, 1999; Hingsburger & Tough, 2002; Shuttleworth, 2007).

Institutions *with* sexuality policies often curtail the sexuality of their clients quite strictly. Van Bourgondien et al. (1997) surveyed total institutions servicing people on the autism spectrum with a co-occurring intellectual disability. Of the 14 institutions that responded, only 1 allowed homosexual intercourse and 3 heterosexual intercourse. The majority of institutions allowed only hand-holding, with slightly less than half allowing heterosexual hugging and kissing. In addition to being very restrictive generally, there was a strong heterosexist bias in institution policies. Some type of sexuality education was available to clients in 12 of the 14 institutions, however only 6 provided their staff with any sexuality training or education. Improper education, punishment for appropriate sexuality, lack of privacy, and resistance by caregivers and guardians are obstacles to healthy and chosen sexuality for people with cognitive disabilities (Hingsburger & Tough, 2002). The salient role of service agencies in the sexual lives of people with disabilities has led researchers and activists to demand "healthy service systems" that include sexuality policies which promote and enable chosen sexuality (Hingsburger & Tough, 2002; Kempton & Kahn, 1991).

Legal context. People on the autism spectrum also face additional regulation

of their sexuality at the level of the law. As Tissot (2009) notes, the notion of sexual

rights for autistic people is very limited, when it is present at all. Under the pretext

of legal competency people with an ASD diagnosis are liable to having their rights to

consent to sexual interaction and reproductive healthcare revoked or truncated

(Carey, 2009, Chapter 8; Sheehan, 2002). For example, federal funds were used to

forcibly sterilize minors and mentally incompetent adults in the U.S. until 1977

(Kempton & Kahn, 1991). Canada permitted non-therapeutic, non-consensual,

sterilization of women with developmental disabilities until 1986 (King & Richards,

2002). Arguments to allow informed, but non-consensual, sterilization of women

with developmental disabilities still circulate (e.g. Pham & Lerner, 2001).

Cognitively disabled people's rights to form and maintain romantic

relationships, and to have them legally sanctioned, are not secure (Carey, 2009,

Chapter 8). In the 1980's, 40 U.S. states restricted marriage rights based on

intellectual impairment (Mason, 1986). As of 2008, four U.S. states and two

territories still restricted marriage rights with statutes that include language such as

"idiot" and "weak minded". People with disabilities are also regularly deprived of

sexual education, access to socio-sexual spaces, and access to sexual products and

services (e.g. pornography, strip clubs, etc) (Koller, 2000; Sanders, 2007;

Shakespeare, 2000; Shuttleworth, 2007). When provided sexuality education,

people with disabilities rarely receive *disability relevant* sexuality education

(Shuttleworth, 2007b). For example, autistic individuals may benefit from education

that explicitly addresses courtship norms, reading non-verbal affect, and managing

sensory sensitivities. In addition, people with disabilities are often held to a higher standard than the general population in assessments of their knowledge and abilities in the areas of sexuality and parenting (Carey, 2009, 172-174; Watson, Venema, Molloy, Reich, 2002). These assessments have consequences, such as revoking a person's parental rights or rights to sexual and reproductive consent.

Contributions of this Research

The current research examines social relations as manifest in the everyday realities of adults on the autism spectrum to sketch the sexual citizenship of autistic adults, conceptualized as their equitable inclusion in the co-construction of shared aspirations for human living and their associated distributive arrangements. I focus in particular on shared aspirations that pertain to sexuality and intimacy. My approach to this research and the understanding that I develop herein is constructed through a conceptualization of (dis)ability as the contingent relationship between individual (e.g. impairment) and structural (e.g. accessibility) factors. One contribution of this research is the development and application of a synthetic understanding of sexual citizenship that is explicitly normative and relational to broaden the embrace of this theoretical tradition to include the experiences of persons for whom ability is a central axis of social differentiation. Review of the empirical literature demonstrates that full sexual citizenship for people with disabilities, those with cognitive disabilities such as ASD in particular, has not yet been realized. I will explain this situation by explicating how sexual citizenship is regulated by the ideology of ability.

In addition, there is much to be learned about the romantic and sexual experiences of adults on the autism spectrum. What we do know indicates that adults who live in the community have typical levels of relationship and sexual satisfaction, but face barriers to relationship formation and demonstrate some particularized socio-sexual experiences (e.g. high rates of sexual minority identification, sensory sensitivities, etc). To the best of my knowledge, the current study is the largest to examine the relationship experiences of adults on the autism spectrum based on first-hand, qualitative data. It is also the only study to examine sexual experiences in this manner. This study makes a unique contribution to our knowledge about the sexual and relationship experiences of this population, adding depth and perspective by documenting these experiences through in-depth interviews with individuals on the spectrum. This contribution lays a critical foundation for our understanding of autistic persons' sexual citizenship, as we must have a base of understanding about experiences before seeking to explain the conditions of their existence.

In addition to adding depth and perspective to existing knowledge about the everyday realities of life for autistic adults, the current study is unique in its approach. Past research has not systematically analyzed the social context in which autistic intimacy and sexuality occurs, nor has it sought to understand the impacts of this context on personal experience. Most previous research has been conducted from a deficits perspective, focusing on "problematic sexuality" or how autistic traits negatively affect partnering and sexuality. No published research on autistic

sexuality and relationships politicize these experiences, connecting everyday realities with social normativities.

The current study does not assume that autism entails sexual or romantic deficits, but rather attends to the particularized experience of sexuality and intimacy from the perspective of persons whose body-mind experiences are produced through atypical neurology. Further, I attend not only to how experience is particularized by body-mind differences, but also to how it is particularized by the occupation of a particular social position. In other words, I answer the question of how power, as deployed in a person's socio-legal and relational context, shapes sexual experiences and identities. Building on this analysis, I also further scholarship on sexual citizenship and (dis)abled sexuality by demonstrating how ability inflects our understandings of intimacy and sexuality and how these entwined normativities shape the social and legal membership of people with (dis)abilities.

CHAPTER THREE

Methodology

My approach to explicating how social positions, and the socially-structured subjectivities that attend them, are constituted through social relations is informed by a materialist feminist epistemology. Naples (2003) synthesizes materialist feminist approaches to the generation of knowledge, noting that attention to the microdynamics of power and an understanding of agency as a site of "representation and struggle over power and resources" (Hesford, 1999, p. 74) are central features of this approach. Drawing from Smith's (2006) materialist feminist methodology, institutional ethnography, I understand institutions as "the social relations enacted in the setting that rule what can happen" (Campbell, 2008, p. 270).

In this study, I examine the everyday experiences of autistic adults living in the community to examine how microdynamics of power are expressed in their everyday experiences. Through this examination of deployed power, I explicate those social relations constituting the conditions of possibility for the conduct of a valued life by persons on the autism spectrum, conceptualizing these relations through the institution of citizenship. I start from the experience of autistic people to understand issues as they are perceived from this social position (Smith, 1990, 2006). I then move from this positionality to investigate the normativities (i.e. social norms and the discourses, practices, and distributive arrangements associated with them) that delimit its possibilities. Consonant with sexual citizenship theory as I developed it in Chapter 2, this approach helps us understand relational rights and the impact of socio-legal relations on sexual accessibility and sexual health.

Procedures

Current empirical literature on the sexuality of people on the spectrum relies largely on data from secondary sources. Unwillingness to include the perspectives of the population under study, whether because it is easier for the researcher to interview their neurotypical parents, teachers, and support people or because of generalizing assumptions about the capabilities of all persons in the population, is disrespectful. It also creates inequalities in access to knowledge generation. It is a limitation on the civic participation of autistic persons.

In line with the ethos of citizenship that drove this study, I sought to generate knowledge about autistic sexuality and citizenship in collaboration with people on the spectrum. Four key strategies helped make this investigation accessible to the autistic community and successful as an empirical research project. First, I decided to target autistic community spaces with an online presence for participant recruitment. Second, I recruited a Community Adviser (CA) – an autistic person active in autistic Internet communities. Third, and partially as a result of consultations with the CA, I offered three different electronic interview formats: oral/video-cam, instant messenger, and email. Fourth, a member check was performed after each interview, allowing participants to review the entirety of the interview and adjust their contributions. These strategies proved effective at generating substantive empirical data while also facilitating the participation of people on the spectrum in research that is meaningful to the community.

Community Advisor. I recruited a CA by posting information about my search for a CA in several online autistic community spaces. I was initially concerned

that it would be difficult to find someone willing to invest their time consulting with

me. However, my request generated significant interest. I had 15 people contact me

about serving as a CA. I narrowed the pool of persons interested in serving as a CA

based on: a) their relative familiarity with and position in the online autistic

community, b) their familiarity with research, and c) their age. I included age as a

criterion for narrowing the pool because I was under the impression that I would

primarily be recruiting young adults and wanted a CA with comparable life

experiences and knowledge of generational culture. Based on these criteria, I

interviewed and began collaborating with two Community Advisors who were

prominent in the online autistic community and/or neurodiversity (NDM) and also

graduate students. One CA regretfully stepped down very soon after we began

collaborating because the additional work was overwhelming in the context of their

already full graduate student life. They did, however, remain in touch and offered to

facilitate recruitment by connecting me with key persons in the NDM. The other CA,

Emily Lynn Williams, remained dedicated to the project throughout. Her

contributions as a CA were critical in shaping this study.

Emily and I discussed the geography of autistic Internet communities, the

history of the communities, netiquette conventions, and her perceptions of

community interests, goals, and sentiments relevant to research and sexuality. We

also discussed potential barriers to participation, including my own unconscious

displays of ableism. We reviewed study materials and protocols together and made

revisions to increase accessibility. For example, I was originally ambivalent about

including the email format as an interview option. Emily advocated for the

importance of an asynchronous format to increase accessibility. I discuss the

importance of this choice further in *E-mail interviewing as an accessible method*. She

also alerted me to avenues of questioning that may prove difficult and suggested

others that may be fruitful. For example, the original interview guide did not include

a section on gender identity. Emily suggested that it would be difficult to understand

the sexuality and relationship experiences of people on the spectrum without the

context of their gender identity given the prominence of gender nonconformity in

the community. She also assisted with recruitment by reaching out to key people in

online autistic communities. Finally, Emily reviewed the results of this study to

check for misperceptions.

   Recruitment. Participants were recruited via the Internet by

announcements (see Appendix F) on relevant websites and list serves (e.g. Autistic

Self Advocacy Network, state affiliates of Autism Society of America, GRASP, etc.).

Inclusion criteria included: self-identification as a person on the autism spectrum,

U.S. denizen, aged 18 years or older, and ability to communicate orally or through

writing on the Internet. Internet-based recruitment allowed me to access a large

convenience sample of autistic people with communication and computer skills. It

also allowed me to target people who were more likely to have considered issues of

sexual citizenship. The online autistic community is closely associated with the

NDM. Certain websites cater to people on the spectrum seeking social support and

information; others exist for the purpose of organizing political self-advocacy. These

sites primarily generate traffic from autistic people, rather than parents or

professionals. These sites also host the discussion and dissemination of information

relevant to group-specific experience and self-advocacy, increasing the chance that visitors will have been exposed to information and sentiment regarding group-specific challenges and socio-political remedy. Research has shown that the importance and value placed on involvement in the online autistic community is positively associated with autistic identity and sense of community for Internet-using autistic adults (Kidney, 2012).

Recruitment advertisements contained a link to my study webpage, www.uwindsor.ca/people/barnettj. The webpage contains information about the approach and goals of the study (see Appendix G). It also had a link which interested persons could click to be taken to the online Consent Form (see Appendix C) and demographics survey (see Appendix A). The Consent Form and demographics survey were hosted by FluidSurveys. After completing the demographics survey, I contacted participants at the email address provided in the survey to arrange an Internet-facilitated interview (see Appendix E). Previous research indicates that people on the autism spectrum may prefer the Internet as a means of social communication and research participation over face-to-face contact (Mehzabin & Stokes, 2011). In addition, Internet recruitment and data collection is common in sexuality research and has been done previously with this population (Byers et al., 2013a, 2013b; Gilmour et al., 2012).

In addition to demographic and contact information, the online survey also asked participants to refer a support person and romantic partner, if they had one, for a follow-up interview. Originally, I planned to triangulate data from the primary interviews with data from supporting interviews conducted with important people

in the lives of my primary participants. However, this component of the study was

dropped due to low levels of referral and subsequent participation on the behalf of

referred support and/or romantic persons. The analyses and results described here

are based on data generated with primary, autistic participants only. As discussed

below, these data are rich and a sufficient basis for analysis in their own right.

Sample

Fifty people accessed the online demographics survey; 34 (68%) completed

the survey and provided an email address at which to be contacted for an interview.

One individual was not eligible because they resided outside the U.S. Five

individuals did not respond to attempts to initiate an interview. Four people began

an email format interview, but ceased responding to questions very early in the

interview process. Their data are therefore excluded from analysis. The final sample

included 24 individuals. Two of these individuals are married to each other.

Participants ranged in age from 18-61 (M=36.5). The majority of participants

identified themselves as White or Caucasian (n=22), with one specifying an

additional ethnic identity of Jewish. Participants endorsed a range of gender

identities, the majority of which fell on the masculine (n=6) or feminine (n=13) ends

of the sex-gender spectrum, with 5 (21%) endorsing a genderqueer or androgynous

identity.[14] Participants were well-educated, with 21 completing some post-

secondary education or professional training.

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[14] One participant identified their gender identity as "odd". This appellation is
retained when personally identifying the participant in the Results. I have
categorized this participant with other genderqueer and androgynous participants
for the purposes of reporting sample characteristics because they do not endorse a
binary gender identity.

Twelve (50%) participants reported an annual income of $15,000 or less. Six of these participants were full-time students; the remainder were employed full-time (n=1), self-employed (n=2), underemployed (n=1), or performing unpaid labour (n=2). Three participants reporting an income of less than $15,000 a year were supporting one or more small children, two of whom were doing so without additional financial support. Three participants reported an annual income ranging from 15,001-30,000; five reported an annual income of 30,001-45,000; one reported an income of 45,001-65,000; and the remaining three participants chose not to disclose their income. All together, 11 participants (46%) were in the paid workforce, 7 (29%) were students, 5 (21%) were doing unpaid labour (3 of whom were looking for or desired paid employment), and 1 was retired from a professional career.

At the time of the interview, all participants were living in the community. Five participants reported previous episodes of psychiatric hospitalization or other supervised living arrangements.[15] At the time of the interview, 4 participants were living alone, 13 were living with their romantic partners, 3 were living with roommates (one of whom benefited from their roommate's support in daily living), 3 were living with their parents (two of whom were full-time students), and one participant supported their mother who lived with them. Many participants lived independently without supports provided outside the context of a spousal relationship. Others benefited from various supports ranging from occasional

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[15] Participants were not systematically asked about lifetime experience with incarceration or supervised living. This information was provided during five interviews in the context of its relevance to topics directly covered by the interview guide.

financial support from family to a part-time personal assistant. The two most commonly reported supports were therapy and vocational rehabilitation.

Twenty-two participants reported receiving an ASD diagnosis from a medical professional. Fifteen of these reported receipt of an Asperger's Disorder diagnosis, with the remainder receiving an Autism Disorder (n=4), Pervasive Developmental Disorder-Not Otherwise Specified (n=2), or Non-Verbal Learning Disorder (n=1) diagnosis. Most participants received their diagnosis as an adult, though age of diagnosis ranged from 2-55 (M=28.5). Two participants self-identified as someone on the autism spectrum without receipt of a medical diagnosis. One reported that their choice not to seek diagnosis was based on the difficulty and expense of obtaining the diagnosis as an adult female, the other was still in college and concerned about the potential effects of labeling. Sixteen participants (67%) reported additional diagnoses. The most frequently reported type of additional diagnosis was a pain disorder (n=8). Other commonly reported types of diagnoses included anxiety (n=4), depression (n=4), learning disabilities (n=4), auditory processing impairments (n=4), muscle disorders (n=3), and attention deficit disorders (n=2).

Participants endorsed a range of sexual identities, with 6 endorsing multiple sexual identities. Eleven (46%) identified as primarily heterosexual, 6 (25%) as asexual, 4 (17%) as bisexual or queer, and 3 (13%) as lesbian or gay. Additional sexual identities included: polyamorous, hetero-romantic, sapiosexual, pansexual, and bi-curious. The majority of participants were currently in a romantic relationship, with 11 (46%) married or in a domestic partnership (one legally

recognized and one without a legal option), 8 (33%) single, 3 (13%) cohabitating, and 2 (8%) in serious, non-cohabitating relationships. Five (21%) participants were parents, 3 of whom were caring for small children, one of whom was living with their adult autistic child, and 1 whose typically-developing adult children were living independently.

Participants' profiles were somewhat associated with the character of the online space from which they were recruited. Most strikingly, participants recruited from more politically active autistic online communities explicitly affiliated with the NDM were more likely to be feminine or genderqueer identified. For example, 2 of the 17 (12%) participants recruited from more politically-oriented community spaces were male-identified, in comparison with 4 of 7 (57%) participants recruited from more socially-oriented community spaces. In addition, participants recruited from more politically-oriented spaces were generally younger. Nine of the 17 (53%) participants recruited from politically-oriented spaces were over 30 years of age, in comparison with 5 of 7 (71%) of participants from socially-oriented spaces. Unsurprisingly, participants recruited from more politically-oriented spaces generally espoused more radical political positions relative to both disability and sexuality/gender. In particular, these participants had more thoroughly analyzed their lived experiences through the lens of disability politics.

Data Collection

Participants were given their choice of three interview formats: oral/video-cam (e.g., Skype), chat (e.g., instant messenger), or e-mail. Three participants chose a chat format, one of whom decided to switch to an oral format early in the interview.

Both chat interviews lasted approximately 4 hours, broken into two 2-hour sessions.

Two participants chose an oral format, a third switched from e-mail to oral early in

the interview. Including the participant who switched from the chat format, four

oral interviews were conducted all together. Oral interviews lasted an average of 4.5

hours, ranging from 2 to 6 hours. Oral interviews lasting more than 2.5 hours were

broken into two sessions. The remaining 18 interviews were conducted via e-mail

only. E-mail interviews extended over 3 months on average, ranging from 1 to 12

months.

Literature on Internet-facilitated data collection. Web-based data

collection has its limitations. For one, it restricts the participant pool to those with

Internet access and basic computer skills. It can be frustrated by technological

glitches and/or user error. Studies have found a lower response rate to e-surveys

than telephone or 'snail mail' surveys (Gunter, Nicholas, Huntington, & Williams,

2002). E-mail and chat, as text-based communications, eliminate non-verbal social

signals from the interaction, such as body language, voice inflection, and physical

self-presentation. These data are therefore not available to the researcher. The

absence of these social signals can also impair the establishment of rapport and

associated participant comfort and disclosure (Hinchcliffe & Gavin, 2009; James &

Busher, 2006).

However, these social signals can also be a source of anxiety and/or

confusion for participants with communication differences (such as ASD), who may

feel more comfortable with text-based forms of communication (Hinchcliffe & Gavin,

2009). In addition, alternative means of rapport building can be effectively

employed, such as multiple contacts and high levels of verbal responsiveness, such as expressing interest and emotional responses to participant contributions, using probes, and giving encouragements (Hinchcliffe & Gavin, 2009; James & Busher, 2006; Mann & Stewart, 2000, Chapter 6). Hinchcliffe & Gavin (2009), in an evaluation of participant (including those with communication differences such as ASD) and researcher experience using instant messenger for qualitative interviews, found that participants evaluated the medium more positively than negatively and reported reduced apprehension in comparison with in-person interviewing. In addition, Hinchcliffe & Gavin (2009) reported that the lost non-verbal data were compensated for by the use of more feeling words to communicate emotions directly. These emotions are then part of the text rather than researcher notes and are therefore more easily analyzed and validated. Reduced participant anxiety and an increased sense of anonymity can contribute to greater participant comfort and associated disclosure during text-based data collection, particularly on sensitive topics (Gunter et al., 2002).

Web-based data collection has additional advantages. Synchronous web-based data collection, such as chat and oral (e.g. Skype), maintains the back-and-forth rhythm of in-person interviewing (Berg, 2007). However, the spatial dislocation of the interviewer and participant allows both parties to choose a 'safe space' without imposing on the other's personal space, creating a neutral yet personal space for both parties (Hanna, 2012). In addition, web-based data collection does not appear to reduce the accuracy of predictive data, is significantly more convenient for both researcher and participants, allows the collection of data

from geographically dispersed participants, reduces researcher cost and error

through automatic transcription; and asynchronous formats consistently yield more

thoughtful responses to open-ended questions than face-to-face or telephone

interviews (Berg, 2007; Gunter et al., 2002; Hanna, 2012; Hinchcliffe & Gavin, 2009;

James & Busher, 2006).

E-mail interviewing as an accessible method. As discussed above, the

majority of my participants chose an e-mail interview format. Four participants

spontaneously told me that they would not have been capable of participating in the

interview in any other format. Generating data with people on the spectrum was an

important aspect of this study. E-mail interviewing was critical to this process,

particularly for those participants who are more affected by their condition. As a

researcher, I found that e-mail interviewing had its own set of benefits and

drawbacks, many of which are not adequately explored in the literature. Many of

these relate specifically to research with populations that experience

communication difficulties or communicate in a different way than the researcher.

Many are also generalizable to data collection with the general population.

Benefits of e-mail interviewing. The benefits of e-mail interviewing fall into

three main categories: increased accessibility for participants, ease of use for

researchers, and facilitation of high quality data generation. E-mail interviewing,

like other text-based forms of communication, enables the participation of persons

for whom oral communication is difficult or impossible. This is a boon for those who

do not speak, those for whom background noise and other sensory inputs disrupt

communication, for those who can write but not speak the researcher's language

fluently, and for those who require more time than the "average person" to organize a response.

E-mail interviewing also obviates the problem of "lost speech". Some autistic persons, including a few in this study, lose the ability to speak their mind cogently from time to time. Stress and strong emotions, such as embarrassment, are a common trigger for lost speech. The increased sense of anonymity, emotional distance, and response time that accompanies e-mail interviewing, in comparison with synchronous and/or in-person interviewing, limit interview-related stress and interaction-dependent emotions. In addition, many people who lose speech are capable of *writing* their thoughts cogently at these times. Finally, participants are free to wait until their stress or strong emotions have passed before responding to the questions in their in-box.

On a similar note, participants are able to avoid participating in the interview on days or at times when they are feeling overwhelmed without inconveniencing the researcher or feeling obliged to keep a commitment that is not in their best interest at the time. This benefit is particularly salient for autistic participants, for whom managing stimulation levels is a fundamental part of self-care. It is, of course, also a benefit for research participants generally and especially those whose lives are complicated by the daily stressors that accompany marginalization, health concerns, and/or impairment effects. It also facilitates the participation of non-clinical segments of populations that experience health disparities, when paired with Internet-based recruitment.

E-mail interviewing provides a certain ease of use for the researcher(s) as well. As documented in the literature, the researcher does not have to schedule or travel to interviews, nor transcribe interviews (e.g. Gunter et al., 2002; James & Busher, 2006). Asynchronous interviewing eliminates potential no-shows and cancelled appointments. In addition, like other forms of Internet-facilitated interviewing, it enables the researcher to sample from a wider geographic region with less money and effort (particularly important when your research is not well-funded or your population relatively small). All interviews are automatically available in text form, which means that any experience-based improvements to the interview schedule (e.g. question phrasing, added/deleted questions) can be reproduced without taking any additional notes or making additional changes to source documents.

Finally, several features of e-mail interviewing facilitate the collection of high quality data. Many of these benefits relate to the asynchronous nature of e-mail interviewing. E-mail interviews can take some time to complete; as discussed above, the average e-mail interview for this study spanned 3 months. For some interviews, the time span reflects active back and forth between the participant and myself. For others, there were significant time lags between responses. In contrast with concerns about the impoverished rapport due to lost social signals (e.g. Hinchcliffe & Gavin, 2009; James & Busher, 2006), the length of correspondence can *facilitate* rapport and associated participant comfort and disclosure. I noticed, in several interviews, that participants shared more details and provided longer responses later in the interview. It appears to me that this change was due to an increased

level of comfort. While this phenomenon is common across interview formats (e.g. in-person, telephone, etc.), it is notable that when e-mail interviewing with this population increased comfortability and disclosure did not happen until we had months of regular contact. In addition, as observed by Hinchcliffe & Gavin (2009), "lost" non-verbal data on participant emotions was usually compensated for by high levels of verbal emotional expressiveness, sometimes including emoticons (i.e. pictorial representations of facial expressions created by the user with punctuation marks) and emoji (i.e. pictorial representations of facial expressions available through some software programs). The lengthy nature of the interview also gives the researcher time to come back to questions better suited for later in an interview, rather than forgetting or omitting them in the rush to complete an interview within a specific time frame.

Participants' ability to take their time reflecting on and answering questions leads to enriched and longer responses. My ability as a researcher to take my time reflecting on participant responses enabled me to be more analytical during the data collection process. With each participant, at each stage of the interview, I had ample time to reflect on necessary follow-up questions, question phrasing, and the order and "chunking" of questions. Finally, with the power of the Internet at my fingertips, books, websites, diagnoses, and much more that came up in the interviews could be researched *during* the interview and potential relevance to the research inquiry examined. This afforded a unique opportunity to follow-up on relevant leads and ask illuminating probes. These opportunities provided by an asynchronous

interview format facilitate the systematized generation of individually deep qualitative data.

     Challenges of email interviewing. The benefits of e-mail interviewing are balanced with a share of challenges. The challenges of email interviewing also fall into three main categories: general challenges for the researcher, researcher challenges specifically related to the length of the interview process, and limitations on participant accessibility. These challenges are important to consider when contemplating the use of e-mail interviewing for a prospective study. In the current study, the benefits outweighed the challenges.

     One general challenge is that the asynchronous nature of e-mail interviewing can make probing questions awkward and "silence" (i.e. too many days between e-mails) anxiety-provoking. The researcher needs to develop a way of tactfully prompting respondents to reengage without respondents feeling harassed or nagged. I found that very brief e-mail prompts that had an informal tone and expressed genuine interest in the well-being of the participant received the best response.

     Managing participant emotional responses can be a challenge as well. Though many respondents were emotionally expressive, this was not true for every individual. When participants are not spontaneously expressive, assessing and responding to participant emotions is a challenge. This concern is particularly salient when conducting research on sensitive topics. There were two interviews early in the process where neither I nor the participant were aware of their discomfort until it had become a barrier to participation. One of these participants

chose to end the interview early (we were 3/4 of the way through the interview guide). The other chose to complete the interview after we discussed their discomfort and strategies for managing it. These experiences taught me to ask about participant emotional responses bluntly, rather than relying on cues, and proactively provide options for the management of potential discomfort. Later in the data collection process, participants would frequently disaffirm the need for emotional management. However, they did not appear upset by my proactive inquiry. Therefore, I think this is a good strategy for assessing and responding to participant emotions. The degree to which such bluntness and proactive management was helpful due to the socio-affective distance of e-mail interviewing versus the particular socio-affective processing common to autistic persons is unclear.

The need to establish and maintain protective data protocols also requires attention. This is true of all Internet-facilitated data collection. However, I found that there were challenges particular to e-mail interviewing because of the casual nature of the medium. Skype and chat interviews are scheduled. In setting aside a particular time for their completion, they become a distinct "event". Planning for them includes ensuring that you are occupying a private space with adequate data transfer protection in place. In contrast, checking your e-mail is something you typically do many times a day, often from multiple locations and devices. Planning to check your e-mail is not intuitive. I handled this challenge by changing my habits. In the future, I would ensure that I had a study-specific e-mail address from which to conduct the interview. Though it depersonalizes the process further, this would

make it easier to keep the interviews distinct from the rest of the day and prevent

slip-ups that could compromise data security.

Finally, there are several challenges associated with juggling multiple,

concurrent e-mail interviews. At one point in my investigation, I had 12 on-going

interviews. This presented four primary challenges: keeping each person's story

straight and not confusing elements of one person's interview with that of another,

missing the application of lessons learned across interviews at the exact same stage,

engaging fully with each e-mail from each participant every time, and, relatedly, the

amount of time necessary to engage with and thoughtfully respond to each e-mail.

With 12 on-going interviews, I usually had from 6-9 e-mails in my in-box each day

(including weekends), requiring an average of 45 minutes each. This intense level of

participant engagement persisted for about 4-6 weeks, making the balance across

different elements of my work life (i.e. work-work balance), let alone work-life,

balance an unanticipated challenge. E-mails must be responded to *promptly*, out of

respect for the participant and to increase your chances of finishing the interview.

The length of an in-depth e-mail interview poses its own set of challenges.

The length of correspondence means that you can *both* get fatigued with the

interview, contributing to a downturn in depth or momentum. Rapport must not

only be established via e-mail, a challenge in itself, but it must also be maintained

over the course of the interview. This requires on-going attention. I found that

emotional responses carefully tuned to the participant's level of openness, asking

occasional questions about topics of obvious interest to the participant (but

tangential to the focus of the study), and rapid turn-around time were helpful strategies for addressing these challenges.

The length of the interview also means that it becomes difficult to remember details shared earlier in the interview. You must put strategies in place to prevent yourself from asking inappropriate and/or redundant questions. I kept an on-going journal with important notes about each interview. I also reviewed the e-mail history as needed.

The question of when and how to apprise participants of their progress through the interview must also be considered. You neither want to encourage your participant to anticipate the end too soon, instill insecurity by leaving them wondering, nor damage their experience by springing the end on them too abruptly. With some experience, I settled on an initial warning of the impending close of the interview when I thought there were 2-3 sets of questions (i.e. e-mail exchanges) left (see Appendix B for the usual location of this warning). This concern relates to the final challenge when conducting an in-depth interview over such a long period of time, maintenance of boundaries. As I maintained rapport, corresponded regularly for a month to a year, and was myself subject to the power of the Internet (i.e. participants Googled me), some participants appeared to become attached to our interaction as a social and/or emotional outlet. I also became quite fond of some participants as well. It is important to ensure that researchers and participants maintain an awareness of the research purpose of the interaction and the relationship.

The forgoing challenges are surmountable with some analysis and practice. However, there are also limitations inherent in the e-mail interview format that structure its accessibility for participants and appropriateness to a particular research project. First, e-mail interviews require private Internet access for participants. This access is structured by wealth, geography, age, and ability. Second, e-mail interviews require at least a moderate level of literacy. Finally, in-depth interviews, such as those conducted in the current study, require *significant* commitment on the part of participants. I am truly indebted to my participants for their on-going interest in and dedication to this project. For some of them the interview process represented a significant commitment of resources. This commitment requirement also affects the data that are generated since the experiences of persons in the target population who are unwilling or unable to invest so heavily in the project will not be represented.

In conclusion, e-mail interviewing is a promising method of data collection, offering the researcher several benefits and aids to the generation of high quality, rich, and deep data. It is particularly promising as a method for increasing the accessibility of research participation for autistic people and others with communication differences. This method, however, does require adaptability and practice on the part of researchers who are new to it. The increased accessibility of this method for some populations, or sub-populations, is purchased at the price of excluding potential participants without private Internet access and/or a moderate literacy level. Though I found that the benefits outweighed the challenges for this

study, this trade-off must be weighed when assessing the appropriateness of e-mail interviewing for a particular study.

Quality assurance - member check. After each text-based interview, I exported the data from the chat or e-mail host and adjusted the formatting to improve readability. After each oral interview, I had the interview transcribed by a professional transcription service. Then I listened to the tape while checking and correcting the transcription. I reread each transcript, adding comments asking for clarification of answers as necessary. Finally, transcripts were sent to participants for a member check. Participants were invited to make any changes that would a) make their meaning clearer, b) add to my understanding of their experiences or perspectives, or c) make them more comfortable with what they shared. Participants were asked to respond to any clarifying questions as well. No participant chose to make meaningful changes to their contribution.

Some participants chose to copyedit their transcripts, some did not. With the exception of editing out potentially identifying information and distracting researcher prompts/encouragements, I present transcript excerpts in the final form approved by participants. As a result of the different interview formats and member check copyediting, some excerpts read essay-like, while others read like verbatim speech, and yet others are staccato, like Twitter feeds. I have chosen to present excerpts without imposing modifications because participants' communication styles are part of the data. I have also chosen to present many excerpts at length. This is due in part to the verbose communication style of many participants. In other words, providing a full description of an event or a response to a question often

required saying a lot. I have tried to respect their experiences and communication styles. In addition, some lengthy quotations allow me to show the analytical contributions of participants, rather than glossing all the analysis as uniquely my own.

Measures and Topics

As mentioned previously, recruitment advertisements (see Appendix F) directed participants to the study webpage (see Appendix G) where they could access the Consent Form (see Appendix C) and demographic survey. The demographic survey consisted of 21 questions, including basic demographic information, disability identity, referral source, and e-mail for further contact (see Appendix A). Participants were able to write-in their racial/ethnic and gender identities. They were also able to select multiple sexual identities from a set list (including space for an "Other" write-in). I structured the survey in this manner to encourage participants to express their sense of identity with minimal researcher-imposed constraints.

The semi-structured interview conducted subsequently covered topics including: receipt of services, sex education, gender identity, socio-sexual experiences, satisfaction with sexuality and intimacy, "autistic" intimacy/sexuality, desired supports, and hopes for research outcomes. The interview guide (see Appendix B) evolved somewhat over the course of the study. Questions were deleted as it became clear that they were not generating relevant responses or were too difficult to answer as asked. Other questions were added or amended to get at constructs and experiences that the initial set of questions was unable to access. In

addition, while the interview guide provided a semi-structured format for the interview, interviews varied considerably as I followed each individual's narrative and probed the diversity of relevant experiences that participants shared with me.

Data Analysis

The empirical goals of this research were to gather information about the position of autistic people as sexual citizens and explicate how this position is constituted through normativities. To accomplish these goals, I conducted two analyses of the data. One analysis serves to describe the experiences and identities of autistic sexual citizens. It answers the question of "what" it means to occupy this social position. The other analysis serves to explain the experiences and identities of autistic sexual citizens through citizenship understood as a framework for articulating the conditions that enable equitable participation in a public struggling to realize shared aspirations for human living. It answers the question of "how" this position is constituted through normativities, particularly their manifestation in relationships with those we live alongside.

First, I conducted an inductive, semantic level (i.e. what was actually said) thematic analysis of the data set that was restricted in focus to the sexual and romantic experiences of my participants. The purpose of this analysis was to sketch commonalities of experience among my participants to provide a "rich thematic description" that identifies important themes (Braun & Clarke 2006, p. 83) in the sexual and relationship experiences of adults on the autism spectrum living in the community. This descriptive analysis was necessary to gain understanding of the everyday experiences and identities of persons located as autistic sexual citizens. It

provides a foundation of understanding enabling the sound construction of

comprehension of how these states of affairs come to be through the second,

subsequent, analysis.

Due to the wealth of data, numerous themes and sub-themes resulted from

the analysis. Results may have been organized a number of ways. There are many

cross-cutting themes. I have chosen to present here the most salient themes,

determined by code frequency and my perception of participants' emotional

investment, organized according to those experiences which engender a sense of

success versus a sense of struggle. The results of this analysis are presented in

Chapter 4.

For the second analysis, I conducted a deductive, latent level (i.e.

interpretation of social relations underlying the semantic content) thematic analysis

(Braun & Clarke 2006). This analysis was guided by a materialist feminist

application of the sexual citizenship framework developed in Chapter 2. As

articulated by Naples (2003), the purpose of a materialist feminist analysis is to

explicate the "links between everyday life experiences and broad-based social

structural processes" (p. 45). In contrast with the inductive, semantic analysis, this

type of analysis provides a rich, nuanced interpretation of a theoretically-imposed

continuity within the data. In other words, this analysis is theory rather than data

led. Several specific questions guided this analysis.

- How are social and legal membership dependent on sexuality?

- How is sexuality dependent on social and legal membership?

- What sexualities and intimacies are made possible (and what are not) for persons socially located as "autistic" in U.S. society?

The results of this analysis are presented in Chapter 5.

For both inductive and deductive analyses, I followed the six phases of thematic analysis outlined by Braun & Clarke (2006). First, I read each transcript, jotting down initial impressions and potential themes as I went. Due to the member check process, this stage of analysis largely occurred contemporaneously with data collection and informed the pursuit of particular avenues of inquiry in later interviews. It was not necessary to repeat this phase for the second, deductive analysis.

For *each* analysis, however, I generated a set of initial codes based on the close reading of transcripts. These codes were then collated into preliminary themes. In the fourth phase of analysis, I checked the integrity of the preliminary themes in relation to the coded extracts that composed them, as well as the data set as a whole. I then refined my conceptualization of each theme and finally selected extracts that exemplified the themes and any counter-narratives (i.e. extracts contrary to dominant themes).

I conducted this analysis using Dedoose data analytic software. Following these thematic analyses, I used this mixed-methods software program to check for correlations between my demographic and interview data. Essentially, Dedoose allows the researcher to examine whether patterns in the qualitative data (represented by frequency or weight of codes) are associated with quantitative data, such as gender and relationship status. Correlations identified by this process are

presented alongside the thematic analysis as a way of contextualizing and delimiting the relevance of themes in the lives of participants occupying various, intersecting social positions.

As with all qualitative research, the contribution of these results is not their generalizability to the members of the social group or population from which the sample was drawn. The purpose of these analyses is not to produce generalizable findings about a group, but to provide detailed description and nuanced understanding of the experiences and/or positioning of the persons participating the the research who have some shared characteristic. In this case, that characteristic is self-identification as a person on the autism spectrum.

The current sample is not representative of the population of individuals ascribed an ASD by a medical professional. Significantly, the average age of participants in this study was 36.5. A person who was 36 at the time of the interview would have been born in 1978, twelve years before Asperger's Disorder became known in the U.S., well before awareness about autism had gained a cultural foothold. Most participants in this study report the receipt of an ASD diagnosis in adulthood. This is not typical for young persons on the autism spectrum today, for whom childhood diagnosis has become the norm. It is impossible to know whether all the participants in this research would have been diagnosed in childhood had the diagnosis been medically and socio-culturally available at the time or how typical they are of the population of adults who would be ascribed an ASD diagnosis, if all U.S. adults were evaluated for their position on the spectrum.

We do not really know what autism looks like "all grown up" because of the recency of its popularization, cohort effects, and shifting diagnostic criteria. This study provides one particular window into this grown up house. Participants in this study differ from the more culturally and medically recognizable population of autistic children and youth in several ways: age of diagnosis, sex (recall that males are diagnosed more than four times as often as females), eloquence, education, and living situation (i.e. independent and often partnered). Though structural factors clearly play a role in certain differences (i.e. age of diagnosis and sex distribution)[16] it is impossible to know the degree to which participants' relative ability (i.e. eloquence, education, and living situation) is the product of internal versus structural factors[17]. As noted in the literature review, social movements typically overrepresent the more privileged members of the social groups on whose behalf they petition for change. For the neurodiversity movement, this privilege includes relative ability. Participants in this study were recruited from the online autistic community, including overtly political spaces. They are grouped here for the purposes of analysis based on their shared identity and participation in the socio-political community attached to it.

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[16] Females are often overrepresented in social science research because they volunteer at higher rates than males. This structural difference has also manifested in previous sex research with autistic adults living in the community, despite the higher rate of diagnosis among males (see Byers et al., 2013a, 2013b; Gilmour et al., 2012).

[17] For example, participants undiagnosed in childhood were not treated as "an autistic person" growing up. In other words, they did not have appropriate supports available to them and also did not have their behaviours or potential evaluated through the stereotypes of autism. Participants who were diagnosed as children or adolescents typically reported high levels of services and/or parental support.

CHAPTER FOUR

Semantic Analysis: Success & Struggle

Participants reported a wide variety of experiences, some of which were positive and some which were not. Both aspects of participants' sexual lives, positive and negative, are presented to provide a wholistic picture. Such a wholistic representation is particularly important given the history of focusing on problematic sexuality in research on sexuality in the lives of persons on the autism spectrum. Experiences participants indicated to be areas of challenge, pain, or displeasure have been categorized under the umbrella theme of *struggle*. The three major themes organized as experiences of struggle are *sensory differences*, *courtship difficulties*, and *abuse & exploitation*. Participants' experiences of *struggle* reveal barriers autistic persons face in accessing full sexual citizenship, as well as sexual health and well-being. Experiences participants indicated to be areas of pleasure, validation, or security were categorized under the umbrella theme of *success*. The two major themes organized as experiences of success are *relationship satisfaction* and *sensual equilibrium*. Participants' experiences of *success* show how autistic persons respond to and manage challenges in their sexual lives to enhance their personal well-being and social membership.

What follows is not a comparative analysis; the purpose is not to compare the experiences of my autistic participants with the neurotypical (NT) norm. However, analysis of any sort always relies on a referent whether implicitly or explicitly. My own base of reference for sexuality and relationships was formed through engagement with an ableist society. The same is true for the readers of, and the

participants in, this research. Acknowledging this ableist ground for the understanding of participants' experiences, I preface the descriptive analysis with a sketch of general ways in which the experiences of this sample diverge substantially from NT norms to provide context for the remaining findings. Differences between the experiences of autistic adults in this sample and the general NT population should be understood as differences of degree rather than kind.

First, I call the reader's attention to the distribution of gender identities given in the sample. Five (21%) participants endorsed a genderqueer or androgynous identity. Though we do not have reliable statistics on the gender identities of the general population, the proportion with gender variant identities in this sample is substantially higher than what would be expected in the general population given what we do know (Olsson and Möller 2003; Rosser, Oakes, Bockting, & Miner 2007). In addition, discussion of participants' gender identity and experiences demonstrated that many who endorsed a binary identity experience a significant amount of personal (i.e. perception of self) and social (i.e. perception of others) gender non-conformity. In short, few participants perceived themselves or were perceived by others to be typically masculine or feminine. This finding concords with previous research indicating higher than typical co-occurrence of ASD/autistic traits and Gender Identity Disorder/gender non-conformity (e.g. Bejerot, Eriksson, Bonde, Carlström, Humble, & Eriksson 2012; Ingudomnukul, Baron-Cohen, Wheelwright, & Knickmeyer 2007; de Vries, Noens, Cohen-Kettenis, van Berckelaer-Onnes, & Doreleijers 2010). Finally, the Community Advisor for this study and several participants remarked upon a general perception of community gender non-

conformity at levels that exceed what is common in the NT population. Vivian, for

example, brought up this perception of community gender non-conformity when

asked how she defines gender.

> Gender has been one of those terms that I'm trying so hard to accurately, um,
> define, because I've been very, very interested in exploring sexuality issues
> and, um – especially within the disability community. And I know that's a
> huge topic within the disability community and, you know, among the autism
> community as well, um, because a lot of people I know or have corresponded
> with, um, uh, self-advocates do, um, see gender differently usually, or
> perceive gender differently than, um, a lot of other typical individuals, um,
> and that perhaps, um, we don't quite identify with a s-, solidly with a gender,
> um, as we're growing up, um.
> (Vivian, 31, heterosexual/bicurious, woman)

Gender non-conformity has important implications for dating and mating in a

society that is heterosexually organized. Relevant findings are presented here under

the sub-theme *performance of normative desirability* and throughout Chapter 5.

Second, related to gender non-conformity, I call the reader's attention to the

distribution of sexual identities. Less than half of participants (n=11, 46%)

identified as heterosexual. Three participants who identified as heterosexual

indicated additional sexual identities, including bicurious, asexual, and sapiosexual

(i.e. primary attraction to intelligence). A full quarter of participants (n=6) identified

as asexual, with bisexual, pansexual, polyamorous, heterosexual, and hetero-

romantic provided as additional sexual identities. In the context of asexuality,

additional sexual identities usually point to relationship style or (nonsexual)

intimate partner preferences. The remaining 29% of the sample endorsed a

bisexual-queer (n=4) or lesbian/gay (n=3) identity, one of whom also identified as

polyamorous. The distribution of sexual identities in this sample concords with recent research that accessed considerably larger samples of autistic adults living in the community (Byers et al., 2013a, 2013b; Gilmour et al., 2012) and reflects rates of non-heterosexuality much higher than those found in the general population (Mosher et al., 2005).

The additional sexual identities given, such as pansexual and polyamorous, also point to a certain sophistication regarding sexuality among participants. In other words, participants were generally informed about minoritized sexual identities and many understood sexuality in a nuanced way. This is not unexpected given the high rate of non-heterosexuality and gender non-conformity. Individuals who do not neatly slot into the social positions available in the hegemonic public sphere, such as cis-male attracted exclusively to cis-females or cis-female attracted exclusively to cis-males, are forced to do more thinking and self-education around their non-conformity than those who operate within given scripts.

Finally, it is worthy of note that only four participants reported dating in high school, with the remaining 20 participants having their first relationship experiences after age 18. Five of these 20 participants reported sexual or relationship initiation after age 30. These figures represent later experience of socio-sexual milestones than is typical in the NT population (Centers for Disease Control and Prevention, 2010; Halpern & Haydon, 2012). This finding concords with previous research on "outcomes" for autistic adults (Marriage et al., 2009), indicating that the developmental delays which characterize ASD may continue well into adulthood for some persons on the spectrum.

Success

  Relationship satisfaction. Most participants reported satisfaction with their current relationship experience. For some this meant contentment as an asexual, unpartnered person. For most this meant satisfaction with their current sexual relationship. Five participants reported dissatisfaction with their current relationship experience (two partnered, three single) at the onset of the interview. Of these, four were male-identified. One of these four participants began a satisfactory relationship during the course of the interview.

  Participants who were satisfied with their asexual relationship situation were all under age 35. Sexual experiences were simply not relevant to the lives of actively asexual participants. As Danielle put it when asked about her level of personal sexual satisfaction, "As sexually satisfied as I need to be. If I could lose my sex drive entirely I'd be quite satisfied with the situation, really. It's kind of like you're asking, 'How satisfied have you been with your access to pro football games?' Well... uh, I don't like football. It's just not my thing." (Danielle, 29, asexual, androgynous female) One asexual participant was happily partnered, two were content to be unpartnered at the moment though potentially interested in intimate partnership down the road, and two were uninterested in intimate partnership at any point. These latter two participants emphasized the importance of intimate friendships in their lives and the lack of substantive distinction between non-sexual intimate partnership and non-sexual intimate friendship.

    For me, I define myself as asexual and say that I have no interest in romantic
    relationships. (To be honest, romantic relationship is a foreign concept I
    can't really grasp - they talk about it as a deep love for someone and I believe

I have a deep love for all or at least almost all people, I am very caring. The difference between my kind of love, which they call platonic, and the romantic kind seems to be the physical intimacy and possibly the interest in spending a life together starting a family...and I want to say that my friends who I love will be in my life forever. See why it's confusing? To me they are the same except romantic has physical intimacy.)
(Billy Joel, 23, asexual, woman)

Including the participant who initiated a relationship during the interview, 16 participants were in relationships that they reported to be satisfying overall. Fifteen of these relationships included a sexual component. There were several sub-themes associated with relationship satisfaction, including *disability status*, *character-treatment, accommodation*, and *radical honesty*.

Disability status. The first sub-theme, *disability status*, refers to whether the participant's current partner was from the disability community (i.e. person with a disability or an ally). Participants generally reported higher levels of satisfaction if they were partnered with someone from the disability community. Partner's disability status was not included in the interview guide, thus information is missing for three participants. Partner disability status came up spontaneously in the remaining interviews. Partners had a range of (dis)abilities, with six participants reporting satisfactory relationships with another person on the spectrum (two of these individuals were married to each other). Participants in relationships with another autistic person indicated that they felt their shared neuro-status was an important part of their compatibility because it enabled them to understand each other in a way they had not previously experienced with neurotypical persons.

The following excerpt from C.Byrd, in which she writes about her relationship with her wife, which is her first committed relationship with either a female or a known autistic person, provides one example of this. C.Byrd reflects on how these two novel characteristics, femaleness and autism, may factor into why this relationship has been more successful than previous ones.

> I think it is certainly helpful to share a common way of thinking when most other people don't understand. I didn't know I was autistic until my late 20's and had spent my life seeking a close bond with someone without being able to reach that. That had always been so important to me to find love. When her and I started talking we didn't know the other one was autistic and all we could figure out was that we got a long so incredibly well and seemed to understand each other. Her being a woman is nice in the physical and emotional department, but her also being autistic is the thing that I think keeps this relationship really strong.
> (C.Byrd, 29, lesbian, woman)

Rusty, who was single and asexual until he was introduced to his wife, Hannah, in his early 40's, indicated that shared neuro-status resulted in the unprecedented experience of receiving the social communication of desire or romantic interest. "My asexuality was due to the poor social connection due to my being autistic. I think that my wife was able to send me signals was due to our both being autistic." (Rusty, 61, heterosexual, man)

Character-Treatment. The second sub-theme, *character-treatment*, refers to partner selection based primarily on participants' perception that the person was of good character or treated them well. Partners selected for *character-treatment*, rather than availability or temporary need fulfillment, were more likely to make participants satisfied long-term. Respectful, considerate, and safe/comfy were the

adjectives most commonly used when describing the characteristics of good

partners. Reflecting on what attracted her to her current partner when they first

met, Vivian provides an example of partner selection based on treatment. "There

was something different about this guy from the other partners I had been involved

with. At the time, I couldn't put my finger on what that was. The manner in which he

treated me was attractive." (Vivian, 31, heterosexual/bicurious, woman) Reflecting

on the same topic, the following quote from Ayla shows how character and

treatment were often imbricated in participants' assessments.

> I: What attracted you about your partner when you first met?
> P: He appeared to be a very respectful, thoughtful and responsible individual.
> (Ayla, 32, asexual/hetero-romantic, woman)

These qualities were also mentioned when participants were asked what they liked

about their relationship, as in the following example from Gabby. "I love my partner

and he is very considerate and respectful and I enjoy being around him." (Gabby, 23,

queer, woman)

    Accommodation. *Character-treatment* is closely related to the sub-theme of

accommodation. Accommodation refers to a partner's openness to accommodating

the participant's (dis)ability. Participants reported greatest satisfaction with

accommodating partners. Partners' failure to accommodate, or treatment as though

accommodation was a burden, was one of the most common areas of complaint

regarding relationships. This concern is demonstrated by Dragon Tears when she

reflects on what was missing from a previous, unsatisfying romantic relationship

and Jack when he reflects on what he dislikes about his marriage.

> I: Was there something you wanted that you didn't get?

P: A trusting relationship. Someone who truely excepted me for who I am
and my difficulties.
(Dragon Tears, 35, heterosexual, woman)

My biggest complaint is how she tries to insert herself between me and my
art. I have told her, my art comes first, because my art is what keeps me
grounded and able to function. Without my art, I would start to go to pieces.
(Jack, 43, asexual/heterosexual, man)

The areas of *accommodation* most frequently mentioned were: executive

functioning and communication with others (e.g. accompanying participant to

doctors' appointments), sensory needs (e.g. avoiding overwhelming spaces like

concerts or malls, respecting noise/touch requests), mismatch in sexual desire

levels (see *Struggle*), mismatch in down-time vs. sociality needs, and communication

preferences within the relationship (see *radical honesty* below). The following quote

from Sandy illustrates how participants talked about *accommodation* in a general

way.

He's the first person to ever love me for myself, he taught me about loyalty
and unconditional love and understanding. He's patient and understanding,
he's my navigator through this world, he translates things so I can
understand.
(Sandy, 46, bisexual/polyamorous, genderqueer)

Hannah was very specific about how Rusty met her needs in their relationship, as in

the following quote where she discusses how his maintenance of a beard

accommodated a strong sensory preference.

You know, so the point is, with a beard, there isn't being pricked by
sandpaper-like little bristles. You know, i-, it's just hair. It's not, you know, a
problem. ... so one of my conditions I told Rusty that one – we, we didn't have,
you know, uh, you know, a prenupt-, prenuptial agreement. Some people do,
but I – but I did talk with him and said, you know, 'There are some conditions

on which I'm gonna marry you, and one of them is that you never, never, never shave your beard.' And I told him why, okay?
(Hannah, 49, heterosexual, woman)

Accommodation made participants feel valued and safe, as illustrated in the following quote from Dragonfly, who uses Augmentative and Alternative Communication devices, where he reflects on why he had sex with his first sexual partner.

She was nice, not frightening, listened to my words even though it was hard. Seemed reasonable to think she was safe. ... Was mostly very confused. It [sex] did not feel right, but not because of her. She was very nice. Very patient. But asked her to stop and she did. Preferred just her holding me was better, less confusing. So she did. And it was okay.
(Dragonfly, 30, asexual/pansexual/polyamorous, odd)

The following quote from millie33 as she reflects on her satisfaction with her current relationship shows how partners' accommodation of participant needs was seen as an important aspect of overall relationship quality, in this case need for down-time (i.e. non-social time). millie33 reflects on her current partner's understanding of this particular need in contrast with a previous relationship, prior to her diagnosis with Asperger's Disorder, where high demands for sociality with family were an area of stress and tension.

Well, um, it's good. She knows that I have Asperger's so she's very understanding and accommodating. She went to school to be a psych nurse. She's just a nice, a very nice person. ... Well I, uh, um, she, uh, she, you know, she knows that I have Asperger's and she, she knows that I, uh, knows that I like to have time alone and, uh, as much as I've been trying to learn I've been telling her about it. So her family knows about it and they don't expect me to do everything with them. ... I have been to, um, dinner several times and I like them, um, but I don't feel as though I have to go and I also can leave when I want.

(millie33, 55, lesbian, genderqueer)

Radical honesty. The final sub-theme associated with satisfactory relationships was what I term radical honesty. *Radical honesty* is a style of communication. It was discussed to some degree by every participant. This style of communication includes direct, explicit communication, especially about feelings, intentions, and agreements. This concept includes the need for discussion and provision of ample information. In other words, radical honesty does not refer only to *how* information is communicated, but also to *how much* information is communicated.

Participants were most satisfied in relationships that included the practice of radical honesty. This practice made them feel safe and valued. One reason radical honesty was associated with feelings of safety was that participants were more confident in their ability to meet their partner's needs and therefore less afraid of relationship dissatisfaction or dissolution. It was associated with being valued in part because participants place a high value on knowledge generally and in part because they recognize that this style of communication requires more effort for NT and autistic persons alike. Practice of radical honesty indicated that participants were individuals whose thoughts and relationships were worthy of investment. As will be discussed further in *Struggle*, violations of radical honesty were a key area of struggle for participants. The following quotes from Laura and Vivian demonstrate how participants developed specific strategies to enact *radical honesty* because such strategies are necessary to enabling mutual understanding in their relationships.

Vivian discusses how the practice of communication strategies has been particularly intentional for both her and her partner, who is also on the spectrum.

> I am also learning to write on a paper what I like [sexually] because I learned that it makes men in GENERAL happy when they know HOW to make their wife HAPPY !
> So I learned to write what I like and he follows my INSTRUCKTIONS ;) and he is EXCITED about it :) !.
> I personally need to write some things down because first of all , I have difficulties verbalizing my thoughts and seconds because I am a bot conservative and as my husband would say BASHFULL about THIS TOPIC :p !
> (Laura, 30, heterosexual, woman)

> I mean, because, obviously, we've been with each other for such a long time, there's certain things that you can pi-, I can pick up now that if he doesn't necessarily say it, I, I can – I can more or less guess that he's feeling, you know, whether it's a certain type of stress or not feeling right. Um, so there's certain things on instinct we've been able to pick up from each other just because we've known each other for so long. But there are certain things that we still – I just still – we both just still can't rely on each other for, like facial expressions. I've learned that, um, because a number of us [autistic persons] just – our facial expressions don't necessarily match our emotions, um, I can't rely on his facial expressions at all to let me know ho-, to, to communicate to me his emotion. So I can't rely on that. Um, so, uh, there's certain un-, subtleties and, um, cues that I don't rely on or I can't pick up, um, to understand how he's feeling, um, so I don't rely on those things. So yeah, I guess in that sense it's – that's why we've had to study people skills.
> (Vivian, 31, heterosexual/bicurious, woman)

The following quote from Rick, where he reflects on the general qualities of his relationship with his current girlfriend, provides an example of how *radical honesty* was brought up as an important aspect of overall relationship quality.

> we're both very respectful of each others' lives independent of each other, which includes our career goals, friends, family, and interests. We both have talked frequently and openly about where we want our lives to go, what we want to do, and what we want out of this relationship. We took it pretty slow

at first, entering into an exclusive relationship a few months after we met. We learned more about each other, spent a lot of time together, but always respected each other's schedules, relationships (platonic and familial) and desires.

I have told her many times that unlike other people, my method of communication is typically upfront, direct and literal. She is satisfied with this, partly due to the fact that she doesn't have to worry about double-meanings or me saying one thing and feeling another, etc., and partly because her past relationships were fraught with men who were not very communicative nor open - almost the opposite of my personality. While I have learned the value of discretion over the years as it applies to my spoken words, I usually tell my girlfriend what I'm feeling, what I believe, what I think, etc, as well as ask for the same to be said to me.

(Rick, 26, heterosexual, male)

Sensual equilibrium. Overall, sensory issues, or body-mind experiences, were an area of struggle for participants, both individually and in the context of dating and mating. For example, partnered sex (physical intimacy involving genital touching) could be overwhelming or anxiety-provoking for many participants. These struggles are discussed further in *Sensory differences* and *Courtship difficulties*.

Participants also reported *success* in the area of sensory and body-mind experiences. Frequently they reported the use of masturbation, orgasm, and/or non-sexual physical intimacy to manage sensory and emotional needs. Sensory and emotional needs cannot always be disaggregated for participants. Sensual practices were often used strategically by participants to manage stress, make emotional connections, relax their bodies for sleep, or achieve an internal sense of equilibrium. Masturbation was used to manage *general* arousal levels by both participants who

did and did not experience sexual climax. The two sub-themes associated with

sensual equilibrium were *therapeutic sexual stimulation* and *physical intimacy*.

    Therapeutic sexual stimulation. Participants talked about how

masturbation or orgasm were useful in meeting sensory and stress relief needs. This

was true for sexual participants as well as some, but not all, asexual participants.

Hank, who is anorgasmic and has difficulty tolerating many sensations associated

with sex, partnered sex in particular, explained how masturbation was a much less

overwhelming way of dealing with sexual arousal from a sensory standpoint .

> I: How is physically desiring self-touch in response to arousal different from physically desiring the touch of your partner?
> P: It's much more of a sensory issue than a desire issue – I don't desire self-touch, but it partially meets a functional need. And although I desire touch from my partner, my body can't tolerate it. Self-touch (which is not really what it is - I still can only deal with the textures of gloves and vibration) is a very different level/type of sensory experience than dealing with another body. And I still don't reach resolution, but have an easier time getting to a numb sensation.
> (Hank, 33, queer, Transgender/genderqueer)

    The following excerpt from an email interview with CS, where I am following

up on her report of masturbation in the absence of sexual arousal, provides one

example of how genital stimulation was used to meet non-sexual sensory needs.

> I: Is there anything in particular, like a thought, an image, or a texture, that makes you want to masturbate?
> P: Nothing in particular, but will do it before going to sleep at night, or before napping. Feels good
> I: You are unsure about how frequently you masturbate. Could you say whether you masturbate at least once a week? Could you say whether you masturbate more than once a day?
> P: Maybe once or twice a day.
> I: How does your body feel after you're done masturbating?

P: I'm usually asleep, so I can't answer that question.
(CS, 34, heterosexual, woman)

Danielle, whose asexual but, unlike CS, does identify experiences of desire

and arousal, also wrote about how masturbation met a sensory need for her.

Though, because they were not experienced as social, neither arousal nor

masturbation were sexualized sensory experiences for her.

> Once I got out on my own, I read some erotica and watched a couple clips of
> porn to see what it was all about, but the porn just made me feel like I was
> invading somebody's privacy. I still read erotica occasionally--I do have a
> physical sex drive; it just doesn't lead me to seek out sexual contact with
> other people. To be honest, I find that physical sex drive more annoying than
> anything else. It's more like scratching an itch when I masturbate. I'd be
> happy to be rid of it entirely. For many people, sex is a way to connect with
> others... for me, it's just a biological function.
> (Danielle, 29, asexual, androgynous female)

Physical intimacy. Non-genital *physical intimacy* (e.g. holding hands,

hugging, snuggling) was important for most participants, regardless of gender or

sexual identity. While some participants, particularly male-identified ones, reported

a sense of loss and unmet needs during times of sexual abstinence, the absence of

adequate physical intimacy was described as more painful and disorienting than the

absence of sexual intimacy by most participants. Physical intimacy helped

participants meet sensory and emotional needs, as explained by Gabby and Billy Joel

when discussing their frequency of desire for intimate touch.

> I am very snuggly and touchy with my partner and when we are apart have
> trouble with the reduction in sensory stuff.
> (Gabby, 23, queer, woman)

I think kissing sounds gross and you couldn't pay me to kiss somebody on the lips! I love hugs and hug people as much as I can, I really like long and strong hugs. I like holding hands with my friends, especially in strange places or when I am stressed because then I feel a little better. Is that being held? To me, hugs and holding hands are expressions of friendship and have no romantic or sexual meaning.
(Billy Joel, 23, asexual, woman)

In addition, while sex was important to many participants, partnered sex was

desired much less frequently than physical intimacy by most.

I almost never desire sex these days. I do crave touch, although I'm not sure how you're defining intimate touch. I like cuddling in bed naked with my husband, and I would like to do that more often. But I like the cuddling better when he's not touching me sexually.
(M, 39, heterosexual, woman)

I: What kind of things do you do to feel sexy?
P: hold my wife when I am relaxed
(Rusty, 61, heterosexual, man)

Two participants who found skin-to-skin contact unpleasant or painful found

that the intensity of the sensation could be neutralized if they created a barrier (i.e.

gloves, blankets) that facilitated indirect contact.

I: How does the use of gloves [for partnered sex] reduce anxiety?
P: Two ways - by limiting the exchange of any bodily fluids which could potentially transmit disease (although unlikely given the framework of our relationship), and also by reducing skin-to-skin and skin-to-goopiness contact, which is are big sensory triggers for me.
(Hank, 33, queer, Transgender/genderqueer)

I: Does it hurt to be held?
P: Yes. But. Layers in between skins helps. Really like being held if wrapped in soft blankets first. Learned that from [first sexual partner].

> Most painful is direct skin-to-skin touch. Anything soft in between makes less painful. Also less uncomfortable if not exposed self body, less uncomfortable makes less painful too.
>
> (Dragonfly, 30, asexual/pansexual/polyamorous, odd)

This adaptation enabled participants to reap the emotional and relational benefits of physical and/or sexual intimacy, as eloquently articulated by Hank when asked about the rationale for engaging in sex that is physically unpleasant and disregulating.

> Sexuality is part of how we have mutually defined our relationship. Sharing myself at my most vulnerable, and feeling totally safe and loved, is very important to me. I enjoy giving my partner sexual pleasure. It's important to both of us that this be mutual, even though it works very differently for each of us. I do experience in with the problematic sensations some more pleasurable sensations, and there are some positive feelings even though it is incomplete. I want very much to share my body with my partner, and we have found some ways to do this.
>
> I make thousands of very deliberate choices about how much disregulation, pain and sensory overstimulation I will participate in every day. Many good and necessary choices that I make offer much less benefit for a much higher cost, such as showering. I choose some limited discomfort that I know how to cope with in order to have a fuller life.
>
> (Hank, 33, queer, Transgender/genderqueer)

Struggle

Sensory differences. As discussed above, most participants experienced some success in the area of *sensual equilibrium*. However, the experience of sensory disregulation and mismatch between personal sensory needs and social context (e.g. relationship partner preferences, construction of socio-sexual and work spaces, etc.) was the single most frequently occurring semantic theme in the data. Every participant discussed struggles with sensory regulation. These struggles were

frequently emotionally upsetting and/or physically painful for participants. The sub-themes I will discuss here are *mismatch in desire levels*, *barriers to sexual satisfaction,* and *sexual pain/dysfunction*. These sensory sub-themes were directly implicated in sexual satisfaction. In the next section, I will address how sensory differences were implicated in *courtship difficulties*.[18]

   Mismatch in desire levels. Most participants indicated that they had experienced or were currently experiencing a mismatch of sexual or physical desire levels that caused strain on a relationship and/or personal dissatisfaction. Though there is debate among sexologists about whether desire is better understood as mental or physical, for the participants in this study such a distinction was often untenable given fused body-mind experience. For participants who processed mental and physical desire separately, mental desire for partnered sex was not problematic. Physical desire for partnered sex and/or physical intimacy were indicated as problematic by participants. For a few participants, this meant that they desired greater frequency of sexual or physical intimacy than their partner, as demonstrated by the following quotes from L.B. and Cisco. L.B. explains that mismatch in desire levels was a key factor in why she broke up with her first boyfriend. Cisco, who was unwilling to divorce his wife, was very unhappy about their mismatch in desire levels and craved explicit expressions of desire.

   My autistic boyfriend and I were not compatable because I needed more
   affection than he felt he could give.

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   [18] I have chosen not to present information on sensory struggles that are not directly related to sexuality and intimacy, though they are relevant to participants' ability to use and/or move easily through socio-sexual spaces and relationships, e.g. food particularities.

(L.B., 22, heterosexual/sapiosexual, female)

My wife and I have been together for 36+ years. Don't know why. I never have known for sure if she wanted to have sex or not, unless it was very overt and direct, still don't. The only way I knew for sure was when she would initiate. Then about ten years ago she stopped. She would say "take a pill [erectile dysfunction medication] tonight if you want", very cold, like you can fuck me if you want to. Her attitude began to be poor, she began to be frigded, she got all holy and didn't like flirting, or grab assin. She just became a prude with no desire for sex at all
(Cisco, 60, heterosexual, man)

For most participants, *mismatch in desire levels* meant they desired more frequent physical intimacy in addition to or instead of sexual intimacy. For example, abby normal, who enjoyed partnered sex, also wrote about his intense craving for physical intimacy as an adolescent in a sexual relationship with his older brother. While R.B., who would prefer not to have sex at all because it is unpleasant and intercourse painful, wrote about how much she enjoyed regular physical intimacy with her husband.

i tried to hug and get closer to his physically, to get him to hold me, to limited success. he is a very stoic type. typical macho male.
(abby normal, 52, bisexual, man)

P: i like cuddling with my husband and doing foreplay but then i get tense during sex
I: What is foreplay for you?
P: giving and receiving massages and kissing and cuddling
(R.B., 29, heterosexual, woman)

As demonstrated by R.B., normative expectations for sexual intimacy in the context of intimate relationships were problematic for some participants. Participants who found sex aversive or uninteresting were highly aware of

normative expectations and often focused on meeting their partner's needs. Some

were actively engaged in exploring options for mutual-satisfaction and others were

not. Laura, for example, who was newly married and in her first sexual relationship,

wrote about how she was actively figuring out how to meet her partner's desire for

sex in the context of her intense anxiety. She was struggling, however, to share this

problem-solving process with her husband.

> But what I am personally learning is what works for me when we have sex because of the sensory issues that I have .
> Like I read on a few websites that some women do NOT like it when their husband has sex with them WHILE they are asleep !
> I actually would PPRECIATE it if my husband has sex with me while I am sleeping because I am far MORE aproachable for sex while I am asleep and I TRUST my husband !
> I mean , I heard that many women do NOT want their husband to have sex with them because they see it as a brake of trust and RAPE !
> I ABSOLUTELY canot agree with that , I actually TRUST my husband enough to know that he would NEVER hurt me and I am giving him %100 percent permission to make love to me while I am asleep because I am fare MORE RELAXED when I am asleep (Relaxing is a VERY TOUGH issue for me !) .
> ... but i do NOT have the courage to speak up although I realize that it is a sensory issue (Blushing!) ! .
> (Laura, 30, heterosexual, woman)

For the remaining participants, *mismatch in desire levels* meant that they had

little or no desire for sexual *or* physical intimacy, though they were receptive to

touch under the right circumstances. For these participants, normative expectations

around the frequency of sexual activity and sexual initiation were more problematic

than expectations that sex occur at all. This dynamic is demonstrated in the

following quotes from Dragonfly and millie33, neither of whom initiate intimacy.

Both of them, however, discussed the importance of intimacy for others and

therefore for relationships. Dragonfly was happy to oblige important partners and enjoyed some physical intimacy. millie33 was also happy to oblige and enjoyed sexual intimacy once initiated.

> Have had partners who interacted with self in ways that resulted in it [arousal] happening more often and did not mind that. Mostly be okay to interact with partner(s) sexually when they wanted to since that is usual part of relationships (respectful relationships only). But for self, not care. Not important by itself. Only important as way of interacting with important people.
> (Dragonfly, 30, asexual/pansexual/polyamorous, odd)

> I: Yeah. So, um, when your, when your partner initiates sex and you are not interested in sex yourself, you just don't desire sex at that moment, do you have sex with them or do you tell them no?
> P: Uh, no they can usually -- I can usually be interested. [*Laughs*]
> I: Okay. So you're easily convinced.
> P: Yeah.
> I: Okay. All right, so it's really you're just concerned about initiation, it sounds like. You're concerned that you don't initiate as frequently as your partners might like?
> P: No, it -- yeah, I, I never would, really, probably.
> (millie33, 55, lesbian, genderqueer)

Barriers to sexual satisfaction. As illustrated in the above quote from millie33, mismatch in desire levels often resulted in participants engaging in sexual receptivity, i.e. having sex because their partner initiates it. For many participants sexual receptivity was associated with sexual dissatisfaction. In contrast with millie33, who enjoys sex once initiated, many participants were not initiating sex as frequently as their partners because they were not enjoying sex. For some participants, like M, this related primarily to circumstances. As encapsulated in the quote below, M was facing a variety of interrelated barriers to sexual satisfaction

that are tied to her current circumstance of raising two small children on a tight

budget without adequate structural supports (e.g. state-subsidized quality

childcare).

> I: How satisfied were you?
> P: Not particularly? I often have sex because I know my husband wants it,
> and I love him and it seems like a nice thing to do for him, and because I want
> the emotional connection with him and there are few opportunities to get
> that. I don't dislike sex, but my drive is very low right now, has been for the
> last 2 or 3 years. I think I probably have a lower-than-average sex drive to
> begin with, but the last few years I think it's been even lower due to a
> combination of hormones (was still nursing my youngest until August of this
> year) plus very little sleep, time, or privacy. I am physically attracted to my
> husband and I want sex in the abstract, but I rarely want it at 6 am after 3-4
> hours of sleep, and that's often the only time the opportunity is available. I
> have a really hard time staying present when I'm worrying that one of the
> kids will wake up and we'll have to stop.
> (M, 39, heterosexual, woman)

For other participants, like Jack, partnered sex was generally unenjoyable. "The last

time I had sex was with my wife, over a year ago. It was a bad experience because

we were not getting along and I only did it because she was complaining about the

lack of sex in our marriage." (Jack, 43, asexual/heterosexual, man)

Participants discussed a variety of *barriers to sexual satisfaction*. *Barriers to*

sexual satisfaction are those things indicated as interfering with or preventing

satisfaction with a participant's personal sexuality or partnered sex life. Participants

discussed limitations on satisfaction more often if they were older, male-identified,

bisexual-queer, or had children. With few exceptions, participants were not

generally dissatisfied but experiencing barriers to complete satisfaction. A

significant barrier to sexual satisfaction for many participants was sexual pain or

dysfunction. However, I deal with that sub-theme separately because its salience

deserves separate treatment from other barriers.

Some participants reported limitations on sexual satisfaction associated with

changes in functioning imposed by physical health conditions. These health

conditions affected sexuality, but were not *sexual* pain or dysfunction per se, i.e.

these concerns were present in the absence of sex. These limits on sexual

satisfaction were discussed with feeling by Sandy, who manages several physical

health conditions and has begun experiencing menopause-related hormone

changes.

> I am frustrated that my sex drive has declined so much in the last couple of
> years. I am frustrated with back pain, chronic pain and asthma that is
> keeping me from enjoying a full sex life.   It takes so much energy to have sex,
> especially as a male.
> (Sandy, 46, bisexual/polyamorous, genderqueer)

Participants experiencing health conditions that impacted their sex lives

generally spoke of this dynamic as something to be managed. It was not ideal,

neither was it the most significant aspect of their sex lives. Management strategies

varied. Gabby, for example, was proactive about finding a physical therapist who

works well with concerns surrounding sexual functioning. Dragon Tears discussed

how it was important to accommodate both partners' variable symptoms.

> I: For what reasons did you not have a desired orgasm?
> P: A number of reasons. My sex drive is very much affected by a number of
> the medications I am on. Also, after my spinal surgery my entire sacral nerve
> root innervated area works differently. Vaginally sensations are different
> than what I used to have and there were a lot of neuromuscular issues for a
> while. I've been in physical therapy for bladder, bowel, and vaginal issues as

a result of my surgery for over a year now. The muscles aren't as strong and so there are a LOT of physiological issues for me when I have sex.
(Gabby, 23, queer, woman)

It's hard to say sometimes [when we'll have sex] because we both have medical issues that can be unexpected, so one has to go with the flow so to say on how we both are doing etc.
(Dragon Tears, 35, heterosexual, woman)

The most common *barriers to sexual satisfaction* discussed by participants related to body-mind experiences. In some cases, participants did not have ready cognitive access to some physical sensations or emotions, as demonstrated in the following excerpt from Dragonfly.

I: How do you define sexual arousal?
P: Not sure, may be body-feeling desire for sex.
I: What do you do when you're aroused and don't have a partner available?
P: Nothing different than usual. Not sure would recognize it anyways.
I: How often do you feel aroused?
P: Less than once a year, may be. Hard to know for sure, not likely to actually notice.
(Dragonfly, 30, asexual/pansexual/polyamorous, odd)

Two participants mentioned the need for stronger than typical physical touch for their mind to register the sensation. Rick, for example, who was very satisfied with his sex life overall none-the-less desired the ability to reach sexual climax through partnered stimulation. Currently, while he is stimulated by a variety of sexual activities, he is only able to climax following a period of manual self-stimulation. Collaborating with his girlfriend on ways to achieve the goal of climaxing from her stimulation, he discovered that he requires a more forceful grip for adequate manual stimulation than is typical.

I: How satisfied were you?
P: Very satisfied. As of now, I am unable to climax without me manually stimulating myself, even with her. We're working on that, though, trying out different topical solutions and other methods. So far, after every sexual encounter, we've gotten closer. I hope it's only a matter of time before I climax without manual self-stimulation, and I look forward to that with her. ... One thing I'm working with her is to replicate my self stimulation technique; she was astonished when I showed her how strong my grip was on my penis, and was worried she might damage me.
(Rick, 26, heterosexual, male)

Other participants had difficulty with fused body-mind experiences. C.Byrd, for example, wrote about how bad interactions from the day, personal insecurities about her looks and/or sexual performance, and other negative psychosocial experiences frequently interfered with her ability to feel arousal and other sexual sensations. "I would like to change my hangups like bad things that I cannot get out of my head which prolongs orgasm or takes away from the quality of the sexual experience." (C.Byrd, 29, lesbian, woman)

Performance anxiety inhibited sexual satisfaction for a number of participants. Some participants, like Cisco, attributed this anxiety to autism. "Performance anxiety affects my erection sometimes, even with the meds, I believe this is AS somehow, someway, anxiety, I don't know." (Cisco, 60, heterosexual, man) Other participants were more likely to attribute this anxiety to life experiences or particular circumstances, as demonstrated by Vivian, below, when discussing the extent of her sexual activity with her first sexual partner. "It involved manual (and other related activities). Almost oral... but I backed off from that because I was

nervous about my own performance. We also got to the point where we were very close to having intercourse." (Vivian, 31, heterosexual/bicurious, woman)

Among the body-mind experiences discussed as barriers to sexual satisfaction, anxiety-overstimulation was the most prevalent. The experience of performance anxiety was articulated as a distinct experience of feelings of anxiety interfering with sexual satisfaction. However, in most instances, the emotional experience of anxiety was not neatly separable from the physical experience of overstimulation. Due to the imbrication of anxiety-overstimulation in participant reports, I combine reports of anxiety and/or overstimulation as barriers to sexual satisfaction here. Rusty identified physical and mental tension as his chief sexual concern when asked about his satisfaction with his personal sexuality.

> I: What are the things you would change?
> P: the inner tension that stops me from being sexually aroused or in physical contact with people. ...
> I: Is your inner tension mental, physical or both?
> P: It is both though it is more mental
> (Rusty, 61, heterosexual, man)

The following quote from C.Byrd, who discussed fused body-mind experiences above, illustrates a prevalent experience among participants. Busy days and days with high social contact left participants feeling anxiety-overstimulation that was not compatible with sexual interaction. Partner accommodation in the form of down-time, followed by participant-centred reengagement (i.e. physical and/or sexual intimacy preferred by participants), was a key strategy for maintaining mutually-satisfying connection at times of high anxiety-overstimulation.

The last time we had sex was after a very busy, busy day. We had made plans to have sex that night after our child went to bed, but i was so wound up and overstimulated from the day that I couldn't even fathom sex at that moment. I just wanted to be left alone for a bit. An hour later, my wife started to slowly touch and caress me and that helped me to get into the mood, and thus we had sex.
(C.Byrd, 29, lesbian, woman)

Sexual pain/dysfunction. Anxiety-overstimulation was often further imbricated with the experience of pain. Many participants experienced sensory overload or particular sensations (e.g. sounds, textures, etc.) associated with sex as pain or as extremely unpleasant. For some participants, this meant that all sex (or all partnered sex) was painful to some degree. For others, overstimulation and sensitivity to particular sensations was something that needed to be managed to achieve a good sexual experience.

I: Aside from what we have already discussed, what barriers have you experienced to sexual satisfaction?
P: Possibly sensations being too intense, and becoming too sensitive. If something feels...TOO good, so to speak, my mind will switch from enjoying the sensation to registering it as pain and going into defensive mode. It switches back within a few seconds, but for that moment my sex drive goes briefly offline. It's hard to describe. The best way is to say sometimes I get overloaded.
(Rick, 26, heterosexual, male)

Often, management of stimulation levels was complicated by delayed cognitive access to sensations and/or delayed ability to communicate shifting needs during sex, as illustrated by M.

My sensory processing differences make some kinds of touch too intense or even physically painful. I sometimes have trouble recognizing this in real time while it's happening and/or communicating this to a partner.

> Sometimes I will realize that I've been gritting my teeth and enduring
> something unpleasant for 5 minutes or so without noticing it, before I get my
> act together to push someone's hand away or ask for a different kind of
> touch. I don't know how long or how much stimulation typical people take to
> orgasm, but I suspect I take longer than most, because it is more difficult to
> find the right kind of touch that feels good but doesn't overwhelm me.
> (M, 39, heterosexual, woman)

Hank, who previously discussed the use of gloves during partnered sex to neutralize

the negative sensory experience of skin-to-skin contact, elaborated on how

partnered sex was much more complicated from a sensory management standpoint

than masturbation.

> The reality of dealing with another body - heat, touch (even when limited to
> gloved), things like hair and breath (which we've tried to limit), sound,
> predictability, not being able to respond instantly to how things feel, not
> being able to be as free in position.
> (Hank, 33, queer, Transgender/genderqueer)

In addition to those participants experiencing pain or discomfort caused by

overstimulation or general health conditions, six participants reported genital-

pelvic sexual pain and/or dysfunction. Three of these participants reported

dyspareunia and/or increased vaginal muscle tension. For one queer participant,

vaginal tightness was a minor medical, but not sexual, concern. The remaining two

participants, who were in heterosexual relationships, were distressed by their

inability to enjoy penile-vaginal intercourse due to sexual pain. R.B., though

personally uninterested in sexual intercourse (in other words, she did not feel like

she was missing anything without sex), clearly articulated a sense of inadequacy and

responsibility for tension in her relationship with her husband related to her low

sex drive due to dyspareunia.

I: You said you don't like how sex feels. How does intercourse feel to you?
P: it hurts and it's very uncomfortable ...
I: How do you feel about having sex with him?
P: i wish i was more sexually motivated and i wish i could enjoy sex with my husband ...
it is very difficult to know that my lack of sexual desire has put a strain in my relationship. i feel inadequate
(R.B., 29, heterosexual, woman)

Three male-identified participants reporting limitations on sexual functioning were also distressed by their inability to perform "as expected". Male-identified participants experiencing premature ejaculation and/or erectile dysfunction reported the onset of symptoms after age 40. Though changes in physiological functioning are associated with the aging process, participants conflated their sexual dysfunction with ASD-related sensory or anxiety issues, as illustrated by abby normal, below. abby normal discusses his concerns with sexual functioning in the context of a relationship that began during the course of our e-mail interview, his first sexual relationship with a female.

> i definitely had hurdles to overcome, relating to late-in-life sexual functioning as well as aspie issues with intimacy. Me willy was VERY shy in the light of day (so to speak), in front of my partner. Performance anxiety also loomed large, as well as consistent penile performance and ability to achieve orgasm while thrusting, as well as premature ejaculation, all of which is somewhat an irritant (performance failures on my part), to say the least. I feel less than proficient still. I hope to improve with more practice and continued loving patience from sweetie :) i do suspect that most NTs don't have these performance issues.
> (abby normal, 52, bisexual, man)

Courtship difficulties. Sensory differences were also implicated in the theme of *courtship difficulties*. Most participants interested in having an intimate

relationship discussed difficulties with courtship. *Courtship difficulties* refers to those things which interfered with successful courtship. Participants discussed *courtship difficulties* more frequently if they were older or male-identified. As discussed above, 16 participants were in a satisfactory relationship at the time of the interview. Most participants found their relationship partners through organized groups (e.g. self-advocacy groups), on-line (e.g. dating websites), through introduction by friends/family, or through work/school. *Courtship difficulties* were, therefore, not a permanent barrier to the formation of a desirable relationship for most participants. However, they do represent challenges that participants had to overcome. Participants, in fact, frequently identified courtship as the most challenging part of dating and mating.

> Once I was in a relationship, I don't feel like there were any particular barriers to moving that relationship forward. Most of the barriers I described above are barriers to meeting people; not necessarily to developing or intensifying an existing relationship. The main barrier to marriage was finding somebody I could relate to and wanted to be in a relationship with. (M, 39, heterosexual, woman)

Sub-themes organized under the theme of courtship difficulties include: *access to socio-sexual spaces*, *communication-sociality*, *performance of normative desirability*, and *intersecting marginalities*.

Access to socio-sexual spaces. Participants' sensory experiences were not compatible with the structure of many socio-sexual spaces. Spaces normatively designated for socialization that provides opportunities to meet potential partners (e.g. malls, bars, parties) and spaces normatively designated for courtship activities

(e.g. restaurants, dance clubs, concerts), i.e. the sites of relevant sexual fields, were

often inaccessible for participants due to sensory violations such as noise and touch.

> Loud, noisy and chaotic environments (dance clubs, restaurants, etc) are
> difficult to process, and I start to lose control. I can't handle the input.
> (Rick, 26, heterosexual, male)

> I prefer to hang out in places that are less crowded. I find malls to be
> overstimulating.
> (L.B., 22, heterosexual/sapiosexual, female)

> One of the reasons, I have to say, for my not making friends, at least in high
> school and college, was that one place to make friends were – was a place I
> couldn't stand going, namely rock concerts.
> (Hannah, 49, heterosexual, woman)

Participants also experienced difficulty accessing socio-sexual spaces due to

limitations on transportation and finances. For example, many participants do not

drive. M & Gabby, neither of whom drive, wrote about how limited transportation

options structured their opportunities to be social and/or sexual, limiting both their

general access to socio-sexuality and their level of control over when, where, and

with whom to be social and/or sexual.

> When I was dating, transportation definitely limited the places I was willing
> to meet people, how late at night I was able to stay out, and sometimes
> whether I went out at all. There were times I left a dance or show early or
> cut a date short because I needed to catch the last bus home. There were also
> times I spent the night somewhere rather than try to negotiate
> transportation home, when I might not have otherwise spent the night if
> transportation was not an issue. Whether or not any of this actually caused
> me to miss out on a relationship opportunity is kind of hard to say.
> (M, 39, heterosexual, woman)

> My ability to see my boyfriend is limited by the fact that I don't drive and the only way to get between my parents apartment and his dorm is the subway [which is overwhelming and stressful].
> (Gabby, 23, queer, woman)

abby normal, who like many participants lives on a tight budget, wrote about how financial constraints limited his access to sexual goods and services as well as the *performance of normative desirability* (discussed in more detail below).

> obviously i could not afford a callgirl/boy, i live pretty close to the bone financially. the few people i encounter can tell i have little or no money to spare on anything fun, so people who see attractiveness in that are repelled by me.
> (abby normal, 52, bisexual, man)

Communication-Sociality. Normative socio-sexual spaces and dating interactions were also a challenge for participants due to expectations for communication and/or sociality. Demands for social niceties, such as small talk and mincing words, were problematic for some participants due to their direct communication style, as illustrated by the following quote from Danielle.

> The worst part of autism for me is when I accidentally say something that offends or hurts someone. I always feel horrible about it, because hurting people is not something I want to do, ever. I obsessively analyze any such incidents so that I can be sure of never doing anything like that again, but there's always yet another thing to add to the library of things-not-to-say. As I get older, those incidents are becoming less common, but I still can't help but beat myself up over it when I accidentally step on someone else's figurative toes.
> (Danielle, 29, asexual, androgynous female)

As discussed previously in *radical honesty*, nearly all participants report practicing and benefiting from the practice of *radical honesty* by others. Ignorance

and subsequent violation of unstated rules governing social interactions (e.g.

appropriate setting and method for expressing sexual desire) created difficulties for

participants in establishing sexual relationships. For example, Hank talked about

how his partner's expectations regarding timing of sexual escalation and style of

communication of romantic interest did not match his own. Hank was practicing

radical honesty, but his partner was not yet communicating so explicitly and

verbosely about feelings, expectations, and intentions. Hank, therefore, was ignorant

of these expectations and the potential consequences of their violation. Fortunately,

Hank and his partner benefited from the social support of their intentional

community.

> When [my partner] and I were first dating, he wasn't sure if I was into him -
> he was used to kissing on a first date and sex soon after, and it took a long
> time for me to want to try kissing (which I soon found out was really
> unpleasant due to sensory sensitivity on my face and lips and motor control
> issues with fine lip movements). I also was telling him that I was interested,
> but in a low-key, not exuding or explicitly sexy sort of way. Fortunately, our
> friends helped and explained to him how I worked.
> (Hank, 33, queer, Transgender/genderqueer)

C.P., on the other hand, found shared community to be a complicating factor

in his unreciprocated courtship of a fellow member of overlapping Autistic Internet

and in-person communities. Here, C.P. recounts how his object of interest revealed a

very different interpretation of events in their relationship based on contact

frequency norms that were not disclosed until after the fact.

> Okay, so then he's, then he's, then he's relating his side of it, and it's like lies.
> I mean things that were just, you know, "Where did that come from?" [He
> said] I had a, I had a crush. I had a, I had a obsessive crush, and all this stuff.
> *No*, an obsessive crush is you texting a person five times an hour – you know

five times every ten minutes and you know doing this and doing that and not being able – I mean there were days that I – you know, I just you know didn't even [contact him] – you know it wasn't obsessive. It wasn't anything like that. But, "it turned into an obsessive crush and all this other stuff, and I need to grow up and I need to do this and that". And he was no fa-... making it sound like it was all my fault, everything that happened, and I never put blame on anybody.
(C.P., 48, gay, male)

In addition, difficulty with or inability to interpret or perform non-verbal and oblique verbal communication (e.g. flirting) put participants at risk for missing out on relationship opportunities or pursuing where no opportunity existed. This difficulty often left participants feeling insecure, as articulated by millie33, because they were not confident about what, exactly, was going on. "Yeah, yeah, I've always been baffled by everything, people. I get blindsided. Then I think that I don't pick up on cues that people think are very obvious about being rejected and and/or, uh, being interested, both, everything." (millie33, 55, lesbian, genderqueer)

Difficulty with non-verbal and oblique communication was not only a struggle for participants in the specific context of courtship for sexual relationships, but created struggle in the creation of social relationships generally, as illustrated by the following quotes from Billy Joel and CS. This struggle, therefore, was equally relevant for asexual participants.

As somebody who is constantly around people and somebody who interacts with a lot of different people in different situations, I find that my inability to recognize faces inhibits my ability to develop a rapport with other adults without disclosing a disability (which is not always appropriate or otherwise necessary).
(Billy Joel, 23, asexual, woman)

Steep learning curve with nonverbal facial/body cues.
(CS, 34, heterosexual, woman)

abby normal, discussing the relationship that he started during our

interview, encapsulated this struggle in the context of a relationship that developed

online for about a year before his partner arranged meeting in-person.

> I: You two corresponded for a long time before this meeting. Do you think she
> was interested in having a romantic relationship during this correspondence
> with you, prior to her decision to meet? If so, did you realize it?
> P: i did not realize it but she later told me, yes. it all caught clueless me by
>
> surprise. 😲 [Surprise emoji = upturned eyebrows with circle mouth]
> (abby normal, 52, bisexual, man)

Older, male-identified participants, in particular, gave passionate

descriptions of how their inability to meet expectations for adept sociality created

significant barriers to relationship formation and access to sexual partners. Adept

sociality may be a key aspect of erotic capital for male-identified persons in many

(hetero)sexual fields.

> Yes, it's just like the Justin Timberlake song with the line "funny, how a few
> words can turn into sex" - So true and also why sex is so very awkward and
> hard for autistic men (maybe women, but girls will always find men willing
> to have sex with them, it's not the same for men) Autism influences how we
> can interact with others and dating can be soooooooooooo hard. Girls are
> prone to fall for smooth talkers, so I've always believed that 50% of the men
> are having sex with 80% of the women. I've worked with idiots, nasty guys
> that have had children from 2, 3, or even 4 different women. So, if someone
> has autism, they are going to have to think and probably have help from
> family and friends about how to date and get sex.
> (Jack, 43, asexual/heterosexual, man)

> In grade school and high school I did have the chance to have several good
> girlfriends (I know, now looking back, because my sisters and class mates

would try to fix us up), however, I didn't know how to verbalize intimacy, carry my end of the conversation, be gentle when carressing or kissing, couldn't dance. When I thought I was teasing or being funny, I was being seen as rude, stupid, an ass or worse. I got cold feet and stood up some girls I worked up the nerve to ask for a date, then avoided them forever.
(Cisco, 60, heterosexual, man)

Though interpreting and performing oblique communication was a challenge for most participants, there were a few who had, with practice, honed this skill set to the degree that it no longer presented a struggle. This is illustrated by C.Byrd when she relates how she intentionally practiced (heteronormatively feminized) oblique communication to show interest to a previous male relationship partner.

I: Who approached the other first?
P: I looked at him a lot and smiled to let him know I was interested but it was him who approached me to talk.
(C.Byrd, 29, lesbian, woman)

Finally, some participants discussed how their general communication impairments (e.g. lost speech) negatively impacted courtship or relationship formation. This struggle, like non-verbal and oblique communication, was equally relevant for sexual and asexual participants in their efforts to form intimate relationships. Some participants experienced communication limitations in most social contexts, such as Dragonfly, who uses Augmentative and Alternative Communication devices for all in-person interactions. Other participants, like Hank, experienced communication limitations primarily in the context of heightened anxiety-overstimulation. As discussed previously, normative socio-sexual spaces and interactions were often contexts of heightened anxiety-overstimulation for participants.

I: What barriers have you experienced to having a romantic relationship?
P: Difficulty meeting people. Can not just start conversation with people, AAC [Augmentative and Assistive Communication] devices not really capable of that. Too slow, too limited. ... Seems like most relationships for people start from accidental meetings where people just talk to people they do not know and did not expect to talk to. Can not have spontaneous conversations. Too hard to communicate with out careful planning aheads and preparing for conversation in advance. So that does not happen for me.
(Dragonfly, 30, asexual/pansexual/polyamorous, odd)

I have difficulty with social communication. I need to script before I speak, especially in situations involving multiple people or sensory stressors. When I am overwhelmed, I have difficulty with word order, word finding and conjugating.
(Hank, 33, queer, Transgender/genderqueer)

Performance of normative desirability. *Performance of normative desirability* here refers to participants' ability to present themselves as a desirable sexual or relationship partner. In other words, it refers to their ability to manipulate perceptions of their erotic capital. The *communication-sociality* struggles and difficulties *accessing socio-sexual spaces* discussed above were closely related to participants' trouble performing normative desirability. For example, C.P. illustrates how inaccessible socio-sexual spaces created barriers to the *performance of normative desirability*, while Rick identifies how normative demands for non-verbal and oblique communication negatively impacted the *performance of normative desirability* as well.

the overall atmosphere is overwhelming for a person like me, and I don't go to bars. I don't like bars. They're very overwhelming for me. I can't stand them. And it makes you very uncomfortable, which obviously shows and people don't want to get to know you.
(C.P., 48, gay, male)

> It [being autistic] has inhibited flirting from time to time, and not
> understanding subtle social/body language cues also has impeded 'sexual
> marketability' and dating.
> (Rick, 26, heterosexual, male)

In addition to issues of access and communication, i.e. (dis)ability

characteristics that are not necessarily read as disability in casual social settings,

some participants explicitly identified their disabled characteristics as undesirable

to potential partners.

> Also, most good people not see self as potential romantic partner, think self
> too limited or think self a child or unwilling to risk cause harm to self. People
> who do have not been very kind, been more of want selfish things not equal
> partnership.
> (Dragonfly, 30, asexual/pansexual/polyamorous, odd)

> Social expectations about what kind of women are desirable -- not physically,
> so much as personality/interests/affect. In my single days, I was willing and
> able to "play the game" to make myself look appropriately feminine, and was
> generally considered physically attractive enough. I have always been very
> skinny, and while I was dating I benefited from a set of extremely fucked up
> misogynistic expectations about female bodies. However, I also radiate a
> weird, socially awkward, outcast vibe -- not necessarily at first glance, but it
> becomes apparent once people spend a little time with me. So I didn't have
> too much trouble getting first dates, but second dates were much less
> frequent.
> (M, 39, heterosexual, woman)

As illustrated by the foregoing quote from M, many participants perceived

that they were not seen as desirable sexual or romantic partners because they failed

to perform, through their bodies or behaviours, normative femininity or

masculinity. This experience was not restricted to participants identifying as

genderqueer. As discussed at the beginning of the chapter, many participants

experienced substantial personal and social gender non-conformity regardless of their gender identity. While non-conformity was a general social concern for all non-conforming participants (i.e. misgendering, gender-based harassment, etc), it was of greater concern in the context of sexuality for participants who were interested in mixed-sex relationships. This dynamic is captured by abby normal in the following quote from early in our interview, prior to the in-person initiation of his first mixed-sex relationship. abby normal explains that he is incel, or involuntarily celibate, heterosexually because of his failure to perform normative masculine desirability, as pointedly expressed by the women with whom he served in the army.

> i am incel heterosexually, in that women do not generally find me attractive in any manner. ... army women by and large had contempt for me, often saying to me "why can't you act like a man?" with much vitriol.
> (abby normal, 52, bisexual, man)

In addition, several participants mentioned that their larger bodies were not considered sexually desirable. These embodied aspects of sexual desirability combined with the social aspects discussed above to limit participants' pool of potential partners, as illustrated by C.P.'s rejection. "And I said, 'Well, what was the problem with me?' And you know what he said? And five words can change your life, and that is, 'It's your looks and personality.' He said it directly to me." (C.P., 48, gay, male) The effects of these deficits in erotic capital were particularly felt by C.P., who emphasized at several points in the interview that the tiers of desirability within the sexual field of the gay community to which he had access were tied to "perfection".

In addition to making courtship more difficult due to a smaller pool of potential partners, judgments of impaired desirability were hurtful and sometimes the ground for exploitive relationships, as mentioned above by Dragonfly when discussing disabled characteristics, and in the following quote from Hannah where she reflects on connections between social norms and her dating experiences in college.

> And yes, I was certainly bullied for being fat and everything by my parents and literally everyone else. Certainly there are people who do not make friends with fat people, let alone get into bed with them. Remember that being fat and being smart are the last two minorities in America that you're allowed to hate, and I was both. ... The two people who were [interested in me prior to me meeting my husband], were basically figuring, 'Well, she's desperate, she'll screw anyone because she's sad and can't get anyone; therefore, I have a chance.' And they were actually quite explicit about this towards the end: 'How could you possibly be turning me down? It's not like anyone would ever be interested in you.'
> (Hannah, 49, heterosexual, woman)

Intersecting marginalities. Participants positioned at the intersection of multiple marginalities experienced further limitations on their pool of potential partners and subsequent opportunities for relationship formation. For a few participants, this related to their transgression of the gender binary, as illustrated by the following quote where Sandy reflects on how her increased gender fluidity over the past few years has impacted dating. "haven't dated much since I began recognizing who I was. I don't get hit on much anymore, but that's okay, because the relationships are more genuine, more honest. Quality over quantity." (Sandy, 46, bisexual/polyamorous, genderqueer)

For other participants, this related to their non-heterosexuality. C.P., for example, who spoke with pain about his failed courtship of another gay Aspie and his loneliness, pointed out the difficulty of dating as a person positioned at *intersecting marginalities*. This difficulty can sometimes lead to a sense of defeat.

> I: And have you tried to make any other connections with other, um, gay Aspies since then or during these couple of years?
> P: Do you know how rare that is? Do you know how rare they are? I mean it's already a very small segment of the population inside of another small segment of the population. ...
> I: Have you tried any other gay spaces [aside from bars] that are maybe more Aspie friendly?
> P: No, they're not – there really are none.
> (C.P., 48, gay, male)

Danielle discussed this struggle from the perspective of an asexual person. Asexual participants frequently talked about how close friendships, i.e. their intimate relationships, were changed by the initiation of a sexual relationship by their friends. It was difficult for asexual participants to find other persons interested in making an asexual intimate relationship their primary commitment.

> "Unable to find partners"? Bingo. I've had close friendships, but none of these people were also asexual. That meant that sometimes, when they fell in love with someone, I had to step back and let them spend more time with their partner. Strangely, I never felt jealous or snubbed; I was always genuinely happy for them. On one instance, I got to be a bridesmaid. But the intimacy of a close friendship is never the same after your friend finds a romantic relationship. It doesn't make me sad because I know, going into a friendship, that the other person doesn't want a platonic romance (and sometimes isn't attracted to females to begin with), and things will stay at what they call being "just friends"--that the relationship, no matter how close, is necessarily temporary; that there's a tacit agreement that when they find love, I let them go. But that's okay, somehow. They aren't asexual; it's not in their nature to be content only with non-romantic friendships, and if you are someone's

friend, you want them to be happy. Falling in love makes people very happy indeed.
(Danielle, 29, asexual, androgynous female)

Abuse & Exploitation. Twenty participants discussed abuse and/or exploitation in some form. This is exceptional given that abuse was not asked about explicitly. Participants discussed experiencing a wide range of abusive behaviours, including verbal-emotional, financial, physical, and sexual violence. It was common for participants to report multiple experiences with different forms of abuse over their lifecourse. The most common relationships in which violence occurred were intimate partner and familial ones. These experiences are presented below under the sub-themes *partner abuse* and *family abuse*.

Participants also discussed experiences of abuse from other community members (e.g. barber, teacher). Elle, for example, spoke of how her experiences with unwanted sexual attention, including physical harassment and having an 8th grade classmate read excerpts about her from a pornographic book he had written, contributed to her discomfort with sexuality. She had experienced sexuality primarily as a means of domination.

> I'm also kind of, occasionally, grossed out by the concept [of sex]. This may have something to do with past... I don't want to say traumatic, because it was not physically traumatic, but past experiences where quite vivid and explicit sexual acts have been described in my hearing to make me uncomfortable, often with a lack of respect towards or consent by the women involved. Edit,[19] due to an experience today: I spent an entire class period today being uncomfortably touched by a guy in my class, who has, I don't know the word, stroked me before, but today he spent 15 minutes rubbing

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[19] This "Edit" was part of the original e-mail interview. It was written by the participant, not the researcher.

my shoulder, and I made it quite clear that it was Unokay and that I was uncomfortable, but it didn't work. THIS is how I experience sexual attention, THIS is why I don't want it. I spent the rest of my day feeling uncomfortable and gross, and I'm still queasy about the whole thing.
(Elle, 18, asexual/bisexual, woman)

In addition to experiences of violence, participants experienced betrayed expectations in the context of a sexual or romantic relationship. A few of these violations of expectations were experienced as minor. The majority of these violations were experienced by participants as confusing, frightening, and/or upsetting. The emotional and behavioral reactions of participants to these more profound experiences of betrayal were very similar to their reactions to violence. In some instances, the line between betrayed expectations and exploitation is not clear in participants' accounts. Given the difficulty in conducting a post hoc adjudication of the line between betrayed expectations and exploitation (and lack of valid authority to do so), in addition to the similarity in participants' accounts of how these experiences affected them, I have chosen to include the sub-theme of *betrayed expectations* under the theme of abuse & exploitation.

Experience of abuse and exploitation was not uniform across participants or their social positions. Participants who discussed *radical honesty* (explicit, verbose communication style) more frequently were also individuals who reported more experiences of abuse and exploitation. Older participants reported more abusive and/or exploitive experiences across contexts (i.e. community, partner, family, betrayal). In particular, *family abuse* was discussed much more frequently by older participants. However, there was little age difference in discussion of *partner abuse*.

In addition, female-identified and genderqueer participants reported more abusive and/or exploitive experiences in general, with the exception of family abuse.

Partner abuse. Participants discussed a variety of experiences of abuse or exploitation by a romantic or potential romantic partner (e.g. "date rape"). *Partner abuse* often resulted from or leveraged broader social power disparities associated with the cultural normativities of ability and/or heterosexuality. The impact of these cultural normativities will be discussed more fully in Chapter 5. Two male-identified participants reported exploitive experiences with a romantic or sexual partner. Neither felt that they had experienced violence, but they did feel taken advantage of. Jack, for example, related the tale of how he lost his virginity to a 35-year-old female patient in the psych ward during his stay following a loneliness-induced suicide attempt at age 18. He concludes that he was in a position to refuse her and made a voluntary choice. He also recognizes the potentially exploitive motives of his partner and the constrained context of his choice.

> P: Her brother came to visit and he said that he was glad that [she] had me to watch over her. So, at that point, a part of me thought that [she] only hanged out with me so that she could be protected from the other male patients. The more I thought about this, the more I thought it was probably true. My virginity was just a bonus to her and one way of increasing the odds of controlling me if she had to. ...
> I: Did you end up doing anything you didn't really want to?
> P: Tricky question. The circumstances were gross and disgusting, sex on the bathroom floor next to a toilet in a mental hospital. Hmmmm. No, I could have said no to her. There were other girls with some very serious mental health issues that would offer sex to the guys on the ward. I had no problem saying "no" to them, even though sex was what I wanted more than anything at that point. So I would say, I choose to do what I did, [she] and myself had different reasons as to why we had sex. Also, I did have some emotional investment in [her].

(Jack, 43, asexual/heterosexual, man)

The remainder of participants disclosing partner abuse or exploitation were female-identified or genderqueer participants in relationships with cisgendered men. Failure to be a cisgendered man often combined with (dis)ability characteristics in participants' narratives of abuse. In other words, it often seemed as if participants were targeted for abuse by cisgendered men because their marginalized social position and associated positionality led to perceptions that they could be treated that way. Participants' differences, usually sensory or social, were also used to inflict abuse. Several participants had long histories of partner (and often family) abuse.

This was the case for Dragon Tears. Dragon Tears discussed several previous relationships that she identified as abusive. At the time of the interview, she was engaged to a man she met while visiting a previous husband in prison. She did not identify her current relationship as abusive. However, she enumerated varied experiences that meet standard definitions of abuse. She also expressed concern for herself and, particularly, her two small children living with her. Use of Dragon Tears differences to inflict abuse is evidenced in the following passage when, for example, her partner screams in her face. Dragon Tears has very sensitive hearing and this behaviour causes physical, in addition to emotional, pain.

> When it gets really bad he is screaming at the top of his lungs and will often get right in my face. He has thrown things twice, although not right at me but damn close at times because we are in the same room.(once it broke a nice crystal cake holder he said he will replace.) If he knew I was telling you anything about our relationship....oh I dont even imagine. A huge blowout would happen, I know it. He told me to never talk to other people about our

problems. Sometimes when he gets into these severe moments I cant get away from him...I go into another room and he will keep following me, I will try to keep the door shut screaming at him so he will hear me over his screaming to please leave me alone...but that still doesnt keep him out. I remember the last extreme outburst he had months ago...I ran into the porch to get away, telling him I need him to stop screaming (it hurts me physically and emotionally so much at times). I was cornered with him screaming at me right at my face while I pressed myself agains the back door, facing the door with my arms wrapped around my head. I slithered down the door crying and yelling at him to stop... he just wouldnt until he had 'settled things' is what he tends to say. One other severe fight, when he broke the cake holder, he cornered me in the kitchen and push be back a little (he has never put his hands on me other than that time..and it wasnt hard but a bit scarey)... he was screaming at me, I have know idea what again...because to me certain things that he has blown up about seem very trivial to me..and challenged me to hit him. I know what he was asking for and I asked him why...he just kept screaming at me to do it and then walked away eventually...his motto is for no man should ever hit a woman unless you need to defend yourself...he just wanted a reason and during that time he was really seeing 'red'.
(Dragon Tears, 35, heterosexual, woman)

In contrast with Dragon Tears, M did not recount a long history of abuse. Her story captures how gender and (dis)ability intersected in participants' experiences of episodic violence or exploitation. M, for example, identifies how the heterosexist expectations of her rapist factored into her experience of sexual violence. In a more extended discussion, not presented here, she also identified limited transportation options as a factor in this event. M does not drive due to ASD-related sensory differences and associated anxiety.

Right after college I went on a trip with two female friends to visit a group of guys we knew -- 3 of them living together in another state. One of my friends was dating one of the guys. My other friend hooked up with another one while we were there. Which left the third guy somehow expecting that I would sleep with him. The apartment had one bedroom and a pull-out couch

in the living room. My two friends were using the bedroom and living room, and I wanted to get out of there, and the third guy offered to take me for a drive. Why I thought this was a good idea is very hard to say, but I was 21 at the time and pretty naïve. He had been drinking and I was terrified of his driving once I got in the car. He took me to a hotel room and raped me. (M, 39, heterosexual, woman)

Finally, Vivian's experience of an abusive intimate relationship with a high school teacher demonstrates how participants' social differences, including isolation from peers and difficulty recognizing grooming behaviours, were implicated in experiences of abuse or exploitation. She described being very obviously socially isolated at her all-girls boarding school and how this teacher became her closest confidant during that time. She spoke with him candidly about her isolation from her peers and difficulties with her family of origin. He was also the first person to whom Vivian chose to disclose her disability identity (she was no longer receiving services or accommodations). Vivian did not identify her intimate relationship with her teacher as abusive during high school, but came to understand her experience that way as an adult. Her identification of her social differences as disability-based vulnerability to abuse demonstrates how participants often understood their own experiences through the lens of a cultural discourse of vulnerability for people with disabilities. This dynamic is presented in more detail in the sub-theme *sex-ability* in Chapter 5.

> P: Well, when I start to suspect the possibility of abuse, I did a lot of research into the susceptibility that people with disabilities can face when it comes to being sexually taken advantage of. And because I think of the types of social vulnerabilities that autistic people especially face, and he knew that about me. I was not at all popular and I had very few friends. Also, I was attending a boarding school and was not living with my family.

My vulnerabilities were clearly evident, and he knew I had an obsession for him. He would talk to me about how concerned he was about my feelings for him, considering he was significantly older, was married, and was raising kids. .He was very aware of my vulnerabilities.

I:Mm-hmm. So at what point did the relationship move beyond just talking to each other?

P: I think we started out our friendship in an unconventional way, in regards to student-teacher relationships. Like, being invited to go to over to their house and having late-night, deep discussions that didn't involve anything physical. ... Emotional intimacy began in the "first chapters" of our book. I was around 16-17 when things began to accelerate. ... We never actually had sex, so it wasn't a black-and-white situation. It's really hard to explain. It did get physical.

I: Could you give me an example?

P: Sure. Um, so there would be several occasions when, um, we would, um, be in a private area or space or room, whether it was outside or inside, um, and there would be a lot of very tight embracing and caressing and touching, um, and kissing. Um, and there, uh, there was a time I recalled when, um, you know, I would feel, like, an erection that was kind of, um, pressed against, like, my thigh. Um, that was probably the most graphic memory I have. (Vivian, 31, heterosexual/bicurious, woman)

Family abuse. Participants also reported experiencing abuse in their family of origin. As with experiences of *partner abuse*, participants' experiences were shaped by ableism and heterosexism. Unsurprisingly, given the topic of the interview, most of the family abuse spontaneously reported by participants was directly related to sexuality. This included verbal-emotional abuse of a sexual nature, as illustrated in the following excerpts from Sandy and Laura. These excerpts demonstrate how verbal-emotional abuse resulted in lost social capital and unhealthy relationships with sexuality.

I learned early on never to go to my parents for support. I was date raped at 17, my mother called me a whore and wouldn't believe that I didn't seek it out. That following Christmas, in front of my grandparents, I opened one of

my Xmas gifts from her and it was a black lace bodystocking. She said that I
was going to act like a whore, I should at least dress nice.
(Sandy, 46, bisexual/polyamorous, genderqueer)

[My father] would jokingly say : Let's have sex :) ! And my mother and I
would be just standing there with our mouths open ! ...
His IDEAS were too shocking for me to even THINK about a respond !
My mother could not do anything about this because she did NOT know how
to stop him .
My father just basicly made me think that sex is DISGUSTING !
(Laura, 30, heterosexual, woman)

Participants also reported sexual abuse. abby normal, for example, who was

quoted previously regarding his need for more *physical intimacy* during his

consensual sexual relationship with his brother as an adolescent, also wrote about

being raped by the same brother around the age of five. abby normal explicitly

identified the incident at five as rape and the subsequent sexual relationship, from

13-22, as consensual with equitable power dynamics.

i was a victim of incest as a young boy, by my older brother. the tables were
turned as a young adolescent when he came back home from the army and
wanted me to top him, which i did until i left home to join the army as he did
a decade earlier. ...
frankly speaking, the sheer out-of-the-blue nasty surprise of having my older
brother wake me up at 0-dark-thirty and shove his cock into my mouth and
to splooge therein [SOUR!!!] messed me up.
(abby normal, 52, bisexual, man)

Dragonfly also made a clear distinction between consensual and non-

consensual sexual activity when asked about his first sexual experience. Dragonfly

considers his first sexual experience to be with the female relationship partner who

taught him that being held while wrapped in soft blankets is nice despite

Dragonfly's general experience of touch as painful. When he wrote about his first

experience with this person, however, he did provide the following caveat.

> P: But. Only if counting consensual sex. Otherwise first time of any sexual
> activity is age 15 with father parent. Do not count that as first time. Was not a
> "participant". Stupid father parent. Should not count. ...
> I: What sexual activities did your father do with you?
> P: Made me rub his penis, his hand over mine so could not pull away. That is
> only remembered. Have been told he "confessed" to other things to a family
> friend, touching me and looking when was not dressed and other things. Was
> never told any more than that. ...
> Mother parent told also. Was not believed. She not so nice to self anyways so
> did not surprise. Do not know how she reacted. Do not remember.
> (Dragonfly, 30, asexual/pansexual/polyamorous, odd)

Dragonfly's experience demonstrates how ableism often inflected experiences of

abuse within the family as well. Dragonfly was not told the full details of his father's

actions by paternalistic adults who knew them.

Finally, some participants reported abuse in their family of origin that was

not directly related to sexuality. These experiences did, however, shape their

relationship repertoire, limit their social capital, and contribute to their hesitancy to

trust others. CS, for example, clearly articulated the potential for future abuse in the

context of marriage based on past experiences. The qualities she sought in a partner

were shaped by this understanding, as was her willingness to trust potential

partners.

> I: What is bad about marriage?
> P: Marriage would be bad if I got involved with someone who reminds me of
> dad, or neighbor. ...
> I: What personality traits or behaviors would remind you of your dad?
> P: My father has a short temper, as well as abusive.
> I: What personality traits or behaviors would remind you of your neighbor?

P: My neighbor was "too fast" as it were.
(CS, 34, heterosexual, woman)

Hannah directly connected the abusive nature of her relationship with her mother to her inability to obtain support from her parents with a variety of personal troubles, including the extensive harassment to which she was subjected at school.

> Imagine that the things that trigger the good mommy turning into the evil mommy are not only what would now be called the Aspie things, but are also getting less than 100 on a test, having any imperfection, hitting a wrong note when you're practicing the piano, making any mistake, or not being in line with their picture of what you ought to be or what a person ought to be or what their daughter ought to be. In other words, I knew for a fact that if they asked me what happened in school and I told them honestly, or was caught out not telling them anything or telling them dishonestly, it would happen.
> (Hannah, 49, heterosexual, woman)

Betrayed expectations. In addition to experiences of abuse and/or exploitation, most participants experienced *betrayed expectations*. In a few instances, these betrayals were experienced as relatively minor, though still worthy of mentioning by participants, as in the following example where Cisco recounts how mystification regarding his wife's intentions contributes to general relationship dissatisfaction.

> Also, she wants to do something like stop at the grocery store for one or two things and an hour later we get home with several bags of groceries. I wonder, did she lie to me or does she get in the store and think oh I need this and that and this and that. I have waited in the car, which is bad unless I have a book. So I usually go along, push the kart and goof on people [people watch].
> (Cisco, 60, heterosexual, man)

More often, betrayals were more serious and negatively impacted participants' well-being. As mentioned previously, it was not always possible to cleanly differentiate between exploitation and *betrayed expectations*. Either way, these violations were very deeply felt by participants and often resulted in the deployment of self-protection strategies (e.g. not seeking out or initiating intimate relationships). Betrayal was most often experienced in the context of violations of explicit agreements and/or when there was a lack of explicit communication. In other words, *betrayed expectations* occurred when participants' need for radical honesty was not respected. The following story from Rick about his first attempt at sexual intercourse provides one example of how partners and potential partners would provide socially-scripted, or "polite", responses that did not provide explicit and verbose information about their actual feelings, expectations, or intentions.

> My first time didn't go as planned. I was dating someone a couple of years younger than I was over the summer of 2008, I believe. She shared an apartment with her roommate, I was still living at home. We got along pretty well; went on a few dates, hung out a bit. One night we were in her bedroom making out, and she told me where she kept condoms. I took that as a clue, grabbed one, set it near the bed and continued our foreplay. Eventually we stripped out of our clothes and proceeded to try and copulate. Unfortunately, either due to my inexperience with condoms, my larger size, or just both, I couldn't get the condom on all the way; it wouldn't roll all the way up to the base of the shaft of my penis. It felt - forgive my language - it felt like my penis was being choked to death, which needless to say isn't a pleasant sensation. To add insult to proverbial injury, I couldn't get a full erection with the condom on - and even with being halfway hard, I couldn't penetrate her. It felt like EVERYTHING was too small. According to society, most guys would be proud - happy, even - with this 'revelation' of their size. I was not.
> I felt embarrassed, clumsy, and immature. She was okay with this, saying that sometimes it just doesn't work out. However, I don't think she was truly okay

with the situation, as she broke off our relationship about a week or two later, when she had a going-away party and didn't invite me (she was going to college in another town). I think I took whatever relationship we had too seriously, but I would have at least liked her to have been more direct with me.

Thankfully, now I have properly-sized condoms and know how to put them on correctly, not to mention using lube as well.

(Rick, 26, heterosexual, male)

In addition to less than completely truthful "polite" responses, many participants also experienced explicit lying by relationship partners, as in the following example where C.Byrd describes why she broke off her engagement to her child's genetic father. As illustrated in this excerpt, lying by relationship partners was often part of a larger pattern of ill treatment.

To make a long story short, we had a long distance relationship for a couple months. I came back to San Diego to live with him as was planned. When I was in SD, I found out that he was seeing other people as well as sleeping with his ex while I was away. What bothered me was that he was lying to me about it the whole time while continuously making me feel guilty for hanging out with my friends on occasion. When I found that out, I asked him about it. He denied it at first and them admitted it. I was out of there within a week. He was also a very verbally abusing person most of the time. It wasn't worth it to stay with him.

(C.Byrd, 29, lesbian, woman)

Notice that C.Byrd did not end the relationship until she received explicit verbal confirmation of lying from her fiancé. Many people do not admit to their lies. Participants often benefited from social support to help them recognize betrayal in their relationships, as in the following anecdote from Dragon Tears describing the last relationship she had prior to her current engagement. Dragon Tears explicitly

identifies the role of social support in getting out of this relationship, as well as how

such experiences contributed to a hesitancy to trust others.

> This other man I met was getting out of jail, and whom I thought was a
> girlfriend..introduced me to him. He would do things for me...yard work, give
> gifts etc. until he asked if I could help with a bill he had trouble with and he
> never paid me back. He kept lying to me, and it was my long term girlfriends
> who showed me that he was using me. It made things even more difficult for
> me to trust again. His whole family was very manipulative...he even had the
> nerve to introduce me to a ton of his family members and say he wanted to
> be with me and straighten up his life.
> (Dragon Tears, 35, heterosexual, woman)

Finally, many participants recounted experiences where they were never

given explicit information about relationship dissolution. These experiences were

especially bewildering for participants, who had difficulty moving on because they

did not know what had happened. This dynamic is illustrated in the following

excerpt from millie33 where she describes the ending of her first college

relationship. This relationship was millie33's first relationship with a woman, her

first sexual relationship, and the only romantic or sexual relationship she ever

initiated. She described the end of this relationship as very difficult for her. millie33

had initiated sex with her roommate, with whom she had an intimate emotional

relationship. They had sex once. They continued to be close until the end of the

school year, at which time they both returned to their mutual hometown.

> I: Okay, so you continued to hang out with her over the summer in groups.
> And then the next year were you roommates again?
> P: Well, um, she was going to be a teacher and yeah, I did, yeah, she went and
> transfered colleges and I transferred also. ... It was not a good idea. ... No I
> transferred to the same school she did and I shouldn't have. ... Because,
> because I, I think she didn't want to be with me.

> I: Okay. Did she ever tell you that?
> P: Well, well no, but she, she started dating, um, guys. And I couldn't
> understand that.
> (millie33, 55, lesbian, genderqueer)

Betrayed expectations were also experienced when another's behaviour violated participants' understandings of "rules" governing behaviour, such as criteria for relationship formation, dissolution, or sexual activity. The following quote from C.P., describing his eventual admission of interest in an Aspie friend with whom he shares overlapping Internet and in-person communities, illustrates this type of betrayal based on the "rules" governing sexual activity (i.e. criteria for having sex) and relationships (i.e. resolving issues in the context of a friendship turned unreciprocated courtship does not include relationship dissolution). C.P. also explicitly identifies how significant this betrayal was to him.

> And I'm like, "Okay." And then I finally, I lose it. I lost it. I was like crying
> and everything. I was like, "You know what? I-I-I've avoided telling you
> anything because you always keep bringing up this age difference thing, and
> then I find out he's not even any much that older than me," and this and that,
> and I kept telling him. You know I told him all this stuff, how I felt then,
> because it just-just blew up – ... in a big, in a big thing. And I-I looked at him,
> and I said, "In-in-in less than two weeks, you're already into a situation like
> that with this guy. You don't even know him." I said, "What was it?" He says,
> "Oh, it was his red hair and his eyes." He wanted to start a relationship over
> red hair. ... And I'm like, "Well, that's-that's not much of a basis to start a
> relationship when you don't even know anyb-... somebody." ...
> And he gave me a letter at some other event we went to explaining
> something. You know it was – oh, it was a – it took him three months to write
> this letter, to write it properly for what he wanted to say, and it was like, "We
> want to get – you know I wanted to make it resolve and everything." And
> then he goes and de-friends me all over the place. That doesn't sound like
> somebody who wants to resolve it. So he said one thing and did another,
> again. ...

I mean just – I – you don't do that to people. ... you know typical NT people will just let that roll off their back. I can – I will always remember this. I will always – it will always be hurtful to me. I will never forget this.
(C.P., 48, gay, male)

Conclusion

An inductive, semantic thematic analysis of the data yielded numerous, cross-cutting themes and sub-themes. I chose to present those themes with the highest code frequency and/or those which appeared to impact participants most profoundly. As a group, participants experienced success in the domain of relationship satisfaction. Sixteen participants were in relationships they described as satisfactory overall and another four were satisfied with being single. Satisfactory relationships for participants often included: a partner from the disability community, partners who treated them well and had good character, partners who accommodated their needs, and the practice of radical honesty. Participants were also successful in using both sexual (i.e. genital) and physical (i.e. non-genital) intimacy to make desired emotional connections and regulate body-mind experiences.

On the other hand, participants struggled with sensory differences. These differences included a mismatch in desire levels tied to different sensory needs or experiences; barriers to sexual satisfaction, such as inaccessible sensations and/or overstimulation; and sexual pain and dysfunction. These experiences were associated with a high level of sexual receptivity, rather than initiation, by many participants. The majority of participants were not completely satisfied with their sexuality and/or sexual relationship. Participants also struggled with courtship,

frequently identifying it as the most challenging part of sexuality and relationships. Courtship struggles for participants included: inaccessible socio-sexual spaces, demands for communication-sociality, performing normative desirability, and having a marginalized sexual and/or gender identity. Finally, twenty participants spontaneously reported experiencing at least one instance of abuse or exploitation in their lives. In addition, most participants reported experiencing betrayal. Experiences of betrayal were most commonly associated with partners' failure to practice radical honesty.

These findings provide an initial sketch of sexuality and intimacy in the lives of my participants. They also provide some indications about their sexual citizenship and demonstrate the utility of the interactional model of disability for understanding the citizenship of persons with neurological (dis)abilities. For example, the interactional model of disability is particularly helpful for understanding participants' sensory experiences. Though social communication is the defining criteria for a psychiatric diagnosis of ASD, sensory differences played an equally large role in participants' lives and their position as sexual citizens. It would be difficult to argue that some participants' sensory sensitivities, desensitizations, or processing would be neutral under any social arrangement, e.g. experiencing all touch as pain. However, these predicaments are greatly exacerbated by structural factors, such as noisy, crowded socio-sexual spaces and cultural expectations for genital sex (particularly penile-vaginal) in the context of intimate relationships. These structural factors point to how *ability* is implicated in the dependence of one's citizenship status on sexuality, as the performance of genital sex is required for

access to a key institution of social and legal membership, i.e. the couple/marriage. They also point to how ability is implicated in the dependence of sexuality upon citizenship, as participants' access to partnered sexuality was structured by the construction of shared spaces that disregarded their embodiment.

There were additional themes in participants' experiences that are not presented here because they are not directly relevant to success or struggle in participants' intimate lives. They are, however, relevant to the place of intimate relationships in participants' lives and therefore their sexual citizenship. For example, participants frequently reported that they learned social skills in intimate relationships that they were either not able to learn in other contexts or simply had not been forced to learn in other contexts (e.g. reciprocating social contact, negotiating competing needs, etc.). Living alongside another in a relationship of mutual care is a critical component of performing one's citizenship responsibilities. Relationships can be seen as citizenizing to the degree that they enable the performance of this responsibility by teaching the required skills for its performance. In addition, many participants relied very heavily on their intimate partner for meeting their sociality needs. In other words, participants frequently did not have extended social networks. These participants were most likely to find social contact anxiety provoking and/or exhausting. They were not interested in developing a large circle of friends, but preferred one (or perhaps a few) committed relationships. As indicated in Danielle's quote on page 129, in a society organized by monogamous heterosexuality, friendships rarely fit the bill of a committed relationship. Intimate relationships, then, served a critical function in the lives of

participants by providing them with a basic good in the context of the current sexual

organization of society. These connections between participants' everyday

experiences and their positioning as sexual citizens will be explored further in the

next chapter.

CHAPTER FIVE

Latent Analysis: Procrustes for President

> Procrustes had an iron bed (or, according to some accounts, two beds) on which he compelled his victims to lie. Here, if a victim was shorter than the bed, he stretched him by hammering or racking the body to fit. Alternatively, if the victim was longer than the bed, he cut off the legs to make the body fit the bed's length. In either event the victim died. Ultimately Procrustes was slain by his own method by the young Attic hero Theseus, who as a young man slayed robbers and monsters whom he encountered while traveling from Trozen to Athens.
> The "bed of Procrustes," or "Procrustean bed," has become proverbial for arbitrarily--and perhaps ruthlessly--forcing someone or something to fit into an unnatural scheme or pattern.
> -Encyclopedia Britannica[20]

(Hetero)sexual normativity and ability were the two main normativities shaping participants' sexual citizenship. Recall that I am conceptualizing citizenship as a framework for articulating the conditions that enable people to participate equitably in the co-construction of our shared aspiration for human living and its associated distributive arrangements. Sexual citizenship for my participants, none of whom expressed any concerns around legal membership, is sketched here as social membership with its associated rights and responsibilities. (Hetero)sexual normativity and ability entwined in participants' accounts to produce (or not) sexual citizenship. The citizenship produced through these entwined normativities had distinct impacts on participants' sexuality.

I use the term (hetero)sexual normativity to refer to social norms and the discourses, practices, and distributive arrangements associated with them that structure society based on sexuality. Heterosexual culture (Berlant & Warner, 2002)

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[20] I am indebted to Hannah for bringing this Grecian tale to my attention. It is a "perfect fit".

is the most salient aspect of sexual normativity in the data. For this reason I rhetorically signal its importance by including (hetero) in the phrase sexual normativity. I do not gloss all sexual normativity as heteronormativity, however. For this reason, I use the term heteronormativity in this analysis when I am referring specifically to that sexual normativity. I use (hetero)sexual normativity when referring more broadly to sexual normativity that includes but extends beyond heteronormativity. Ability refers simply to the social norms and the discourses, practices, and distributive arrangements associated with them that structure society based on ability.

These normativities were taken up and experienced by participants in many ways. Sometimes participants' pursuit of desired ends was confined or limited by these normativities. I understand these experiences as disciplining. Other times participants mobilized these normativities to pursue desired ends. I understand this as empowering. Sometimes participants sought to fit themselves into the available, though ill-fitting, social positions enabled by these normativities. I understand this as subjectifying. Other times participants worked to articulate new normativities and associated arrangements that better enable their access to citizenship. I understand this as fluidity.

Given the close ties between them in the data, as well as conceptually, I have organized the themes of this latent analysis under the umbrella themes of *discipline-subjectification* and *empower-fluidity*. I am not suggesting by this arrangement that these aspects of experience or their associated social relations are neatly separable. Indeed, there are very clear connections between them throughout the data.

However, it is analytically useful and practically helpful to distinguish when conditions support equitable participation in the co-construction of our shared aspiration for human living and its associated distributive arrangements and when they do not. Themes organized under the umbrella of discipline-subjectification include *structural ableism, cultural ableism, heteronormativity,* and *(hetero)sexual normativity*. Themes organized under the umbrella of empower-fluidity include *sexual economy, normalization, right to pleasure, proactive strategies, Autistic identity*, *and alternative normativities.*

    The concept map presented in Figure 1 illustrates the main concepts and themes presented in this analysis. Sexual citizenship is centered, a product of interactions between ability and (hetero)sexual normativity. Sexual citizenship is fashioned through relations that produce both *discipline-subjectification* and *empower-fluidity.* These two spheres of experience overlap. The data themes are organized conceptually around these normativities and their relationship with sexual citizenship.
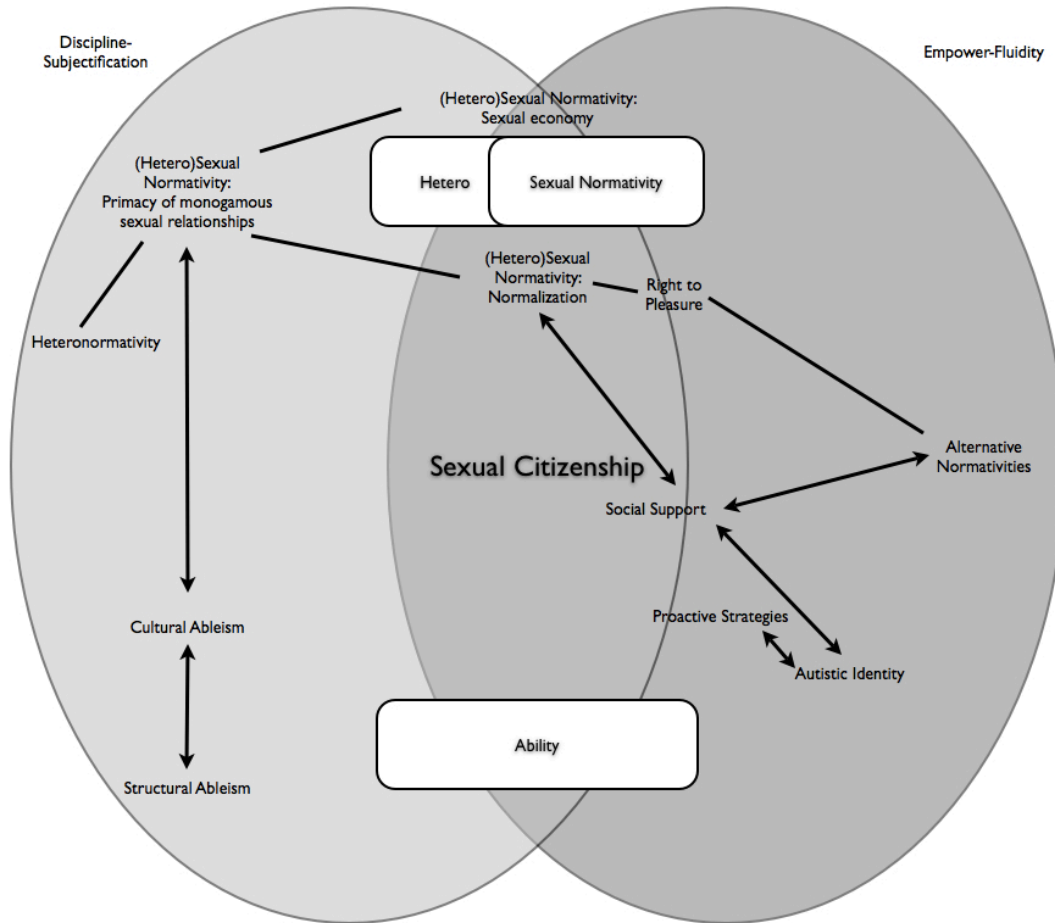
Figure 1. Concept map of latent analysis. *The arrows represent bi-directional influence. The lines represent association.*

Discipline-Subjectification

    Structural ableism. Participants experienced a wide variety of encounters with structural ableism. *Structural ableism* refers to experiences generated through the implementation of social structures that privilege particular abilities and the people who demonstrate them at the expense of those who do not. Though culture may be properly understood as one aspect of social structure, I have parsed encounters outside the bounds of formal institutions (e.g. health care, governmental) as *cultural ableism* in this analysis to distinguish between those

experiences of ableism that resulted from "hard" versus "soft" structures. Sub-themes organized under structural ableism include: *socio-sexual spaces, transportation, economic opportunities, laws & policies, sexuality education*, and *service providers*.

Participants' limitations on access to *socio-sexual spaces* and *transportation* were discussed in the previous chapter. There, I detailed the effects of these two aspects of structural ableism on participants' sexuality. Rather than re-presenting that data, I would like to note that these two themes also represent limitations on use of public space and access to a wide variety of goods and services. Danielle, for example, wrote about how the PA (Personal Assistant) provided as part of her disability services at university would not transport her anywhere for recreation, including the library. Danielle took up the distinction made for her between "need" and "desire" in the distribution of resources. "I don't ask about going to places just for recreation, mostly because I feel like my PA is there to get me through school, not to serve as a taxi service." (Danielle, 29, asexual, androgynous female) Failure to provide adequate structural supports to enable access to public spaces often resulted in local others becoming responsibilized for the provision of this right, as illustrated in the following excerpt from L.B.

> P: I can't drive, so I have friends take me shopping. Once a week the school van will take anyone grocery shopping who needs it. At home my parents take me, and there is also good public transport at home ([major metropolitan] area) than in this little town.
> I: Has there ever been somewhere you wanted to go that your friends/parents couldn't or wouldn't take you?
> P: Sometimes I have run out of food at school because I missed the school van and my friends were busy. That wasn't fun, but I have someone who I can count on this year.
> (L.B., 22, heterosexual/sapiosexual, female)

Economic opportunities. Economic opportunities refers to aspects of

structural ableism that limited participants' accumulation of material wealth, as well

as limitations on their access to goods and services caused by distributive

arrangements. Many of the limitations on access to wealth and/or goods and

services experienced by participants resulted from policies stratifying the

distribution of resources. I organize policies directly relevant to distribution under

economic opportunities and deal with other *laws & policies* in the next section. The

impact of economic limitations on participants' sexuality was discussed in the

previous chapter, e.g. limited ability to access sexual goods/services or perform

normative desirability. Participants frequently experienced these economic

limitations on their sexuality because, despite their relatively high level of education

and professional training, many participants experienced economic hardship. As

presented in the sample, 12 participants reported an annual income of $15,000 or

less.

Participants reported losing jobs once their diagnosis became known and

sometimes hid their disability, even when this meant not requesting desired

accommodations, because of concern about employment discrimination. One

illustration of employment discrimination was provided by Hannah, who related the

following story.

> This one was among the several times that I lost jobs because people who
> had hired me to come teach their kids –and who then found out that I had
> something on the autism spectrum – decided that this meant that I MUST be
> a paralyzed mute in a wheelchair, diapers, and a crash-helmet.
> One of them decided this AFTER a long-distance phone-call (initiated by her:
> seeking help for her nine-year-old [...] daughter) during which she found and
> read my web-site.

"Don't feel offended, but I am not sure about having my daughter working with a person who has autism. I feel my daughter would benefit more from a tutor who is able to speak."
"We've *been* speaking." [for 5 - 10 minutes by that point]
"You really don't see my point, now, do you? [click!]"
(Hannah, 49, heterosexual, woman)

Participants also faced difficulties on the job or job interview that led to not being hired, losing their employment, or not advancing. Hank, for example, wrote about how expectations for the performance of particular social communication abilities during job interviews were a barrier to employment. "difficulty with interviews with HR staff, despite having no trouble doing jobs, because I present with alternative social skills which are valued in the fields I work in, but not standard to HR expectations." (Hank, 33, queer, Transgender/genderqueer)

Once on the job, participants reported experiencing spaces that were inaccessible due to sensory violations (e.g. flourescent lighting, background noise, etc), difficulty with colleague socialization, unwillingness to accommodate their learning style, and disability harassment. R.B. provided the following illustration of disability harassment on the job. The harassment was so upsetting that R.B. eventually terminated her employment and was still looking for alternative employment at the time of our interview. "i worked with a client who lived in a community residence and the staff there used to make fun of me. when i saw the staff at the office they didn't want me to sit near them at lunch so i ended up eating lunch in the bathroom stall." (R.B., 29, heterosexual, woman)

Lost employment due to ableism was a contributing factor in participants' limited material wealth. Some participants accessed the limited social provisioning available to them to meet their basic needs (e.g. social security disability).

Participants discussed the stigma and shame associated with receiving public

assistance. One example of this is provided by Laura, who, despite professional

certification, is underemployed (due in part to limited accessible transportation)

and uses the Supplemental Nutrition Assistance Program to meet her nutritional

needs. "Yes, I do have a case manager as I recieve Foodstamps (I feel a bit

embarrsed about it)." (Laura, 30, heterosexual, woman)

Participants also reported experiencing stress as a result of economic

hardship. This stress sometimes strained their intimate relationships, jeopardizing

their access to intimate relationships and diminishing their well-being. Dragon

Tears, for example, who is unemployed and providing for two small children,

discussed chronic stress due to financial insecurity and the strain this placed on her

relationship with her fiancé when they disagreed on how to stretch limited

resources to meet competing demands.

> Now, Im just trying to figure out how not to lose the little house we live in... I have had it for 13 yrs, and with back house taxes that were not paid (my previous exhusband did not pay them as he told me he did)... I may not have my house much longer, unless my fiance and I figure out how to work through these financial things...
> so when he told me he needed help to get a futon for ma and that I needed to help pay half the phone bill and the car bill. (keep in mind I cut the car bill down to 1/3 of the price very recently because I filed bankruptcy). I kept telling him that I cant keep doing that because it leaves me with very little to take care the kids etc. I pay all the other bills. (he gets ssi as well...the same amount as my daughter). I told him I felt like he forced me to do this because when I said I dont know if I can...then he would yell at me and tell me that he wont pay the phone bill then...so I had to do it. I said I will not do this again or it will end things...I cant be going without like that, especially when getting this futon wasnt neccessary only to have more room in the bedroom instead of the regular bed. He said its to help pay off what he owes to ma..but I told him that this isnt the best way to do that.
> (Dragon Tears, 35, heterosexual, woman)

Limitations on material wealth experienced by participants, in combination

with health insurance policies, often resulted in inadequate access to health care.

Health care limitations were particularly salient around services for ASD and

transitioning (i.e. body modifications to change one's gendered appearance or legal

sex) because these types of health care are frequently not covered, or inadequately

covered, by health insurance programs. This intersection shows how access to

health care is stratified by economic class, ability, and gender. The impact of

inadequate health care was profound for some participants. One participant, whom I

do not identify here to protect their confidentiality, got divorced so that they could

access autism-related services for their daughter. This maneuver resulted in

increased economic insecurity and health concerns for the participant. I present this

story in some length because it captures the relationship between ability and wealth

disparities, and their imbrication with intimate relationships and health, very well.

> P: [Spouse] and I had to get divorced not long after we got married. [Their]
> insurance would not cover my daughter's diagnoses of bipolar and autism
> and she was not doing well. We thought we might have to give up custody to
> the state. By getting divorced, she qualified for Medicaid. She and I were on
> Medicaid for eight years until she turned 18, and the state dropped her,
> [spouse] and I remarried. ...
> Things had been rocky with [daughter] when she was a baby/toddler, she
> wound up in the children's psych hospital at age 7, for being so violent, she
> was there for 3 weeks and they put her on Lithium and a bunch of other
> meds. Under the bipolar diagnosis, she was getting meds, not much else, but
> it was affordable.   2 years later, she had an autism diagnosis, and we had
> crappy insurance - Medical costs went from $200/month to over
> $1600/month. Most of her meds weren't covered, plus we got a letter in the
> mail saying that the insurance would not cover any care connected to her
> autism diagnosis. There were times he had to leave work to take me to the
> ER because she had hurt me. Sometimes I was so ill with migraines that I hid
> from her, I locked myself in the bedroom. She needed supervision, and at the
> time, I wasn't able. I knew that if I didn't figure out something to help her,
> she was going to wind up in the juvenile system, and I didn't think she would

survive that. I didn't think I could survive losing her like that.   So we got divorced, then she qualified for Medicaid and services ...
I: How did the divorce impact your own financial security?
P: We had to separate all the finances. We'd already been wiped out by the cost of my disability. In a year, we went from a 6 figure income with a house, decent savings to bankrupcy, struggling to buy groceries and giving one of our vehicles back to the bank. ...
I paid for [daughter's] access to therapy with my lack of access to specialists. I hated Medicaid. I hated the way doctors treat you when you are a Medicaid patient. I hated the bureaucracy, the gameplaying, the hoops you have to jump through to get little things that ought to be common sense. My health got worse because I had to be on Medicaid, instead on being on [spouse's] insurance. I had go without medical care often - either no access to specialists or I couldn't tolerate the drugs on the formulary. I have lung issues, asthma now that I didn't have before. I use a wheelchair more frequently. I'm on 3x as many meds.

Finally, some participants discussed the impact of financial hardship on their ability to maintain and/or terminate intimate relationships. For example, the cost of gas, flights, and other transportation limited participants' ability to visit children and other family members with whom they did not live. This placed limitations on participants' social support and structured their access to intimate relationships. For example, Dragon Tears reported that the cost of legal services delayed divorce from the husband who was sexually abusing her eldest daughter. This placed her and her children in physical and emotional jeopardy. In addition, Dragon Tears wrote about how economic disparities impacted child custody proceedings, resulting in ongoing limitations on her relationships with her older children and a sense of dispair. Note that ability is specifically leveraged by the spouse's "high priced attorney" in the legal regulation of this intimate relationship.

I didnt have money for an attorney to help me... so I feel like I lost everything because he had a very high end attorney and I had nothing, not even legal assistance because they only take certain cases... it still hurts me so much on and off when I think about it. ...

> I wrote him an email because I dont understand why he chose to [throw away the Christmas gifts I sent the children]..being everything is brand new too. He sends it to his 'constantly' used high priced attorney to write me a letter, telling me to own up to my mistakes etc. They also keep using a past issue I had with some hoarding behavior...although I was told it was mild compare to most cases people see. It doesnt matter, everything detail wise they get their hands on they twist it into the worst case ever and Im the worse mom on earth. It's hard to even look forward to trying to fight more... (Dragon Tears, 35, heterosexual, woman)

Laws & policies. In addition to policies directly implicated in the distribution of wealth and wealth-stratified access to other goods, participants encountered a variety of other ableist *laws & policies* that affected their sexual citizenship. The theme *laws & policies* refers to state laws, state policy regulations, and the policies of specific formal institutions (e.g. schools). All participants were living in the community at the time of the interview and few received on-going services. As a group, their sexual citizenship was not as impacted by *laws & policies* as would be the citizenship of more highly institutionalized (dis)abled persons. Nonetheless, they still reported varied encounters with limiting *laws & policies*.

Several participants discussed how obtaining the "right" diagnosis and/or performing the "right" kind of disability was requisite to receive supports (i.e. qualify for benefits programs or services). In other words, the performance of *inability* was required to receive the "special" rights offered to "vulnerable" citizens. Rick, for example, wrote about how access to public health insurance was dependent on ability-based disqualification from paid employment. Notice how Rick takes up the discourse of independence in this excerpt and struggles to make sense of a state policy regulation that would disqualify him from achieving this norm.

> I will state that in order to receive health care through the government, I would have to go on Disability and/or social security, both of which would

substantially limit my income to below poverty levels. I find this to be counter-productive to my goal of full independence and self-sufficiency, as most of us save money each month, incrementally working towards larger purchases and a steadier financial status. I have stalled on finishing the paperwork required for either program, as I am fearful that once I get on either program I won't be able to end my connection with it. I have heard it is difficult to get on either program and difficult to get out of them as well. (Rick, 26, heterosexual, male)

Rick points out that the supports offered do not enable transition between the classes of abled and disabled. The effect of policies that require performances of inability is to reify the boundary between the abled and disabled, the citizens offered freedom and respect versus the citizens offered protection and care.

The reification of disability through policy mechanisms and its subsequent effect on sexual citizenship was also evident in the stories of participants who were "too" disabled. Danielle, for example, lost housing and was expelled from university after an episode of cutting. Despite the minor nature of the physical self-injury, she was deemed a "danger to self and others" who could not mix with the abled lest she pose a threat to them. Two participants shared stories that demonstrate the direct effect of such policies on sexual rights and access to intimate relationships. R.B. wrote about how she was incarcerated in a community residence at age 19. She had just begun dating the man to whom she is now married before the incarceration. As a result of institutional policy, her contact with him was limited and she was not permitted to have him in her bedroom. It was years before she was able to perform ability adequately enough to wrest control of her life away from the state because she was legally disenfranchised from the right to make fundamental decisions about her life, like where to live or what medications to take, through a state law that enables court ordered assisted outpatient treatment (AOT).

P: [The doctors] sent me to be evaluated at some hospital and then i was
placed in a community residence

I: How long were you at the community residence?

P: a couple of years

I: okay. How did you end up leaving community residence?

P: i begged to leave and finally my treatment providers allowed me to move
into a supported apartment program where i lived in my own apartment ...

I: You said that [your husband] was caught off guard when he learned that
you had OCD and depression. How did he react?

P: he was very concerned and asked me why i never told him. i said we had
just started dating and i didn't want him to be turned off if i came with
"baggage" ...

I: How did living in community residence affect your relationship?

P: it was kind of difficult because i was so embarrassed that [husband] had to
see me living in a place like a community residence. i think for a little while
our relationship was strained because i was not happy where i was and i held
alot of anger ...

I: How did you get off AOT?

P: i went to court and kicked legal a** - basically i told the doctor that there
was no reason why i needed to be on aot. i advocated for myself ...

I: Did being on AOT restrict your relationship in any way?

P: yes

I: Could you please tell me more about that?

P: as part of my aot order i was supposed to take medication. i did not need
the medication however because it was for a condition i did not have. i had
terrible side effects so i did not like to take it. when aot found out i wasn't
taking my medicine they did a "pick up" order on me and police came to my
house and took me to a hospital to be evaluated. [Husband] didn't know what
was happening to me and he never knew if i was going to be picked up
he was always worried

(R.B., 29, heterosexual, woman)

At several points in her story, R.B. works with the discourse of ability. She

expresses concern that she will be found unworthy as an intimate partner because

of her (dis)abilities. She is shamed and angered by placement in a space designated

for the disabled and being treated with "protection and care" that is incompatible

with autonomy and respect. Dragonfly, whom you may recall experiences all touch

as painful, also related several anecdotes where paternalistic perceptions of his

abilities and needs resulted in disrespectful treatment. One such incident came up

when discussing how people, privileging their abled experience of sex, told him it

should not hurt. Dragonfly was placed in the position of protecting his intimate

partner from prosecution due to perceptions of ability combined with state

requirements for mandated reporting. This experience reflects the importance of

the legal consciousness of others to our exercise of citizenship rights.

> I: How did your therapist react when you told them that you had sex that
> hurt? (i.e. what did they do or say)
> P: She said was very upset. Her words got louder and faster. She talked more,
> asked very few questions, than usual. She only asked, repeatedly, who had
> sex with that hurt and when happened. But did not answer.
> I: Did your therapist know that all touching hurts you?
> P: Had told her so expect yes. But had told her other things she did not seem
> to remember. Or may be did not understand. So, not sure. Was many years
> ago.
> I: Did your therapist ask you any questions to try and figure out why the sex
> was painful?
> P: No. She did not ask. She said painful was because was bad, abusive, wrong.
> She said good sex by person with real love would not hurt. Told her that was
> not true for me but. She said that was universal truth. She said was just
> confused as usually am about such things. Is true do get confused easily
> about many things complicated like that. But did not believe her about this. ...
> I: Why didn't you answer your therapist's question about who you had sex
> with?
> P: She said needed specific details for make report. Did not want report.
> (Dragonfly, 30, asexual/pansexual/polyamorous, odd)

Finally, ableist state laws regulating marriage were a concern for one

participant. Danielle, whom you may recall is asexual and interested in forming an

asexual intimate partnership, expressed concern that the validity and legality of a

potential marriage could be disputed due to lack of sexual activity. I may equally

have organized this policy concern under (hetero)sexual normativity, as it reflects

the primacy of sexual relationships in social organization. However, I chose to

include this policy concern here because of the overt link between sexual

intercourse and ability. There are a wide variety of impairments and conditions that

prevent intercourse.

> I: Aside from finding someone interested in an asexual partnership, which
> we've discussed, what are barriers to getting married?
> P: I do NOT think a marriage needs to be "consummated" to count as a
> marriage, and I wish they would change that part of the law. It's entirely too
> likely that sooner or later an asexual couple will have their marriage forcibly
> annulled because they don't have sex, and they may lose custody of children,
> be unable to make medical decisions for an incapacitated spouse, or be
> excluded from an inheritance--essentially the same problems gay people face
> when they aren't allowed to marry. I don't think it's going to be possible to
> change that until there's a test case for the courts to decide on, and I hope for
> all our sakes that they conclude sex is not necessary for a valid marriage. I'd
> hate for asexual couples to have to force themselves to have sex, even once,
> just to be allowed to be officially married. It would be a real violation.
> (Danielle, 29, asexual, androgynous female)

Sexuality education. With few exceptions, participants did not receive

adequate sexuality education. *Sexuality education* refers to instruction about

sexuality and/or relationships from an institution such as the family or school. A few

participants were provided adequate education for a typically abled individual. No

participant was given (dis)ability-relevant sexuality education. As discussed in

Chapter 4, participants experienced a variety of (dis)ability-relevant sexual

experiences, such as sensory processing differences and courtship difficulties, that

should be addressed in comprehensive sexuality education for persons on the

spectrum. Sexuality education was also pervasively heteronormative. Over half of

participants are not heterosexual. Generally inadequate, ableist, and heterosexist

sexuality education left participants with fewer resources to navigate difficult

situations or capitalize on opportunities to achieve desired ends. In other words, it

compromised their sexual citizenship.

Few participants reported receiving any useful sexuality education from

their parents. Several participants reported that their parents never discussed

sexuality with them at all. When parents did broach the subject, the most common

form of sexuality education provided was a book about the biology of reproduction.

Several participants reported that the treatment of sexuality by their parents, often

meaning complete silence, contributed to an understanding of sex as shameful.

Some participants overcame this sense of shame with age and others carried it

throughout their lives. M's description of sexuality education from her parents

encapsulates many common experiences.

> I: Do you remember when your parents first talked to you about sex?
> P: I remember them reading a "how bodies work/ how babies are made"
> book to me when I was 5 or 6. They also attempted to talk to me about it
> when I was about 14 and thought I was having sex.
> I: What did they tell you?
> P: Don't remember much about the conversation at age 5 -- mostly remember
> the pictures in the book. At 14, conversation was about how sex needed to be
> part of a relationship, and should not be "a flash in the pan." They were
> making an assumption that I was having casual sex based on some papers
> they found in my purse (an appointment with the county family planning
> clinic).
> I: Is there some other way they taught you about sex?
> P: Was not ever discussed much. Parents were never physically affectionate
> in front of me.
> I: How did you feel about that at the time?
> P: Didn't think about it much at the time, but it probably contributed to
> feelings that sex is shameful / taboo. I never felt comfortable talking to my
> parents about sex or relationships.
> (M, 39, heterosexual, woman)

A few participants also did not receive any sexuality education at school,

whether due to general education norms at the time of their schooling, because they

skipped *the* grade in which it was provided, or because they were segregated into

special education classrooms. Those who *did* get sexuality education at school found

it wanting in several consistent ways. First, participants often mentioned that

sexuality education did not seem relevant at the time it was provided. For some this

was because they had not yet developed sexual feelings and could not imagine

experiencing them. For others, this was because they were and remain asexual. Jack,

for example, wrote about how confusing he found the sex ed provided by his school

while he was going through puberty.

> No mention was made about how you were supposed to feel about sex. How did you ask a girl out on a date? School talked about the mechanics of sex, but none of the moral or social conventions around sex. And no mention was made if you were not interested in sex. The impression is that you were supposed to be interested, no questions.
> (Jack, 43, asexual/heterosexual, man)

These data suggest that sexuality education should be on-going through a

person's 20's to ensure it is provided at the developmentally appropriate time for

persons who are not typically developing. Second, information about non-

heterosexualities is needed. Comprehensive sexuality education for all persons

should include information about the range of sexualities. This information is

particularly important for individuals on the spectrum, however, given the relatively

high rates of gender and sexual non-conformity in this population. Typically,

participants received no education about non-heterosexuality and, as captured by

Gabby, identified this as a gap in their education. "Also, a more queer friendly

approach. The little we learned about non-heterosexuality was still about lesbians

and gays as being inherently different and I don't even remember the first time I

learned about bisexuality." (Gabby, 23, queer, woman)

In addition, participants frequently reported that the sexuality education

provided was not (dis)ability-relevant or accessible. Several participants identified

the need for sensory differences to be explicitly addressed and normalized. In

addition, participants reported the need for social aspects of sexuality to be

explicitly taught, such as negotiation of competing sexual needs/sensory

experiences, courtship skills, the signs of a good relationship, and the subtle signs of

abuse-exploitation. Rusty, for example, identified the need for education on

courtship skills when discussing his experiences with sexuality education, and

Vivian identified the need for education on the subtle signs of abuse-exploitation as

she reflected on contributing factors in her abusive relationship with a high school

teacher.

> I: Is there something that you wish had been done differently? (learn sooner, different way)
> P: Yes I would have learned how to connect romantically with another person.
> (Rusty, 61, heterosexual, man)
>
> A problem I had growing up was not receiving adequate sexual education. My parents were not comfortable talking about it with me. Even though I learned a lot about sex through my peers and through the media, I don't feel like I received a proper formal sexuality education. I only learned about the obvious indicators of sexual assault (physical force, rape, etc.) and not the subtle indicators (grooming techniques).
> (Vivian, 31, heterosexual/bicurious, woman)

Participants' identification of the need for explicit education around

courtship and abuse-exploitation are linked with the communication style of *radical*

honesty discussed in Chapter 4. Participants did not "pick up on" this socio-sexual

knowledge through casual social interactions or peer relationships. Social

knowledge and social skills relevant to sexuality and intimate relationships should

be explicitly taught so that persons on the spectrum may access full citizenship in

key areas such as bodily integrity, relationship formation, and choice of when and

how to be sexual.

Communication style was also relevant to complaints about what *was* taught.

Several participants identified as misleading the graphic images of diseased genitals

and morality tales provided as part of sexuality education. Rick captures this

dynamic below and also identifies how scare tactics are not only misleading but

demonstrate an understanding of youth as less than fully human, or not fellow

citizens.

> I felt the graphic pictures of STDs and STIs were too much (especially since
> my lunch break was right after health class). I felt as though I was being told
> that sex was extremely dangerous, and I could contract hellish diseases if I
> wasn't careful. Yet they only told us that (in a deliberate choice of words) to
> wait until marriage, which seemed to me quite odd. How did marriage
> protect against these awful diseases? I couldn't figure it out, so I chose to
> abstain from sexual activity through high school, both to avoid the STDs/STIs
> and getting a girl pregnant (which was terrifying at the time). ...
> I still feel the pictures were too much, and a blatant use of fear to promote
> abstinence. I feel that I wasn't treated as a thinking individual, but a bag of
> hormones that needed to be scared into complying with a certain set of social
> norms. No doubt I was a bag of hormones, but we needed to be taught about
> birth control methods, alternate ways of sexually connecting with someone
> (mutual masturbation, etc.) and how to handle an STI/STD if we got one. In
> short, I feel as though I was misled and duped out of actual sex education that
> would have helped me a great deal as a teenager.
> (Rick, 26, heterosexual, male)

You may recall that one of the consequences of inadequate sexuality education for

Rick was that he did not know how to properly use a condom when he attempted

intercourse for the first time. This ignorance placed his sexual health at risk and

contributed to the loss of an intimate relationship.

Consistent with the communication style of radical honesty, which includes

not just explicit but verbose communication, when participants did not receive

adequate sexuality education from authoritative sources, they went looking

elsewhere.

> I think autistic people should be given more specifics, instead of the vague
> generalizations (when you love somebody...) that sex ed sometimes devolves
> into. I like specificity. If I'm not given information, I'm going to look it up, and
> sex isn't a topic that should be trusted to the denizens of Google.
> (Elle, 18, asexual/bisexual, woman)

The denizens of Google were in fact the most common source of sexuality education

for participants. Many participants discussed on-going efforts to learn the

information they needed about sexuality and intimate relationships, identifying

blogs, books, and pornography as their main sources of information. Some

participants were fortunate enough to develop social relationships where they could

be open about their need for sexuality education. Billy Joel, for example, wrote about

how the other young women on her floor at the college dormitory had taught her a

lot about sex, helping her understand for the first time the structure of different

types of romantic relationships, what sex sounds like, and why people have sex at

all.

> I: How do you define "romantic relationship"?
> P: I am not really sure. First and foremost, I think of it as something that
> doesn't apply to me. It is a special relationship between two people where
> they explore feelings of caring about each other and a physical attraction to
> each other, often times in order to see if they would be compatible partners
> for life. I tend to attribute it to people who do dating or people who are
> married. As a college student, it's a common concern for the people I spend
> time with (and a frequent conversation topic) so they have actually made me
> a "Relationships Chart" so I can better understand the different possible
> stages of romantic (not-just-friends) relationships. ...
> I: Did you try to get more information? How?
> P: Not until college, then just being around people was having information
> thrown at you. Girls came back drunk and compared the sizes of the penises
> they had seen (and put in their mouth) from different guys. Hearing those
> [sex] sounds [coming from dorm rooms] led me to ask other bystanders if
> people were okay in there and they laughed and assured me that they were

"great" in there. Last year I was a senior in college and I asked one of the
freshmen on my floor (who does sex a lot) why she likes sex and she told me
it feels really good. So basically I just ask the people who a) are open about
sex b) I know really well and who say I can ask questions.
I: Is there something that you wish had been done differently? (learn sooner,
different way)
P: I feel like I just didn't get it. School provided information but with my lack
of feelings of attraction I wasn't able to comprehend at that age what sex
really was or why I had to learn about it. I know it's late now for me to be
learning, but I prefer learning from my peers. Being around college where
people are sexually active, they are more open to talking about it comfortably
with me than a parent would be, and they would explain things more
realistically than a school nurse (like that freshman who told me it just feels
good).
(Billy Joel, 23, asexual, woman)

Later-in-life peer-led education was particularly useful for older, non-

heterosexual participants like millie33 and C.P. Both millie33 and C.P. reported that

they did not receive any sexuality education from their parents, no relevant

sexuality education at school, and grew up with a heavy awareness of homophobia.

This had particularly negative implications for C.P., who remains closeted in most

social contexts and did not begin having contact with the gay community until after

mid-life. He has never had an intimate or sexual relationship, though he wants one.

C.P.'s enduring sense of stigma is reflected in the following excerpt where he reflects

on the relevance of school-based sexuality education that only covers getting a

woman pregnant.

I: how did you learn about sex then, about sex that's relevant to you, gay sex?
How did you go about learning about that?
P: Oh, I don't know. It just – you know I-I had no information, and that was
before the time of the Internet really became – because I've spoken to
another peer of mine who ca-... you know about ten years after I you know –
you know graduated from the same high school ten years after I did, and he
had the benefit of the Internet. So it was easy for people to find that
information. I don't know. I just you know never thought about it because
you know what am I supposed to do? I just knew how I felt and you know
knew just no-... never to say anything.

(C.P., 48, gay, male)

Though most participants sought additional sexuality education through cultural and social avenues, a few participants reported attempts to receive additional education from formal institutions or service agencies. Hannah related a particularly telling story about making arrangements to have Planned Parenthood provide an educational session for the adult Aspie group she and her husband attend. The conflation of autism with childhood and other misunderstandings of ASD that will be discussed more fully in *cultural ableism* are evident in the assumptions of the Planned Parenthood staff. In addition, the belief that sexuality is inappropriate for persons with cognitive (dis)abilities, another theme to be explored more fully in *cultural ableism*, is displayed by the previous facilitator of the local Autism Society of America group described below. This story demonstrates how *cultural ableism* is taken up in institutional settings to create structural barriers to sexual citizenship for persons on the spectrum.

> P: In, in the group in which I mentioned, we had a very odd experience with Planned Parenthood, which is definitely a sexuality concern. And the leader, by the way, of our Autism Society of America affiliate, which is the, you know, [particular] Region affiliate, namely the [city] area, can tell you about this 'cause she was a witness. We are – we – the group that I help to lead has different people come in sometimes as guest speakers to do different activities or presentations. And at one point, we decided to have one on Asperger's and sexuality, because that was a concern for us, just as it is for you.
> Now, at one – we had earlier wanted to have one, but one of – but a non-Aspie person, who was our group facilitator and organizer at the time, had objected because she didn't see this as an appropriate concern! Mind, this is a group of all adults, and she thinks we shouldn't have it as a concern! It bothered her, and it turned out it bothered her 'cause her mental image of Aspie or autism is: 'child.' And even though the Aspie who's most in her life was 17 at the time or was just graduating college or something and – graduating college or getting into college, I forget what, but she was already

having problems with her own daughter aging out of the stereotype and not knowing – and really started to hate her own daughter.

So we got rid of that facilitator for that and many other reasons, all of which have been basically she'd been treating us like babies. But – so, so now that the – we had the leader of the group, no facilitator. Okay, 'now we can have a sexuality workshop. We'll have Planned Parenthood do one of theirs.' They do some very nice ones for community groups, as you know. ... Now, now, Planned Parenthood was asked to do this, and when Planned Parenthood's people came down, they looked at a roomful of adults and they knew that they were going to be doing two workshops that week and that one was for a parents' group, of parents of people on the spectrum, to find out how they could talk with their kids about sex; and one was gonna be for Aspie people themselves.

And so they looked around and they saw grownups, and they said, 'Oh, you must be the parents' workshop,' and when they – and I spoke up and I said, 'No, we are pe-, the people with Asperger's that you were scheduled to do the workshop for tonight.' And we had – there were like three people from Planned Parenthood. There was a guy and two women, and their jaws dropped down practically to the floor! If they – it had never occurred to them that th-, that if they were called to do Aspies, you know, that this would be adults.

It turned out that what they thought was that they'd have a room full of people 13 and under, and they would have to be explaining to them how to use contraception or something, you know. And it turned out – I have to say, I was very up front. I challenged them. I said, 'Let me ask you a personal question, Dr. So-and-So' – or just So-and-So, whoever it was. 'You didn't expect to see in this room, when you knew it was the Aspie room, you know, peop-, so to speak, people even looking quite human, did you?' And they all actually said, 'Come to think of it, no, we expected you not to look like regular people.' And this is Planned Parenthood, who are supposed to be enlightened and are supposed to be able to deal with all kinds of diversity! ... I mean, it turned out that during the session, about half of it, every other minute was us conc-, correcting a misconception. Someone in Planned Parenthood had the misconception that we didn't have sexual feelings. Someone had the misconception that we wouldn't have been aware of sexual distinctions. Someone – it was unbelievable. In fact, we are actually planning to have, uh, our group leader, you know, the director of the ASA affiliate, go to Planned Parenthood and teach them, and then have them come back and do this thing right, because, of a three-hour meeting, we spent at least an hour and a half, probably closer to two hours, teaching them about us, when we had asked them to come there and teach us.

I: So what was it about sexuality that the group had *wanted* to learn or talk about?

P: We *wanted* to talk about how to get relationships, how to get more friends, things to be aware of as you are having a sexual relationship and so on. You know, we'd wanted to, you know, talk about the things that any group of

people that was dealing with sexual issues would talk about, and of course specific problems. We have someone in the group who is a post-op t-, post-op transsexual, I believe. We have someone else who is gay. You know, I think we have someone who is a lesbian. I think we have someone who is bi. I – we wanted to talk about issues like, you know, and how to improve one's sex life, you know, how to get a sex life, for instance, if you don't have one. Okay?
(Hannah, 49, heterosexual, woman)

To Planned Parenthood's credit, Hannah reported that they indicated plans to do

their homework and return to provide a more appropriate session.

   Service providers. The above narrative provides one example of

participants' encounters with a variety of *service providers* that limited their

exercise of sexual citizenship. Often, these *services providers* were located in key

institutions such as health care and law enforcement. Service providers were

frequently cited as ignorant of autism, unaccommodating, paternalistic, and/or

patently unable to help. Difficulty accessing competent service providers often

contributed to participants not addressing or putting off seeking care for particular

concerns, especially sexual ones. Encounters with incompetent service providers

also had substantial negative effects on some participants' lives.

   Several of the excerpts presented under *laws & policies* and *sexuality*

education could have been organized under the theme of *services providers*. For

example, Dragonfly's encounter with a therapist who would not accept the reality of

his embodied experience or his right to consent to sexual contact would qualify, as

would Hannah's story about Planned Parenthood. Recall from that excerpt that a

previous facilitator of Hannah's Autism Society of America group did not approve of

sexuality for autistic adults. It turned out she did not approve of their meaningful

participation in the electoral process either.

P: At one point, she had decided, as Election Day was, uh, like, a month or two away, to post a sort of – one of these get-out-the-vote things, which is all very well. You know, people should know that it's their civic privilege and responsibility to vote. But the way she did it was she said – what she – what she did was she said – or, rather, wrote – was to simply copy and paste the entirety of an advertisement for her particular candidate for state senator or state representative, I forget which it was, whose platform was a one-party – it was a one-question issue, you know, a one-issue platform. And what the issue was, was ban vaccines because they cause autism.

I: Oh.

P: Oh, my god, right. Worse than that, she had said – she had posted this and said, 'And becau-, and we need everyone to get out – you know, to get out the vote for, you know, so-and-so,' which, like, this little nothing can-, it wasn't, thankfully, a major candidate. And she posted, 'We want you to sign up, and we need everyone to go and get petitions and go rally and march and sign up and vote for this person, vote for this person, vote for this person.'

And I questioned the legitimat-, legitimacy of this. I said that I, you know, I did not know that our group, you know, had a political officer, or I questioned the – I questioned the appropriateness of this. If you – if you believe that this is a good cause, why not just post a link to it and say, 'Please go here and read this thing that's on my mind,' rather than, you know, copying a, a two-page political ad from a website.

Okay, I then got a message back – actually, the whole group got a message from the facilitator, saying, 'Well, you realize I know that people like you are not necessarily as involved as they should be in the political realm, so I'm simply trying to point out that we all need to be involved in good causes and be part of our government and be good citizens.' And words to that effect. I said – I said, 'Ms. So-and-So, I very much agree that go-, that active citizenship is important. And this is why I have been, for the past five years, a poll inspector at the – at the elections every time that elections are held in Albany County. I'm one of the poll inspectors. And I b-, and I vote in every election and, and so on, and I do believe it's important. I'm simply wondering what the, you know – what made you decide that this was an important, uh, thing to copy and paste in full through the group, rather than a link, and would you be as accepting of something that showed the other side of the issue?'

And she, she wrote back on how, uh – on how, un-, inappropriate it was that someone, you know, like me, someone with issues should be a poll inspector. She said, you know, 'Your proper issue needs to be – your proper position on issues needs to be to vote and needs to be, to be informed about the issues by others who know better, which is why I posted this.'

I: Wow.

P: And she went on about how she didn't think we were real-, we really should be allowed to form our own political opinions, we really didn't have the cognitive capabilities. You know, mind that the average IQ in the group is probably higher than the average member's *weight*, you know?

(Hannah, 49, heterosexual, woman)

Several participants related concerns that the only ASD support groups and/or

services in their area were for children and, particularly, that there are no supports

available for parents on the spectrum. The absence of supports for *adult* autistic

persons and those performing adult roles limited the resources available to

participants in their exercise of sexual citizenship.

In addition to autism-specific service providers, participants reported that

law enforcement and legal proceedings were inaccessible. A few participants

discussed how cultural stereotypes about ability and sexuality and/or demands for

ability in legal settings negatively impacted their potential to seek justice for sexual

assault or navigate custody and divorce proceedings. The inaccessibility of standard

reporting requirements, for example, factored into M's decision not to seek legal

redress for her sexual assault.

> It happened in another state, and our flight home was the following morning.
> I didn't have a car or access to a telephone or know where I would report it.
> The logistics of doing it later, after I got home, in the days before Google and
> cell phones, were completely overwhelming. Even if I had wanted to report it,
> figuring out how and where to do it was way too complicated.
> (M, 39, heterosexual, woman)

Dragon Tears also encountered difficulties with stereotypes, as well as

inaccessible systems, during her extensive encounters with the legal system

surrounding her divorces, the prosecution of one ex-husband for sexually abusing

her oldest daughter, the pursuit of custody and an order of protection against her by

another ex-husband, and the resulting supervised child visitation. You may recall

that her limited *economic opportunities* resulted in reliance on pro-bono lawyers or

none at all. Dragon Tears indicated that her access to and relationship with her two

oldest children has been unfairly limited as a result of legal proceedings that did not

account for variations in ability.

> I: Was your disability brought up during the custody proceedings? If so, how?
> P: Yes, but very inaccurate because they ordered a psych eval. and the doctor
> doing it never even bothered to really look at all he details of my medical
> challenges..how tests were done etc. This psychiatrist actually placed me in
> three catogories of personality disorders because I couldnt fit into just one. I
> mentioned this to my last doc I had (she had known me for years!) and she
> said that sounds typical when they arent familuar with what to look for, let
> alone he only met me once. Anything they had disability wise was twisted
> around to make me look like a bad mom, and some information the gaurdian
> for the two kids for the custody proceedings failed to have in her report.
> Things were inaccurate and missing information...I mentioned this various
> times later, but no one cared. ...
> I: Do you think that your autism affected how you were treated during the
> two legal proceedings? If so, how?
> P: I sure do. Because of how I communicate and how I may interpret what
> others say or do around me. It makes everything look worse, people treat me
> as a piece of trash..not sure why, other than Im not like other people in a
> variety of ways..why cant I be treated equally, but with respect and help
> when I need it most. ...
> I: Do you think that your autism affected how you handled the legal
> proceedings? If so, how?
> P: Yes, very much so. My anxiety and depression would go sky high. I would
> try to understand what others were talking about, or ask for them to please
> explain further or rephrase...but most didnt seem to care and even told me it
> pretty straight forward, u should understand that.
> (Dragon Tears, 35, heterosexual, woman)

The misdiagnosis by the court psychiatrist provides an example of another

common limitation on participants' sexual citizenship. The average age of diagnosis

for participants was 28. Participants diagnosed after adolescence typically reported

a trail of previous diagnoses. Each one came with an inappropriate array of

treatments, services, and accommodations. While some previous diagnoses

reflected concurrent and on-going conditions, they still failed to address the

participants' ASD. This limited participants' capacity to pursue desired ends. R.B.'s

story of involuntary incarceration, in *laws & policies*, provides another example of

how misdiagnosis resulted in limitations on participants' citizenship. As discussed in *economic opportunities*, access to ASD-relevant services and supports is dependent on the particular diagnosis of ASD. In addition, the self-knowledge and potential for community provided by the ASD diagnosis are key citizenship resources for many participants, as will be discussed further in *Autistic identity*. For all these reasons, the limited availability of service providers competent to diagnose ASD, particularly adult ASD, functions to limit autistic adults' participation in the co-construction of our shared aspiration for human living and its associated distributive arrangements.

Finally, participants also reported difficulties with health care due to paternalism, unwillingness to provide accommodations, and ignorance about autism and/or sexuality. These health care difficulties were experienced both in the context of general care and in the specific context of sexual health care. None of the six participants experiencing sexual pain or dysfunction reported that their concern had been adequately addressed.

Hank was one of the participants who wrote at length about his struggles to find appropriate health care. Hank's chronic health concerns include extreme vaginal tightness and painful, difficult urination due to the tightness of muscles around the urethra. Hank is also anorgasmic. The following excerpts from Hank's story illustrate ignorance about autism as an embodied condition, Transphobia, and paternalism. Hank's ongoing difficulties accessing basic health care led him to deprioritize his sexual pleasure, a key component of comprehensive sexual health.

> I experienced sharp pain, bleeding and spasming with every gynecological exam. The last time, the doctor scolded me for not relaxing. I explained that I

physically could not do so, and he just laughed and said I should "talk to somebody about that." I recently had some unexplained bleeding, and my current primary doctor (who I very much like) sent me for an ultrasound instead of the regular exam, since I'm not at risk for infections that would be found in a regular pap exam. The tech was great, and let me insert the ultrasound instrument myself - it was small, and I didn't have a problem. ... I have had too many experiences with specialists who assume that everything is "just anxiety," and offered dangerous and at best, ineffective same set of resources that have made things worse rather than better in any health issues in the past and lead to delayed diagnosis and treatment, causing complications. If I were I enter into that process again (to find a professional who understands my body), I would not do so for something [orgasm] that may or may not marginally improve a small part of my quality of life ... So I instead saw the only urologist at the university clinic that was willing to see a Trans patient (of 6), who took one look at me fully clothed, and decided that I had Overactive Bladder (OAB) due to anxiety. I explained that I had fairly well managed anxiety, and that I knew when I was anxious and I had been much less so in the last year than in other periods, but that my muscles were very tight due to autism which was often misread as anxiety. After the Dr. explained why he thought I had OAB, I explained that I did not have any of the symptoms he mentioned, and that they were opposite the symptoms I actually had. I asked if he would look at the 2 weeks of symptom logs, but he said it was not necessary.
(Hank, 33, queer, Transgender/genderqueer)

Cultural ableism. Participants also experienced a wide variety of encounters with cultural ableism. *Cultural ableism* refers to experiences generated by the exercise of social norms and cultural beliefs that value particular abilities and the people who demonstrate them at the expense of those who do not. The experiences of *structural ableism* discussed in the last section represent the uptake of *cultural ableism* in institutional spaces and its reification in, for example, *laws & policies*. I deal here with additional themes that demonstrate the disciplining and/or subjectifying nature of *cultural ableism* in the context of sexual citizenship. Sub-themes organized under cultural ableism include: *NT privilege*, *out-grouping*, and *sex-ability*.

NT privilege. *NT privilege* refers to the privileging of neurotypical experiences and abilities. We have already seen many examples of this. Salient examples of *NT privilege* presented in *structural ableism* include the belief of Hannah's group leader that only neurotypical persons are capable of making informed decisions about governance and Dragonfly's therapist's assertion that it is a universal truth that good sex is pain free. Participants experienced a really wide range of NT privilege. Some discussed the general, but pervasive, experience of being misunderstood, as captured by Laura writing about her choice to pass rather than request work/school accommodations and C.Byrd writing about the dissatisfying aspect of a previous sexual relationship.

> I do not tell people about my disability because on one hand many people will not be able to GRASP (It goes waaaaaay over their head (Even if I take the time to explain!) And on the other hand , There seems to be stigma around disbilities meaning that YOU SHOULD NOT WORK IF YOU HAVE A DISABILITY and discrimination in hospitals if you need basic health care !
> (Laura, 30, heterosexual, woman)

> I: Was there something you wanted that you didn't get?
> P: At the time I didn't know I was autistic, but I knew that I wanted her to understand me more than she did. I didn't want her to think I was strange and I wanted her to be more accepting of my oddness.
> (C.Byrd, 29, lesbian, woman)

This lack of understanding and privileging of NT experience affected participants in all domains of life. C.P. provided one example of how the privileging of NT experience can have negative implications for autistic persons at work, relating the following incident with a co-worker.

> He's the one that you know – so once in a while, when I get frustrated and I get upset, it looks like I'm about – you know I clench up and I look like I'm going to hit somebody, he actually thought I was going to hit him, and he was going to go to H.R. and complain about me, because he thinks he's a H.R. type

person. He's our engineer on the job I do. And he thought that you know he
wanted to make trouble.
(C.P., 48, gay, male)

Dragonfly, who was diagnosed with Gender Identity Disorder and began

transitioning during the course of our e-mail interview, provided the following

example of how NT assumptions about autistic functioning can impact health care

and identity formation. Dragonfly identified his gender as odd, rather than more

common identities such as genderqueer or Transgender, in part because he had

been told such identities were not compatible with the "limitations" of autism. It is

fortunate that he eventually happened upon an informed therapist.

> I: Why are being transgender and being autistic incompatible (or not possible
> together)?
> P: That is what was told. The only explanation given was inability to
> understand social gender roles made it impossible for self to even know if
> was trans or not. But not really explained why could not be both, just that it
> was not possible.
> My therapist disagrees. Says that is not true at all. Also says that statistics
> claim more trans people in autistic community than in non-autistic
> (Dragonfly, 30, asexual/pansexual/polyamorous, odd)

NT privilege often came in the form of paternalism. Billy Joel spoke to how

the wide range of reactions NT people have had to her were rooted in context-based

assumptions of (dis)ability. She also provided the following example of what

paternalism can look like.

> Being autistic, I have experienced a HUGE range in how people have treated
> me. At my dad's work, people treated me like a normal kid who helped out
> around the shop. I liked that, but I was also in an environment where I could
> succeed without any special accommodations - they didn't have loud noise
> around me because I was a kid and it wasn't safe for me to close to big
> mowers. (normally, those sounds would bother me but I grew up hearing
> them and not too close so while they are uncomfortable they are tolerable.)
> School is where I got the biggest variety. Some friends treated me like a
> friend and others bullied me and others simply treated me like a baby. In
> high school, the nurse's assistant who gave me medicine (for a non-

neurological medical condition) talked to me like I was literally a baby. "My name is Barbara. Can you say Bar-bara?" in a slow voice...this was most days. Based on that set of interactions, I learned to "shake it off" when people bothered me by treating me like that. My friends were incredulous that she talked to me like that and so we jokingly referred to her as Arabrab (her name backwards) when talking about her.
(Billy Joel, 23, asexual, woman)

Billy Joel "passed" at her dad's work. She was not treated any differently because she was not perceived to be different. Passing was discussed as a strategy by several participants. The previous excerpt in which Laura discussed passing as a way to manage NT ignorance and stereotypes is one example of this. Passing is a subjectifying strategy for accessing some of the goods of citizenship in the context of structural and cultural ableism. Gabby spoke to the price of passing.

I live in NYC and transportation is horribly overstimulating and exhausting. Much of the sensory trouble I have stems though from my 'passability' as non-Autistic and therefore my conditioned containment of sensory processing instead of overtly stimming and being able to better self-regulate. Since I pass I don't find that I'm treated differently by others.
(Gabby, 23, queer, woman)

Given their intimate nature, passing is not an option in intimate relationships. As the excerpt from C.Byrd that opens this section demonstrates, even when undiagnosed participants' "oddness" (their atypicality) is apparent in the context of intimate relationships. This posed a problem for participants whose partners were not part of the disability community. Several participants with neurotypical partners who did not have a high consciousness of disability as a *social* condition experienced substantial tension and/or dissatisfaction in their relationship due to *NT privilege*. Cisco, for example, wrote at length about how his wife did not like him being Aspie. Their differences around sociality and sexuality needs were a source of constant tension and distress for Cisco. Cisco had also been

struggling with sexual dysfunction, including erectile dysfunction (ED), for the last

10 years. When inquiring about his options for support around sexuality, Cisco

mentioned that he could not talk with someone about their sexual difficulties

because he felt responsible for them; his wife's NT needs required an NT partner.

His initial reaction was to take up the discourse of *NT privilege*. When prompted,

however, he provided a more complex rendering of contributing factors and

reframed his reference to her need for an NT partner in a way that no longer

privileged neurotypicality. This excerpt demonstrates how participants wrestled

with ability as a normativity in their intimate lives and in their understanding of

themselves and their relationships.

> I: Is there someone you can talk to about sex?
> P: No. I would be too ashamed. I feel like it's my fault. She needs an NT who
> likes the things she likes. I just can't go there. ...
> I: You mentioned that you feel like you and your wife's sexual discordance is
> your fault, and referenced that she's NT.
> What are your reasons for feeling like the discordance is your fault?
> P: Not entirely my fault. I didn't mean to say that. She obviously has issues
> too. Such as, her having grown up with her mother's bitterness following
> divorce from my wife's dad, I believe has poisoned her. It seems at times she
> is still projecting her parent's issues into our relationship (her putting him
> down, telling the kids he cheated, blaming him 15 years after their marriage
> for her colon cancer, just sick co-depent stuff. Plus, my wife has no
> imagination about sex, says I don't care when asked what position she would
> like, won't share fantasies (I asume everyone has fantasies). She always has
> to bolt and get cleaned up before we can snuggle in the after glow so to
> speak. Like my semen is acid or dirty. She is quit the fridgid prude.
> My feeling that it is mostly my fault is my Herpes, my ED, my desire is
> stronger than her's (I would like to have sex every 2-3 days, she could go 2-3
> times a year and has), I get angry (about anything, but, especially her not
> wanting sex) and she shuts down. I'm poor at handling money so she gets
> mad about that at times, which allows her to say "I'm not feeling close to you
> right now". An often repeated fraze about anything I do that causes her to
> feel negative. We are opposits in a horrible way. I never want to leave the
> house, even anxious working in the yard, going for a walk with her, getting
> the paper or the mail, just going to my vehicle. She likes parties, double dates
> with her friends from Church or work (I have no friends). So I see not having

enough sex (for me) as my fault, because of all this. As hard as I try to change, it's never enough. I wonder if this is why people get divorced after many years of marriage, one or the other wakes up to the fact that it's all been about the other one, never about what I want/need.
I: What does your wife being NT have to do with it?
P: Ever see the movie "As Good As It Gets"? I'm Jack Nicholson and she is Hellen Hunt. She wants more of a socially appropriate mate and now she knows it will never happen, she can't accept that THIS IS AS GOOD AS IT GETS
(Cisco, 60, heterosexual, man)

M, who was generally satisfied with her relationship with her husband, was one of several participants who discussed how her partner often framed her (dis)abilities as choices. In this way, intimate partners responsibilized participants for their symptoms and any related effects. M provided a clear analysis of this dynamic in her relationship.

> Most of it boils down to his understanding of disability. It's just not something he's examined very carefully, so a lot of his thinking is (what I consider) backward / medical model / victim-blaming. Most of my understanding of the power dynamics of disability in our relationship has come together in the last two years--the issues have been there all along; I just hadn't thought about them in a systematic way until I started reading about disability politics a few years ago. But we haven't had the time or space to talk about the way my thinking has changed at anywhere near the same pace that I've moved in my own mind. He consistently refers to my disabilities as 1) a choice I'm making, 2) an exaggeration or overreaction, and 3) a burden on other people. He sees the responsibility for adaptation/accommodation of the disabilities as mine, rather than his.
> (M, 39, heterosexual, woman)

She provided a long list of detailed examples of how this dynamic played out around her various disabilities. She also provided an insightful discussion of how these struggles around *NT privilege* played out in the "mundane" context of the organization of household labour, demonstrating the intersection of ability and gender as axes of social stratification.

Our relationship has a sort of internal economy that tracks the exchange of child-free time. If I ask him for a ride to a doctor's appointment, I'm asking him to give up free time he might otherwise spend working in the yard. In exchange, he may ask me to watch the kids so he can go out to dinner with a friend.

The problem is that the two "favors" are not equivalent. In one case, my husband gets a night out to do something fun. In the other case, I get a ride to a doctor's appointment, which I need because I can't drive, and it's 28 degrees outside, and the doctor's office is 3 bus rides away with a half-hour wait between transfers.

There are hundreds of other examples of accommodations for my disabilities that are framed as favors. Because I always feel like I'm asking for too many favors, I avoid asking for anything extra -- I need to save up my goodwill points for the stuff I really need. My husband rarely has to ask me for help with basic ADLs [activities of daily living], so he can save his "points" for luxuries like going out to dinner.

We usually split up weekends so that each of us gets one child-free day. On my "free" day, I do laundry, dishes, bill-paying, and freelance work. On my husband's "free" day, he works in the garden. Most of this work is beneficial to the whole family, but it is also his passion and his preferred way to spend his free time. When he needs time to do household chores during the week, he asks me to watch the kids -- he doesn't sacrifice his "free" day to do undesirable work.

I recognize and resent the unfairness of this system, but usually choose not to challenge it, because, again, I'm already "asking for a lot of favors." When I do express discontent with this system, my husband gets defensive and angry and accuses me of "keeping score," and I usually regret bringing it up at all. My choice to put up with this rather than invest the energy in challenging it is a symptom of a disability-based power disparity in our relationship.
(M, 39, heterosexual, woman)

Out-grouping. One result of *NT privilege*, and the general privileging of ability, was *out-grouping*. *Out-grouping* refers to experiences in which participants were clearly placed outside the dominant (abled) community. Participant recognition of *out-grouping* is evident in the attempts at and benefits of passing discussed in the previous section. Participants reported a variety of experiences with *out-grouping*, such as harassment, social ostracism, representations of the self as "exceptional", and a *lack* of representations of the self.

Though it was not asked about directly as part of the interview, many

participants reported experiences of disability harassment. Some experiences of

harassment have already been related, such as R.B.'s harassment at work. Hannah's

experiences with harassment and her analysis of them, below, well encapsulate the

theme of *out-grouping* as experienced by participants.

> I am considered unhuman, like a robot or a mutant or 'fair game ' to be
> absolutely ignored if not tormented (abuse these days is USUALLY verbal or
> being treated as invisible) ...
> I feel angry, as these events amount to treating me as a sort of "cheap
> imitation" version of a human being. (As one college roommate put it to me,
> when I asked her and my other two roommates to explain why they
> treated/spoke to me so differently from how they treated/spoke to each
> other or anyone else: "Well, with other people there is the feeling that they
> ARE people and that there are right ways and wrong ways to treat them.
> With you, there isn't." ...
> One very frustrated classmate, who had been next to me and had seen me ask
> questions that she thought were totally ridiculous questions, said, 'You know
> what's wrong with you? You don't have a learning disability. You have a
> human-ing disability.' ...
> It was scary to her, literally scary, that someone could have a difficulty with
> something that came very easily to her and that she, she literally never met
> anyone who had trouble with.
> (Hannah, 49, heterosexual, woman)

In addition to harassment, participants reported being treated as if their

needs were exceptional. In other words, though all people have needs, strengths and

weaknesses, they were treated as if their particular needs were above-and-beyond

what is acceptable. Vivian, for example, reported that once she no longer received

intensive therapeutic interventions her parents stopped disclosing her diagnosis to

the private schools in which she was enrolled.

> they did let the schools know, but – up to a certain extent, so up to maybe
> around the first-, second-grade year. That's when they stopped telling the
> schools about my diagnosis, because they, they first – first of all, they didn't
> feel like it was necessary, and also they were concerned that if they did have
> the knowledge, they would be – the schools would be concerned about the

potential extra costs of services or, you know, assistance I might need, so, you know, they wanted to keep me in the school, so.
(Vivian, 31, heterosexual/bicurious, woman)

Vivian's parents were clearly concerned about the stigma attached to autism and the potential reactions of the schools, including exclusion. Danielle also experienced the effects of such concerns about stigma. She was one of several participants for whom *out-grouping* included literal removal from general society.

The whole thing actually started in childhood. (You might want to get coffee. This is a long story.) My mom is an occupational therapist, but she is (ironically) very frightened of disability, especially of being disabled herself. She knew I was autistic; had, in fact, worked with autistic children; but she refused to get me evaluated. Instead, she pulled me out of school and home-schooled me, and never clued me in about why I was different. She used to tell me that I was strong-willed, badly-behaved, irresponsible, immature, and over-dramatic. Because I was "so smart", I was presumed to be rebelling whenever I could not do something due to my autism. So I grew up autistic, but not knowing I was autistic, and without any sort of help. At fourteen, I had my first depressive episode, and my mom used to make fun of me for my "self-pity". I had no treatment until I left home to go to college, except for a stint with a counselor when I was about ten years old, within which I learned for the first time that it was not okay for stepfathers to hit their stepdaughters. (BTW: Don't worry about any possible traumatic memories related to this experience; I've integrated it fully and am able to recall it without anxiety.)
(Danielle, 29, asexual, androgynous female)

These experiences of *out-grouping* limited participants' access to *social support*, including intimate relationships, and its associated goods. The role of social support in realizing participants' sexual citizenship is discussed further in *social support*.

This excerpt from Danielle's story also illustrates the impact that lack of access to disability-relevant representations and/or knowledge had on participants. M clearly articulated the impact of this absence when raising a critical concern about question phrasing in the interview guide that betrayed my own *NT privilege*.

But there is a difference between a researcher asking (in the abstract) if there is something 'autistic people' should be taught about sex, and asking an individual autistic person "Is there anything you think autistic people should be taught about sexuality." I have no data to draw on about the sexual experience of "autistic people" in general, other than the stereotypes fed to me by an ableist culture. And neither does anybody else who responds to that question. When you aggregate those responses, you may learn something about how the dominant cultural narrative about autistic sexuality is internalized and re-stated by autistic people, which in itself might be interesting, but that's not the same as learning about how autistic people actually experience sexuality, separate from that narrative. ...

I wanted to add one more thing to the discussion about the questions about 'autistic people' in general: you mentioned earlier that you thought a question like this was analogous to a question about what 'women' or 'Latinas' should be taught about sex. I think the fundamental difference here is that women and Latinas have a very different set of data to draw on in answering questions about what other people "like them" might experience. Women and Latinas grow up in families with other women and Latinas, go to school, work, and form close friendships or romantic partnerships with other women and Latinas. When they think in generalities about this whole group, they are drawing on two sets of personal data: their own personal experience, plus the experience of the family, friends, and neighbors who are also members of this group--people with whom they share life experience and a set of cultural references. In addition to this personal experience, the ideas women and Latinas develop about themselves as a group are influenced by the stereotypes, institutionalized discrimination, and media messages they absorb throughout their lives.

The autistics of my generation all grew up without knowing we were autistic, without access to autistic culture, and in many cases spent most of our lives without ever meeting another self-identified autistic person. Even autistics born in the last 20 years, who were aware of their diagnosis since childhood, grew up before the neurodiversity movement and the development of autistic space online. Our entire body of knowledge about 'autistic people,' therefore, is often limited to our own personal experience plus the media stereotypes -- we're missing the bank of data about other people "like us," because we are isolated from one another. So a statement made by an autistic about other autistics as a group seems much more susceptible to heavy influence from dominant media stereotypes than a similar statement by a Latina about other Latinas.

(M, 39, heterosexual, woman)

Sex-ability. As insightfully intuited by M, participants rarely had a base of

reference about autistic sexuality. In fact, participants frequently anticipated getting

the results of this study because they wanted to find out how common their own

experiences are. Realistic representations of autistic sexuality are in short supply.

Meanwhile, participants faced a barrage of negative messages about autistic

sexuality. The negative messages that participants' received reveal a clear discourse

of *sex-ability*, or the idea that sexuality and/or procreation are directly linked with

being typically abled. Participants wrestled with this discourse, often conflating

sexual normality with general normality in their own lives.

One common message included in the discourse of *sex-ability* was that

sexuality was inappropriate for persons with cognitive (dis)abilities. We have

already seen several examples of this, such as Hannah's story about the group

facilitator who tried to block the Planned Parenthood session, Dragonfly's

therapist's assessment that he did not have the capacity for meaningful consent, and

the policy in R.B.'s community residence that forbade her partner to be in her

bedroom. Participants who were more noticeably affected by their condition, such

as Dragonfly, reported receiving this message most consistently. In fact, despite his

forced sexual initiation at 15, Dragonfly reported that important persons from

whom he had sought sexuality education consistently denied him that right as part

of a general infantilization to which he was subject.

> P: People words. Say am a child. Say not willing to talk about adult things. Say
> uncomfortable me hearing adults talk of adult things. Like sex. Having kids.
> Drugs. Alcohol. Driving. Say not okay me going places alone, when not
> worried for adults going to same places alone. ...
> I: Have your parents ever talked to you about sex? If so, what did they tell
> you?
> P: Only to say it is bad. Not explain anything else. Found out about special
> parts of body from books. ...
> I: Did you try to get more information? If so, how?
> P: Did ask some people questions a few times. That teacher tried to answer
> some, most others refused. Except on internet people answered then. But

answers did get were contradictory. Ask more people same question, get different answer. Not helpful. Just more confusing.
I: Who did you ask that refused to answer?
P: Mother parent. Family friend. Older brother. Health education teacher. Priest at mother parent's church.
I: Did those people who refused to answer your questions give you a reason why they would not answer? If so, what did they tell you?
P: Inappropriate, to answer or to ask not sure. Also told did not need to know, not relevant to me, not necessary for me to know.
(Dragonfly, 30, asexual/pansexual/polyamorous, odd)

Note that the consistent denial of Dragonfly's right to sexuality education did not prevent him from seeking information about sexuality, being sexualized by others, or having desired sexuality himself. This denial of rights *did* result in general confusion, limiting his ability to make informed choices in the pursuit of desired ends. The general infantilization of which it was a part also curtailed Dragonfly's right to bodily integrity, as illustrated by his discussion of troubles with his sex life. For context, in addition to his father's perpetration, Dragonfly also experienced unwanted sex in the context of intimate relationships.

I: Is there anything about your sex life you have had trouble with or see as a problem?
P: Difficulty saying/expressing no and/or difficulty in having no be respected. Was taught very strictly to be compliant and obedient, not so helpful as adult.
(Dragonfly, 30, asexual/pansexual/polyamorous, odd)

Dragonfly's experiences illustrate the relationship between ableism and the vulnerability aspect of the *sex-ability* discourse (i.e. persons with cognitive (dis)abilities as inherently more vulnerable to abuse-exploitation) in two key ways. First, Dragonfly's *consensual* experiences were conceptualized as abuse-exploitation by ableist others. Second, Dragonfly experienced *actual* abuse-exploitation that intersected with ability, demonstrated by his father's comment that the abuse

occurred because he was "not maturing quickly enough" and the fact that trained

compliance and enforced ignorance created a positionality with few resources for

asserting bodily integrity.

Other participant experiences substantiate this relationship between ableism

and experiences of abuse-exploitation. For example, M's experiences with unwanted

sex that occurred in situations created by a lack of accessible transportation. These

actual experiences of abuse-exploitation are not conceptualized as the result of

structural inequality in the *sex-ability* discourse, but instead are understood as the

result of an essential vulnerability that characterizes persons with cognitive

(dis)abilities.

Participants assumed and defended their capacity to consent to and enjoy

sexuality. They rejected that aspect of the *sex-ability* discourse entirely. However,

they almost uniformly engaged with the vulnerability aspect of the *sex-ability*

discourse in some way. This came up in the interviews in several places, but was

most strikingly present when participants were asked about recommendations for

what autistic persons should be taught as part of sexuality and relationship

education. Following M's analysis of the differential availability of dominant cultural

representations versus shared community for autistic adults in forming their

understanding of "autistic sexuality", I understand this uptake of the vulnerability

discourse as partially resulting from this dynamic. Sometimes participants directly

referenced cultural materials when discussing vulnerability, as in the following

excerpt from CS, whose sense of group-based vulnerability was essential to her own

experience of sexuality.

Autistic people don't read facial expressions, and don't have fear with NT individuals (people not on the spectrum) which can be really bad with bad consequences. I've read a newspaper column in the [local] where people who have disabilities are frequently preyed on by NT individuals. ...
Is there anything I haven't asked about that you think is important to understanding your experience of gender, sexuality, and relationships?
I believe that autistic individuals are more likely to be assaulted by NT individuals.
Why do you think that autistic individuals are more likely to be assaulted by NT individuals?
NT individuals are more likely to assault autistic individuals because they sense the autistic individual is different (or can't communicate the abuse-- non verbal autistic).
(CS, 34, heterosexual, woman)

Of course, many participants *had* experienced abuse-exploitation. It is understandable that they would find instruction about abuse-exploitation important. Their translation of personal experience into a general warning for autistic persons, though, related to their understanding of these experiences as relevant to autistic vulnerabilities.

I: Is there anything that autistic people should be taught about sex?
P: Yes. Everything. Communication. Porn isn't appropriate expressions of sex. Parents unclothed, siblings having sex isn't ok. Boundaries, communication, anatomy, asking permission/getting consent prior to sexual activities. Verbal abuse is not ok, especially of a sexual nature, between adults in front of kids.
(Cisco, 60, heterosexual, man)

I: Is there anything that autistic people should be taught about sex?
P: Sex on television and magazines is not a proper representation so don't hold onto those ideas. I also think that they should be taught that although sex isn't a bad thing, it is something that is very serious and can have consequences. They need to learn what it means to be taken advantage of by other people in a sexual way and perhaps be taught strong morals about it while they are coming of age.
I: What about relationships?
P: I still think it's important for autistic people to be taught about ways that people may try to take advantage of them. I know that I wasn't born with a sense that people would tell me they loved me only to sleep with me or get other things from me. It isn't natural for me to lie about such things nor

> anticipate it. I learned the hard way in my young adult life and am still very cautions of people as a result.
> (C.Byrd, 29, lesbian, woman)

In addition, abuse-exploitation was taken up in educational recommendations by participants who had not experienced abuse-exploitation or had not experienced abuse-exploitation that was relevant to sexuality (e.g. physical abuse by a parent). "It's especially concerning when people with special needs aren't told what could happen if they are abused, because they are at higher risk for abuse." (L.B., 22, heterosexual/sapiosexual, female) Though pervasive, not *all* participants took up the discourse of vulnerability. Some instead emphasized similarities in persons' educational needs regardless of their (dis)abilities.

> I: Is there anything that autistic people should be taught about sex?
> P: Autistic individuals should be taught all of the same sex education lessons as that of their neurotypical counterpart.
> (Ayla, 32, asexual/hetero-romantic, woman)

Participants also received the message that they were unable to partner and/or undesirable as a partner. We have already seen examples of this, such as the assertion of Hannah's college dates that she should have sex with them because no one else could want her presented in *performance of normative desirability*, Dragonfly's analysis that no good people want to partner with him because they see him as too limited, and M's struggle with the internalized ableism that tells her she is difficult and should feel lucky to have any relationship at all. In addition to partnering, some participants reported that persons known to be on the spectrum were not seen as fit parents either. Discussing conflicting feelings about having children, R.B. mentioned that her obstetrician/gynecologist promoted eugenics, trying to dissuade her from reproduction.

P: i don't want to gain alot of weight and not be able to lose it. also, my
ob/gyn told me i was probably better off not having children if i have autism
because then my children might get it too
I: How did you feel when your ob/gyn told you that?
P: i was a little surprised because having autism isn't a death sentence ...
I: Did you discuss this experience with [your husband]?
P: no i haven't told him what my doctor said. for the past two years during
my annual visit, my ob/gyn has told me the same thing
(R.B., 29, heterosexual, woman)

Sandy, whose daughter received behavioral health services, wrote about how

her awareness of this stigma often led her to pass during interactions with

professionals and the institutions of which they are a part so that she could

effectively advocate for her daughter.

If I'm interacting with a professional in the role of parent and I were to
disclose my being on the Spectrum, then in their eyes, I've lost whatever
credability I might have had. I stop being a functional adult in their eyes with
one word.   Sometimes I feel like an exotic animal at a zoo exhibit.   So I am
slower to disclose in those situations, if at all.
(Sandy, 46, bisexual/polyamorous, genderqueer)

In contrast, when asked about his experiences seeking adoption, Hank

responded that the adoption agency with which he and his partner have been

working have been supportive of their access to parenting. Notice that he places this

positivity in light of the educational privilege and demonstrated competencies of

him and his partner, as well as the devalued status of children with disabilities. He

thereby demonstrates clear awareness of the discourse of *sex-ability* and ableism at

large, evaluating his experiences through this prism.

The agency that we're working with has been very positive. They have
experiences with successful adoption by families with autism as well as
transgender and queer families. Legally, in our state, there are no restrictions
about either. The possible obstacles would be with individual social workers
for children who may have prejudices about what type of parents kids need.
For most social workers, though, they have shown much confidence in the
fact that I have an MSW and significant professional experience with

preschoolers and adults with attachment and trauma needs, and [my partner's] experience and demonstrated work and skill with children and adults with disabilities labeled as "behavioral problems." We're also quite excited about and equipped to adopt a kid with disabilities, including some of the categories that they have the most difficulty placing.
(Hank, 33, queer, Transgender/genderqueer)

Finally, participants frequently and passionately discussed the imbrication of (hetero)sexual normativity and the *human* experience. In other words, they spoke of how particular, normative sexual experiences were fundamental to the experience of a life with essential human qualities. Much of these data are presented in *normalization*. Sometimes this discussion overtly intersected with the *sex-ability* discourse, as in Rick's reflections on a recent relationship milestone. He discusses here the impact of cultural representations of autism on his evaluation of his own humanity as reflected through the prism of intimate relating.

> P: We recently told each other "I love you" on New Year's Eve, which came as a stunningly marvelous surprise; I didn't think we were there yet, but when she told me that, I felt great emotion and connection and responded back with the same. While she isn't the first woman I've said that to, it feels...different than with anyone else. Love is an incredibly difficult - almost impossible - emotion to describe, much less know when you are experiencing it. Sometimes I feared that being autistic meant that I didn't truly understand love or what it was; at this point in my life I understand that what it means to me and who I love is what matters. ...
> I: You mentioned that you used to be afraid that "being autistic meant that I didn't truly understand love or what it was". Could you please tell me more about that?
> P: Sure. While my parents never pushed autistic stereotypes onto me, society and others certainly did. Through shallow media stories and rumors - especially in the wake of mass shooting tragedies, as well as murder/suicides of families with autistic children (both are quite horrifying) - I was consistently told that I didn't have any empathy, I was almost bereft of emotion, and I was little more than a walking android.
> Add to that my confusion and repeated misunderstanding of others' emotions - not to mention my own - and I began to think that the most active of emotions would not be obtainable for me. After all, the simpler feelings others seemed to have (empathy, sympathy, etc.) weren't easy to understand; why would love be any easier?

I was young and inexperienced. As I grew older I realized that love is
different for everyone, even though we all experience it. ...
I: Why is understanding love important?
P: It is assumed to be a common goal for all humans to find the one they love.
Also, the love of close friends and family members is held as something more
important than material wealth. Yet when asked to define it, most people face
significant difficulty in doing so. Also, it is critical to know the difference
between love and mere fondness for a person.
The emotion of love seems to be a central part of us as humans.
(Rick, 26, heterosexual, male)

A common theme in these types of reflections was the sense of double

marginalization created through being (dis)abled *and* not normatively sexual, as

illustrated in the following excerpt from C.P. C.P.'s sense of double marginalization is

further exacerbated by his sexual minority status.

P: I look at my life back now, now that I know what's wrong, what inhibited
me from doing anything when I was younger, I can't get that back. Nothing
will ever bring that ba-... I'll never have that first experience at 18 with an 18-
year-old, you know what I mean?
I'll never have that experience at 21 years old with other 21-year-olds, you
know what I mean? I'll never have that, like my peers did, like anybody else.
No one understands that. "Oh, you got to live now. You've got to move on."
You know, well, how am I going to know what it's like having sex with an 18-
year-old boy, you know what I mean? How am I ever going to know that?
I: So how do you feel about those lost opportunities?
P: Like I've had a wasted life. I never got what other people did and take for
granted. ...
It's difficult, and they don't – no one gets it. "Oh, well, you should live for
today." Yeah, what if my – you know, what – I'm the, I'm the apple of the eye
of a 60-year-old guy? I don't think so. ...
I: what about the mainstream gay community? Can you tell me a little bit
more about your experiences?
P: I am a, I am an outsider in both worlds. [Pause] I'm an outsider. You know
I'm not perfect in – you know there's-there's people that are prejudiced in
the Aspie world as well as there is people prejudiced against mentally not all
there people in that – the other world.
(C.P., 48, gay, male)

As a final example of this trend in the data, I am going to again quote M at

length. M wrote with particular passion and insight about the entwinement of

sexuality and (dis)ability, describing how passing as typically abled is required for

full citizenship and how the performance of (hetero)sexual normativity is a key

component of that.

> P: I have always felt the intense social stigma associated with being single, especially as a woman over 30. Partnership, and particularly heterosexual marriage and children, is a nearly universal measure of social success. Without it, you have to work extra hard to pass (and I had already been working overtime my whole life, long before the age at which partnership becomes expected). Even though I consciously reject the systems that define single people as failed humans, I have always felt huge internal and external pressure to be in a relationship, because I need to pass to survive ...
> I: How does being coupled help you pass?
> P: Being coupled is unmarked. After the age of about 30 for women, being single is marked. Anything that makes you stand out from the norm undermines the effort to pass. The standard assumption is that nobody chooses to be single, so therefore single women have tried and failed to find a partner. We speculate about why they failed: if they are not physically unattractive, then they must be psychologically unfit in some way. When you're autistic, your neurological/psychological atypicality is exactly what you're trying to hide in order to pass. ...
> I: What extra work (specific actions) do you have to do to pass when you're single?
> P: There are two parts to this: the extra work required to just exist in the world as an "appropriately" single person, and the extra effort at passing required to actually look for a partner.
> When I was single, I felt a lot of pressure to monitor the way I presented to others. Do I appear too needy or desperate? Too uninterested in finding a partner? Am I successfully faking gratitude for all the unappealing social invitations, unwanted blind dates, and unsolicited advice? Is my personal grooming sufficient to fend off accusations of Not Trying Hard Enough? It takes a certain amount of psychic energy just to be around other people. When being appropriately single sucks up a bunch of that energy, there is less left over for juggling all the other marked identities I need to mask or downplay to succeed in daily social interactions.
> In addition, the process of looking for a relationship (which is separate from just existing as a single person) requires extra effort at passing. Weirdos and social outcasts don't get dates. Dating requires constructing a "marketable" persona every time you meet a new potential partner. Everybody does this to some extent (dressing nicely to make a good first impression, for example), but it takes a lot more energy if you are actively trying to mask or modulate the parts of yourself that you know from experience are unacceptable. I was extra conscious of my posture, gait, and speech patterns, which I knew were "abnormal" and therefore unattractive.

I: Could you please tell me why you "need to pass to survive"?

P: Access to society is contingent on passing. If I appear too "weird," I won't get hired or keep the job I have. Nobody will rent me a house or approve a mortgage. Nobody will want to date or marry me. Nobody will take me seriously when I advocate for health care or educational services for my son, or report a crime or speak out in a public meeting or otherwise attempt to participate in society. If I appear disabled, I am exponentially more likely to be a victim of bullying or violent crime. People with neurological or psychiatric disabilities are less likely to keep custody of their children in a divorce, because they are presumed incompetent. People who are visibly mentally ill are routinely evicted from public spaces, denied the right to vote, incarcerated, and institutionalized. If I don't conform to societal expectations, my citizenship is revoked.

All of this may sound abstract and melodramatic, but it feels very real to me. When I was in high school, two of my friends were physically attacked. One attack happened in front of me and the attackers threatened me too, but by that time the police were there and they ran away. Another friend was raped at knifepoint. In both cases, it was very clear that my friends were attacked for being visibly different -- gay, gender-non-conforming, "weird-looking," not neurotypical. My sister, who is not as good at passing as I am, has been in and out of inpatient psychiatric care for 20 years. She is not financially self-sufficient, has not been in a relationship for many years, and struggles to get through most days. Without the help and support she gets from family, she would likely be homeless. I am not very different from my sister -- I just have more resources to devote to passing. It makes a huge difference.

Historically, marriage has always been a strategy for economic survival. Some amount of passing is a requirement for getting and keeping a relationship. I have real doubts about my ability to survive financially and emotionally without a partner. I earn barely enough money to support myself and my kids, and that works only because my husband and I split child care and housework. If this relationship ends, I would certainly lose my house and possibly my job.

(M, 39, heterosexual, woman)

M has personal experience, i.e. data, that informs her critical analysis of the intersection of sexuality and ability in the construction of citizenship. I would like to add further empirical support for this analysis, with which I concur, by pointing the reader's attention to supporting excerpts from other participants. First, she mentions the need to mask "abnormality" in order to appear (normatively) attractive and therefore mate. Additional evidence for this was presented in the

performance of normative desirability section of *courtship difficulties.* Second, she

lists a variety of ways she may be disenfranchised if she does not pass. Further

support for this is evident in a number of excerpts already presented. For example,

problems on the job related to perceived abnormality, such as R.B.'s experience

being harassed and C.P.'s coworker reporting him to Human Resources for

displaying overload. Further support is evident in how Dragon Tears' disability

interfered with her custody proceedings, through the court's psychiatric

assessment, *economic opportunities,* and ableist, unaccommodating *laws & policies*.

Finally, Danielle's expulsion from school and lost housing and R.B.'s incarceration

provide additional support. Indeed, what M describes is not abstract, nor

melodramatic, but a sound analysis of how (hetero)sexual normativity and ability

intersect to create everyday realities that position persons with (dis)abilities as

marginal citizens.

Heteronormativity. The previous two sections have focused on how the

normativity of ability was evident in shaping the sexual citizenship of participants in

a way that was disciplining and/or subjectifying. The last sub-section, *sex-ability*,

focused on the direct links between ability and (hetero)sexual normativity. In the

next two sections, I will present disciplining and/or subjectifying experiences that

reflect the power of (hetero)sexual normativity. I will deal with *heteronormativity*

first. Sub-themes organized under heteronormativity include: *traditional gender*

roles and *LGBTQ discrimination.*

Heteronormativity and (hetero)sexual normativity are clearly enmeshed.

Though I would argue that heteronormativity is only one, very important, aspect of

dominant sexual normativity, it is in truth often difficult to identify aspects of sexual

normativity not reducible to the preference for heterosexuality because of its

preeminence in social organization. Hence my choice of the device *(hetero)sexual*

normativity to refer to dominant sexual normativity as a whole. I parse

heteronormativity and *(hetero)sexual normativity* in this analysis because while

imbricated they are also clearly distinguishable in some aspects of participants'

experiences. *Heteronormativity* here refers to experiences shaped by the

normativity of heterosexuality. I will deal with participant experiences shaped by

sexual normativities *not* reducible to a preference for heterosexuality in the next

sections.

> ***Traditional gender roles.*** As previously discussed, five participants

reported a genderqueer or androgynous identity. In addition, most participants who

identified on the binary reported that they did not perceive themselves, nor were

they perceived by others, as normatively gendered. There is not room here to

present a detailed analysis of participants' gender identities and experiences.

However, it is necessary to address the critical ways in which gender as an aspect of

heteronormativity shaped participants' sexual citizenship. *Traditional gender roles*

refers to participant experiences reflecting the use of dominant gender

normativities to discipline and/or subjectify participants.

> Many participants reported that they were not perceived as adequately or

properly gendered in the context of heterosexual relations. This impaired their

ability to perform normative desirability and therefore lowered their value in the

sexual marketplace, limiting their ability to exercise choice in partner selection

and/or access relationships at all. We have already seen some examples of this, such

as abby normal's report of women harassing him by asking him why he could not

"act like a man" and M's description of how her (dis)ability characteristics were

often read as not part of feminine desirability. Importantly, participants' inadequate

performance of *traditional gender roles* was often produced through their

(dis)ability. Billy Joel's reflection on the relationship between her gender and

(dis)ability captures many common elements in participants' reports.

> I: Do you think there is any connection between being autistic and your
> experience of gender? If so, could you please tell me about that?
> P: Yes, I do think there is a connection. Many of the things I do and don't do
> relate to my perception of senses, like the clothes and shoes I wear, the
> simplicity in my self care routines, and my preferences for sameness as
> opposed to style. Additionally, my delayed expressive oral communication
> led to my choices on the playground for sports (and growing up in a family
> where everyone did sports). Sports don't require talking and so I found
> myself interacting with guys and relating to them. I think autism is
> responsible at least partially for my decision of comfort over style, and this is
> more or a "guy" lifestyle. My difficulty with social interactions (autism) also
> led me to interact more physically with others through action like the boys
> instead of chatting like girls - and having this experience so early in life and
> for so long contributed to my less-feminine or social way of spending time
> with others.
> (Billy Joel, 23, asexual, woman)

Several participants who identified on the binary transgressed gender

presentation norms enough to experience misgendering, or being mistaken for a

gender with which they do not identify, as illustrated by the following excerpt in

which I follow up on Ayla's report that she is sometimes mistaken for a boy.

> I: Why do you think people read you as a "boy"?
> P: I believe that it takes place simply because of the way that I dress - mostly,
> when I wear one of my fitted baseball cap, together with one of my hoodies
> (usually with the hood down, unless I'm very cold, and outside), and a pair of
> my jeans, or corduroy pants. Other times, it happens when I occasion to
> bundle myself in my leather winter jacket, and my ear-flap-equipped, knitted
> winter hat.

(Ayla, 32, asexual/hetero-romantic, woman)

Female-identified participants were most likely to report experiences linking

their performance of *traditional gender roles* with their desirability as a mate.

Female-identified participants reported numerous instances where being "sexy", or

attractive-desirable, meant being feminized in a traditional way. Participants

sometimes fit themselves into this social role; often they were helped. In either case,

they reported feeling pressured to perform a particular feminized desirability.

C.Byrd provides one example of this, where she identifies the performance of

feminine desirability as an *ability*.

> I: Can you give me an example of a sexual or relationship event that you
> identify as impacted by ableism (social expectations that everyone 'function'
> a certain way and negative judgments against those who do not conform)?
> P: Being "sexy". In previous relationships it was really pressing for me to look
> and act sexy. From very early on I was taught that if you don't want your man
> to wander then you must be the one to catch his eye and keep it. It was easy
> for me to attract a man, but damn near impossible to keep him from
> wandering...and it makes sense to me because it was me being sexy in the
> first place that attracted them to me. If I let my guard down it was like letting
> them down. I was living a lie and not because I wasn't truly sexy, but because
> the sexyness that I projected was something that I was making up rather
> than feeling.
> (C.Byrd, 29, lesbian, woman)

Participants took up and put down femininized desirability at different points in

their lives and in different social contexts. The following excerpt from Gabby

illustrates how participants worked with this aspect of *heteronormativity* in their

lives.

> I used to wear make-up but haven't in a long time. I will occasionally wear it
> for fun but I don't regularly. I used to shave but I stopped years ago. Make-up
> is expensive and putting it on is time consuming and seems silly to me except
> for times when you are dressing up. I don't dress up that much but when I do
> I sometimes wear makeup. I used to shave and then for a while I stopped
> shaving my arm pits but still shaved my legs since I almost never wore tank

tops. Then I would let my legs go longer than usual. I just didn't understand why I had to shave and once I stopped I don't really see a point in doing it again. My mom made me shave my arm pits to be a bridesmaid at a wedding but I wore a long dress so I didn't shave my legs. Also, shaving my legs meant I would occasionally cut myself and then later I'd pick at the scabs or I'd have something on my legs from picking to begin with and the shaving would make it worse. It is a lot of work and time and potential discomfort and pain for no reason. I think once I realized that my partner didn't care if I shaved I stopped altogether.
(Gabby, 23, queer, woman)

The performance of gendered desirability mediated participants' access to

desired intimate relationships and their associated goods. The following excerpt

from Hannah illustrates how gendered desirability can also be understood in the

context of intimate same-sex friendships, illustrating it's importance for asexual

partnering and sociality more broadly. Hannah was explaining to me why she lost

opportunities for friendships when she tried to perform femininity for strategic

social reasons or under social duress.

They think I'm a more feminine person than I really am, and they might talk to me in that way. They might talk to me as the kind of person that they expect to have had certain experiences, that they expect to have had friendships, that they expect to have had friendships with other girls and women when I was growing – when I was growing up. I – in other words, I – let's just say that a lot of the suffering I have in life is from people assuming that I would be a certain way when I'm not.
It's normally assumed that people growing up have certain experiences. It's assumed that if you were a girl, that you had girl friends, that you had friends, that you jumped rope, and that you had tea parties and played with your dollies, and it's assumed that you ended up being a certain person and a certain kind of person, and it's assumed that even if you didn't do some stereotypical things, girl things, that they would've seemed – naturally would've seemed things that you wanted to do.
(Hannah, 49, heterosexual, woman)

In contrast with female-identified participants' reports that desirability *to*

others hinged on the ability to perform femininity in a particular way, male-

identified participants wrote about how heterosexual sex influenced their

evaluation of their *own* gendered humanity. Jack wrote with particular passion and

detail on this topic. Below I piece together excerpts from Jack's interview to

demonstrate the discourse of heteromasculine humanity illustrated by Jack's

account. Below Jack reports on three seminal moments in his sexual history, each

with a different woman who initiated a sexual activity that had special meaning for

Jack within the discourse of heteromasculine humanity. First Jack describes losing

his virginity. Aspects of this experience were presented in *abuse & exploitation* in

Chapter 4.

> At 18, I was so lonely I tried to OD and ended up in [a] Psych. Hospital in 1987. I ended up meeting a 35 year old woman and we had sex in the hospital. It made me feel that I was a man and human, a whole wave of emotions. Because she was twice my age, she was very tender, supportive and had a sense of humor. ...
> I was overwhelmed by feelings and thoughts, I was finally happy to have done it. I didn't think sex was good or bad, it just was. I had to lean on my right wrist to support myself and my wrist was sore for 2 or 3 days later. ...
> Yes, thank God for that. She was very tender and supportive, "Oh, you're happy to see me" "Wow, you're pretty big", etc. etc. etc. I think I allowed the relationship to happen with [first sexual partner] because she was older. I couldn't connect with girls my own age, so older women were far easier to talk to. In fact, looking back, I always dated older women, except for one time. ...
> Oh, I thought that by having sex, it would gain my admission to the human race, that I would feel like a man, that I would belong. Finally. I was wrong. Having sex was not the emotional Holy Grail I thought it might be. It might prove as an equalizer to make up for all the differences I went through with other people. I could be more like them. I was wrong. I didn't feel any closer to groups or identities, but even more so, I realized how superficial this was. ...
> (Jack, 43, asexual/heterosexual, man)

Next Jack describes his first blow job.

> I let her and I was, not sure what the best word to use is, pleased that she could deepthroat me. It was one of those social...um...not sure, it was like I belonged in a certain club. I was still feeling amazed to have a beautiful, busty, blonde sucking on me, so I figured this was one of those moments guys

> lived for. I wondered if this would make me "fit in" more with the more
> normal people. ...
> She ended up swallowing at the end, a first for me and again, I had a notion
> that this put me into a certain "club", stuff that happens to real guys. ...
> I thought on one hand, that this was what was going on every night, to a lot of
> different people. This was what people do. What adults do. ...
> No. I was disappointed, again neat for the 2 new experiences, but I felt that
> there weren't really any new frontiers to reach, that the hidden realms that
> all teenagers thought were a part of being a grown-up where gone. It's like
> seeing a billboard that said "The Best Part of Life!" and then you walk behind
> the billboard and see just wood supporting it. There weren't anything to
> reach for, to strive for. I had tried more of what everyone else was doing and
> wasn't impressed with it. ...
> (Jack, 43, asexual/heterosexual, man)

Finally, Jack describes the beginning of his relationship with his wife, who was

married to someone else at the time.

> She wanted to give me blowjobs and after a while I let her. They were
> fantastic and to have a girl swallow every time, day after day, for a couple of
> weeks really impressed me that she wanted to be with me. It made me start
> to feel like I was attractive to the opposite sex. Then after she got kicked out
> of her house, we had intercourse when she moved in. Our strange
> relationship in a way happened, I know I wasn't planning on it.
> (Jack, 43, asexual/heterosexual, man)

Jack's experiences demonstrate a different, but still traditionally gendered, way in

which participants sought to fit themselves into available, though ill-fitting, social

positions.

In the context of heterosexual relations, demands for feminized desirability

and pursuit of heteromasculine humanity illustrate the prioritization of

heterosexual men's (assumed or actual) preferences. This priortization was a

common experience. A classic[21] example of this was provided by Vivian during our

discussion of her sex life with her cohabiting male partner.

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[21] By classic I mean archetypal of how male privilege is experienced in
heterosexual sex in the general population.

I: Mm-hmm, sure. Um, and is there anything about your sex life that you've had trouble with or that you see as a problem?
P: Yes, there's definitely room for improvement. That's the case for many couples. For me, I have the tendency to be self absorbed. Sometimes I forget the particular needs of my partner -- whether it be emotional, physical, or sexual. For some autistic individuals, I believe that self absorption can inhibit sexual interactions.
I do wish that there was a little bit more, um, um, attentiveness to my particular needs. They are different from his and involve more time for me to get aroused. I have communicated that with my partner, and I believe my partner does make an effort, but it's a work in progress [laughter], so. ...
I: Okay. And what are the things that you like about it, your sex life? ...
P: I do enjoy when we are intimate -- especially when they are long sessions where I am receiving adequate attention by my partner (rather than a "quickie" where it simply involves getting his needs met). Sadly, there's not enough of those sessions. I have to substitute on my own on having my sexual needs met. I'm glad that I've spent the time to explore my own body enough to know what those particular needs are and how to meet them. Otherwise, it would be extremely frustrating. ...
I: Okay. And then of those times that you are intimate, um, with him, how, um, frequently or as a percentage of the number of those encounters, um, would you say that your needs are met? ...
P: I would probably say 40 to 50 percent.
(Vivian, 31, heterosexual/bicurious, woman)

In this example, Vivian describes an inequitable distribution of sexual labour and limitation on her sexual satisfaction. Though prioritization of men's (assumed or actual) needs was common, C.P. provided an example of how *traditional gender roles* worked to disadvantage male-identified participants, describing an interaction that occurred in his facilitated Aspie social group.

P: Like [this one member]. Now she starts saying, well, y-... telling the facilitator that, "Oh, whenever he talks about it I get uncomfortable because he gets..." you know I get loud. You know I get upset.
I: Sure.
P: And she's uncomfortable with that. Now, here's a young lady that cries at the drop of a hat. Now, there's nothing worse – or to me, anyway, or more you know upsetting than seeing a young girl cry. That's very distressing to me. ...
Never once criticized anybody for doing that. I only wanted to be there to help people. And I-I don't find – I find it distressing, but I don't treat people

> differently because of it. I want to help. I don't want you to be sitting there crying, because obviously something's bothering you.
> (C.P., 48, gay, male)

In this excerpt, greater acceptance of female displays of emotion generally, in addition to the cultural conflation of male anger with violence, lead to C.P.'s opportunity to share feelings being restricted more than his female group member. This limits his access to social support and self-expression.

Participants also reported displays of male authority. In other words, experiences in which men are presumed to have more authority than women. Elle's experience being non-consensually rubbed by a classmate during class is one example of this. He assumed he had more authority over her body and the public classroom space than she did. Laura's excerpt below provides an example of a different way male authority was displayed, people behaving as if what men had to say was of more value.

> So my husband and I go to couples counceling and it seems to help , But I am figuring out right now how to get across to my husband that he is MORE inclined to listen to men than to listen to my feedback and also i have the issue with my husband that he has NO theory of mind at ALL !
> (Laura, 30, heterosexual, woman)

When men's words are invested with more value than women's, women are not able to participate equitably in the co-construction of our shared aspiration for human living and its associated distributive arrangements.

Finally, many participants reported experiences of gender-based harassment. These disciplinary experiences police the boundaries of *traditional gender roles* to maintain social stratification that ensures heterosexual, cisgendered men's monopolization of socio-economic resources. I chose to make an analytic distinction

between harassment to enforce *traditional gender roles* and *LGBTQ discrimination*,

discussed next, though they are both ways of reproducing the dominance of

heteronormativity. I made the distinction between gender-based harassment as a

component of *traditional gender roles* and harassment related to *LGBTQ*

discrimination based on focus of the harassment. If the focus of the harassment was

gender *crossing*, then I categorized the experience under the sub-theme of *LGBTQ*

discrimination. If the focus of the harassment was inadequate gender performance

by someone assumed to be cisgendered, then I categorized the experience under the

sub-theme of *traditional gender roles*.

> Participants reported gender-based harassment that started in childhood.

> As a child, I was considered a tomboy, I fought with my mother about gender.
> I wanted to dress like a boy, have short hair, play with the boys. I didn't like
> dresses or dolls or hanging out with girls.
> (Sandy, 46, bisexual/polyamorous, genderqueer)

As illustrated by Sandy's excerpt, the most common type of gender-based

harassment reported was females coercing other females into a more feminized

mode of self-presentation. R.B. and millie33's excerpts demonstrate common ways

this dynamic played out in both familial and non-familial settings. Here I follow up

on R.B.'s report that she does not create a traditionally feminine aesthetic through

the use of make-up and uncomfortable clothing.

> I: Have you ever felt motivated to do those types of things?
> P: my sister has always encouraged me to wear more makeup. if we go
> somewhere where it is common to wear makeup (like a wedding or party)
> my sister applies my makeup for me
> I: How do you feel about that?
> P: I'm ok with it but i don't like her touching my face and applying too much
> makeup, just enough that it looks nice and natural
> (R.B., 29, heterosexual, woman)

When asked if anyone other than her parents had harassed her about her gender

presentation, millie33 related the following examples. millie33's examples

demonstrate how gender-based harassment can negatively impact *economic*

opportunities.

> P: Oh, uh, well one that stands out in my mind is I was in California and I, and
> I, um, I got a, I lived up in Bishop, California, in between the Sierra Nevada
> Mountains and the White Mountains. And I had a job for a while; this is when
> I was 21. ...
> I, I had a job for a while on trail crew, which I loved, I really loved that job.
> But it was like a one-year position and so it ended. So then I got a job at this,
> at this 24-hour gas station at the edge of town for the 11:00 to 7:00 shift in
> the morning, which was like when all the drunks came in and all that. And,
> and so the man, the guy that, the manager's wife was like -- she was like she
> was trying to give me barrettes and for my hair and stuff; she didn't think I
> was feminine enough and it made me laugh because I was like here I am at
> four o'clock in the morning with all these drunken people coming and I, I
> would just as soon look as scary as possible. [Laughs].
> I: [Laughs].
> P: So that was one. And then when I went to school at voc rehab, you know,
> they do all this counseling for how to dress and all that and, and they were,
> they were having a problem with my appearance. But I just told them, I said,
> "You know, I notice a lot of things about you too but I, I don't talk about
> them."
> (millie33, 55, lesbian, genderqueer)

millie33's stories also illustrate the difficulty of enforcing a strict analytic

boundary between gender-based harassment to enforce *traditional gender roles* for

those assumed to be cisgendered and gender-based harassment to punish gender

crossing. Without additional context from the harassers, I cannot say for sure which

was occurring. Hannah, who experienced significant gender-based harassment

throughout her life, also illustrated the link between *traditional gender roles* and

LGBTQ discrimination with the following story about how schoolmates began

teasing her for being a lesbian as early as elementary school.

but there were people telling me that I was a lesbian. And once I knew what that even meant, I was like eight. At some point someone explained to me what it, what it was, because actually I knew the literal meaning. I knew lesbian as a person who was born on the island of Lesbos in Greece. ...
And that, I knew this from the time I was seven because I read, I read the encyclopedia. And I had no idea why anyone would think I was Greek and why they would think I was from there because I'd never been to any place in Greece, including that. I don't know one – you know, I don't even know one word of Greek. And finally I literally went and asked a teacher whom I sort of trusted.
(Hannah, 49, heterosexual, woman)

LGBTQ discrimination. In addition to experiences like millie33's and Hannah's, in which the policing of *traditional gender roles* and *LGBTQ discrimination* are impossible to separate, participants also reported experiences that clearly fall under the sub-theme of *LGBTQ discrimination*. *LGBTQ discrimination* refers to experiences in which participants were harassed or discriminated against because they were known or assumed to be non-heterosexual or not cisgendered. We have already seen examples of *LGBTQ discrimination*. For example, Gabby wrote about the biased and partial representation of non-heterosexualities in the *sexuality education* provided at her school.

In developing this sub-theme, it is important to first acknowledge the framework of legal discrimination operating in participants' lives. For example, two participants who desired it were not able to access the legal institution of marriage because of state laws preventing same-sex marriage.[22] One of these participants was able to access registered domestic partnership, which invests individuals with some (but not all) of the socio-economic resources for citizenship that marriage does.

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[22] Both federal and relevant state laws regulating same-sex marriage changed during the course of this research. The situation I describe reflects the conditions under which participants had been living prior to this research.

Both of these participants had participated in marriage ceremonies with their partners. These ceremonies, or enactments of legality (Hull, 2006), were associated with access to particular goods, such as perceived social support and enhanced self-esteem. I will discuss these experiences further in *normalization*.

Another example of legal discrimination was the lack of protection against discrimination in the work place. One participant, who asked not to be identified in connection with the following story due to fear that it would make them recognizable, related a particularly gross experience of *LGBTQ discrimination* that negatively impacted their *economic opportunities*. Notice in their reflection on the experience how they are careful to parse supportive others from unsupportive others and the aspects of the experience which were disciplining from those which were empowering.

> P: For most of my 20s, I was in seminary and candidacy, the process to become an ordained pastor in my denomination. There are official, written rules that pastors may only have sex in straight marriage. My denomination is really actually pretty progressive, but this rule comes from the mergers in the 1980s, when gay candidates were approaching ordination and the new merged church decided to ban out gay/lesbian people from ministry (it really had nothing to do with straight sex). While there are areas of the country where committees are very concerned about straight sex also, and everyone is required to verbally commit that they will not have sex outside of marriage, the majority of the time, committees don't care if straight people have some sex, as long as it doesn't embarrass the church (scandals for example). So I know candidates very publicly having sex in seminary dorms, fiancées who became pregnant, etc. who had no difficulty in either lying about their compliance, nor in getting through the process.
> But as an out queer candidate, everything I did was scrutinized. I was out, but had not yet made a firm commitment to the pledge, because I did not have to until the end of the process, and there was the possibility that the rule might change before then. So while I and most everyone around me did not agree theologically or practically with this rule, I was not willing to lie (despite it being common practice for straight people), but I also was not willing to risk my career for casual sex, especially since that wasn't what I wanted anyway.

My candidacy ended when I was on internship due to an article being written and distributed about that I was transgender in a ultra-conservative private newsletter that was sent to the entire denomination's congregations. The rule says nothing about being transgender, but they don't need a formal rule in order to make a decision. I was in a relationship with [my partner] by then which I did not disclose yet, asking them to formally decide based on gender identity (the first such case to come through the denomination). We weren't living together and only barely exploring sex (which doesn't fit any definition of sex the denomination has ever made, incidentally). I was able to transfer to finish candidacy and become ordained with the group that was ordaining GLBT people to serve in the denomination, which does not have such a rule. ...

I: How did this incident affect your career trajectory?

P: It's difficult to separate the effect of this incident versus the policies and climate of oppression. It took me a full extra year to find an internship site (prior to this incident). It also took two years to find my first call - generally, graduating candidates are immediately assigned through a "draft" process when the bishops pick their candidates to assign to their regional openings. It very much limited the congregations willing to take a chance to call/ordain me. While at that time many congregations were doing so without negative denominational action, it varied regionally and was still a risk. But it also meant that instead of getting assigned to a rural 3-point congregation (3 tiny rural churches sharing a pastor), I was able to enter into a better-fit urban call into specialized ministry when I was finally ordained.

I: How did this incident make you feel?

P: I entered into candidacy knowing that it was likely to happen at some time. I was angry and frustrated when it happened, but also was at a very privileged, supported and resourced place to be able to continue internship and finish my last semester of seminary without interruption.

I: How did this incident affect your faith?

P: My relationship with God and with my communities was strengthened. My trust and belief in the body of the denomination was weakened, although there was so much support from within the denomination. My tradition believes that the church is made of people, which means that its inherently imperfect, which I knew very well before the incident and kept the sense of church at I still felt about the denomination after.

The belief that the church is made up of humans who make both Spirit-led and also selfish/fear-based decisions (as opposed to a branch of God that always follows God's will) has helped me to cope with the ways that the denominational body has let us down – I never expected perfection from the church, nor did I conflate the people or denomination with God's self.

The participant who related the above story was able to critically analyze

heteronormativity and had built intentional communities to provide them with

social support. Other participants struggled more with managing the challenges of

LGBTQ discrimination. C.P. was one such participant. I wrote previously about how

C.P. did not tell others about his sexual identity. He had started to make contacts

with the gay community and was known to be gay by his Aspie social group.

However, he was not out to his family or at work. C.P. showed many signs of struggle

with *LGBTQ discrimination.* He avoided saying the word gay throughout the

interview, usually opting for ambiguous phrases like "that way" when referring to

his identity as a gay man or the gay community. He showed deep concern about

LGBTQ discrimination, prefacing our interview with the following query.

> I: Do you have any questions before we get started?
> P: do you have any difficulties with the LGBT communities at large
> (C.P., 48, gay, male)

His expectation that he would be treated poorly for being gay came up several times

throughout the interview. The following excerpt, where I follow up on his report

that he is not out about being Aspie at work, provides one example of this.

> I: What about, um, being gay? Are you out at work about that?
> P: No, not at all. ... No, because you've got to understand. This is
> Pennsylvania. The co-... the company is, uh, is, uh, rooted in the [small city]
> area where it's God, guns and you know country. ... And you know they're
> very-very narrow-minded people, very you know bible-thumping people.
> They... I don't even get into that with them because it's none of their business.
> The part – the other part with being on the spectrum, that can be part of their
> business, but that part I don't even speak of it because you know they're very
> narrow minded people.
> I: Okay. So you – I – what I'm hearing is that you feel like you would not be
> treated well if they knew?
> P: Oh, no, not at all.
> (C.P., 48, gay, male)

Sandy's expectation that she would be treated poorly for being a member of sexual

and gender minority groups also factored into her decision not to report rape to the

police.

I didn't anyone would believe me or that anything would be done. I live in a county that has received national attention for hundreds of reported child rape cases that went uninvestigated by the local sheriff. I'm poly, pagan, genderqueer, into BDSM [Bondage, Domination, Sadism, Masochism]. Going to law enforcement here would be akin to putting a target on my back. (Sandy, 46, bisexual/polyamorous, genderqueer)

Chronic expectations of stigma and discrimination contribute to minority stress and its deleterious effects on health. They also, as illustrated by Sandy's experience, restrict access to key rights such a protection from harm. millie33, who also related numerous incidents of harassment and discrimination, summed up the experience of *LGBTQ discrimination* most succinctly when asked what supports could have helped her have a good sex life.

P: Um, first of all, acceptance for gay people.
I: That's a big one.
P: That's a biggie. .. That's pretty big.
(millie33, 55, lesbian, genderqueer)

(Hetero)Sexual normativity: Primacy of monogamous sexual relationships. Aspects of sexual normativity not reducible to heteronormativity have been organized under the sub-theme of *(hetero)sexual normativity*. The central feature of *(hetero)sexual normativity* is the primacy of the monogamous nuclear family in the organization of society, including its sexual, social, and economic aspects. The primacy of the "Standard North American Family" (Smith, 1993) in organizing society and the ill-fit of this organization for many citizens is not a new finding. Here I document how this central feature of social organization impacted the lives of my participants. Sub-themes organized under (hetero)sexual normativity include: *primacy of monogamous sexual relationships, sexual economy*, and *normalization*.

The theme of *(hetero)sexual normativity* does not fit neatly under the umbrella of either discipline-subjectification or empower-fluidity. This normativity profoundly shaped participants themselves and their lives in ways that are simultaneously discipline-subjectification and empower-fluidity as well as discipline-subjectification at one moment and empower-fluidity in another. This is also true of ability. However, it was easier to make analytic distinctions between positive and negative encounters with ability in participants' lives. I suspect this is due in part to the fact that participants were largely members of the neurodiversity movement who had done some degree of critical analysis of ability as a normativity and its impact on their lives. Ability was also an axis of clear social difference for them, with which they were confronted on a daily basis.

(Hetero)sexual normativity, however, remained unquestioned by most participants. Unlike typical abilities, traditional gender roles, and heterosexuality, participants often understood (hetero)sexual normativity as central to a life of meaning or value. I present here the experiences of those few participants who clearly experienced (hetero)sexual normativity as discipline-subjectification, organized under the sub-theme *primacy of monogamous sexual relationships.* The two remaining sub-themes of (hetero)sexual normativity, *sexual economy* and *normalization*, will be presented next. However, they are presented under the umbrella of empower-fluidity. As the concept map on page 151 shows, these two sub-themes are analytically positioned at the juncture of discipline-subjecification and empower-fluidity. They are the ground on which participants were most able to achieve inclusion in their difference.

Several participants were actively polyamorous or open to consensual non-monogamy in future relationships. These participants faced monogamism, or the preference for monogamy. For L.B., a young participant in the midst of her first sexual and relationship experiences, consensual non-monogamy seemed like a practical response to social realities.

> P: I liked being with the guy I hooked up with but he changed his mind about being my boyfriend.
> I: Could you tell me more about him changing his mind?
> P: ok. when I first asked him out, he said he was interested in another girl who goes here and that is in his year. I told him we could have an open relationship, and he seemed fine with that at first. The next day he said he thought that we went too quickly and that it made him reconsider whether he wanted to date anyone.
> I: hm. Are you open to having open serious relationships or open casual relationships, or both?
> P: I'm not sure yet. I think both.
> I: Ok. Open relationships are not the idealized social script. (Though they are pretty common and work well for many people.) How did you first decide that open relationships may be something you are interested in?
> P: Through what I read online and through the media, I learned how common cheating is when relationships are closed. This made me think about polyamory as an option. One of the blogs I read was written by a woman who is married, but also has a boyfriend that her husband knows about. She said she was someone who needed more sex in her life than her husband did.
> (L.B., 22, heterosexual/sapiosexual, female)

Sandy, who had been practicing consensual non-monogamy for many years and had built satisfying polyamorous relationships, also saw it as a practical response to social realities. After answering researcher-posed questions about her separate relationships with her two main, cohabiting partners, Sandy wrote in and answered parallel questions about her poly relationship conceptualized as a whole. She wrote about how polyamory afforded a resiliency not enabled by monogamy. She also acknowledged the social and legal discrimination that placed hers and her poly family at risk.

> P: How satisfied am I with the poly relationship?
> Extremely satisfied.
> What do I like about it?
> I like that our strengths and weaknesses balance each other out. None of us
> would be very functional individually, but as a family, we are strong and we
> have been able to accomplish much.
> What do I dislike about it?
> I could stand to have a little more time to myself. Dealing with insurance,
> bank, etc is challenging because poly isn't legally recognized.   They don't
> make cars for poly families, as in back seats that seat adults comfortably. I
> worry about us building credit as a family, how do we do stuff we need to do
> like retirement and financial planning.
> (Sandy, 46, bisexual/polyamorous, genderqueer)

Sandy, as you may recall, has a daughter who receives behavioral health services.

Between Sandy's and her daughter's (dis)abilities, the family has had a high degree

of contact with professionals and service organizations. When asked, she elaborated

on experiences of monogamism in that context.

> I: Have you ever had any comments from professionals or incidents related
> to the family being poly? If so, could you please tell me about that?
> P: I was a pretty strong advocate, I was pretty visible in the children's
> behavior health community, so that was something they were very careful
> about. It was all about promoting family involvement, so it would have been
> completely counter for them to complain about having extra family. There
> was that implicit threat of what would happen if Child Protective Services got
> involved, what would they do about it.
> I don't recall specific comments, but when I was briefly a client in the adult
> behavior health system, it would be implied that poly was dysfunctional
> behavior or high-risk behavior. But the way they were, I think they would
> have found something else to try to shame me about, poly was the most
> visible.
> (Sandy, 46, bisexual/polyamorous, genderqueer)

The *primacy of monogamous sexual relationships* was also clearly

experienced as discipline-subjectification by sexual participants who were not

successful at forming intimate relationships and by asexual participants. C.P.'s

lament that he will never be understood by others in *sex-ability* and Danielle's

discussion of how intimate friendships with sexual people inevitably become

marginalized when those intimate others form and give primacy to an intimate

sexual relationship, in *courtship difficulties,* both exemplify this experience.

Danielle's concern regarding marriage consummation laws provides yet another

example. Billy Joel, who, like other asexual participants was content to be asexual

and did not have a sense that she was "missing out" on anything by being asexual,

also clearly articulated the structural challenges to sexual citizenship for asexuals in

a society organized around monogamous sexual relationships. This theme came up

at several points in the interview, was the most difficult aspect of the interview for

Billy Joel, and was, as she says, the point she wanted to leave me with.

> I: Are there friends you spend time with?
> P: Yes. The people I spend my time with are the people in my dorms. I consider them my good friends and each year I have new people that I become friends with. Once they move out of the dorms (as most people do after a year) I see them less. I keep in touch with some of them and a couple of them are still good friends. Many of my friends from [my campus disability group] I met through the dorms and recruited for the group. During the summers when I don't live in the dorm, I really struggle with finding friends to spend time with. Most of the friends I had in high school have moved away and/or gotten adult jobs and are never free or interested in hanging out and playing music or shooting hoops any more. The friends that are around now prefer hanging out in bars and dancing and trying to find significant others so I have no interest in joining those activities usually. ...
> I: Do you have any desire for a "life partner or partners", for lack of a better word? Someone with whom you share the tasks of daily living (i.e. paying the rent, doing the housework, etc.) and everyday experiences (i.e. eating together, discussing shared interests, engaging in preferred activities).
> P: This is another tough one. This year (being a senior) I am looking more directly at what the "real world" (as in finally getting off campus and potentially leaving home, also as in getting a professional job based on my degree) entails for me. Growing up, I always wanted to live at home. I took a chance and tried dorm life, loved it, and have lived in the dorms the past 5 years. What I love about dorms is the sense of community, having a lot of people around, and having the Resident Assistant who is there if I need help with anything.
> I understand that some grown-up places have similar features. Apartments have landlords, who are supposed to help with *some* problems. But to be honest, my ideal is living in the dorms. That could just be my denial that I

have to figure something else. I don't think I would like living alone, so if I could share an apartment or condo with someone one or two other people that would probably best. While this is hopefully what will happen, if there were a dorm-type setup for adults that would be better for me. Having a larger group of people to be around on a daily basis outside of work, having a cafeteria and a group of people to go eat with, and having an RA so close. ...
I: Who do you talk to about relationships and sexuality?
P: Primarily I talk to peers, usually the friends that live in dorms near me. Usually when I talk with people about it I do more of the listening and asking questions and they do more of the talking - simply because I don't have much to say or share.
I: Can you talk to them about concerns or questions you might have?
P: Yes, there are friends I can talk to about questions and concerns - usually for me those are like the questions you asked in the last email (my concerns about what happens to people who don't want to get married when they finish school/grow up). ...
I: Is there anything I haven't asked about that you think is important to understanding your experience of gender, sexuality, and relationships?
P: We've talked a lot and I can't remember it all exactly, but the one point I'd leave you with is that even though I am confident that I understand my lack of desire for romantic relationships, I am still scared about what that means for the future. I wish there was more acceptance and more portrayal of alternative living situations (maybe it's just where I grew up...) and society expectations. Oh and one last thing - you just have to laugh sometimes! I don't understand why things are the way they are but humor helps.
(Billy Joel, 23, asexual, woman)

Section Summary. Themes organized under the umbrella of discipline-subjectification included *structural ableism, cultural ableism, heteronormativity,* and *primacy of monogamous sexual relationships*. Participants experienced structural ableism as a limitation on their sexual citizenship in the domains of economic opportunities, laws & policies, sexuality education, and service provision. Structural ableism existed in a reciprocal relationship with cultural ableism, representing its uptake and reproduction through formal institutions. Cultural ableism manifested as NT privilege, out-grouping, and the sex-ability discourse. The sex-ability discourse explicitly linked ability with sexual normativity. Sexual normativity was experienced as a limitation on sexual citizenship through the discipline-

subjectification of traditional gender roles and LGBTQ discrimination associated with heteronormativity and through the primacy of monogamous sexual relationships in social organization and material distribution.

Empower-Fluidity

(Hetero)Sexual normativity: Sexual economy. The theme of *sexual economy* refers to experiences in which sexuality was used as currency to obtain goods, material or otherwise, and/or structured the distribution of resources. One important aspect of the sexual structure of resource distribution was identified in the previous section, marriage. Dyadic sexual relationships are the normative structure for adult living. It is expected that people will form these relationships and then devote their personal resources (economic, emotional, labor, etc.) primarily to them. Marriage is the legal codification of this arrangement, wherein citizens have increased rights to the personal resources of another citizen. Many laws and policies shore up this economic arrangement, ensuring greater economic security for those in legally codified (presumed) monogamous sexual relationships. It is important to acknowledge that the sexual structuring of society not only impacts the distribution of *material* goods, but also the goods of social support, care, and daily labor (e.g. housework, financial management, home maintenance, etc.).

Participants' awareness of this dynamic is evident in M's concern that she would not be able to support both her children and keep her home were she to divorce, Sandy's grievance about the complications (and sometimes impossibility) of ensuring financial security for all three adults in her poly relationship, and Billy

Joel's deep concern about how and with whom she will live after college. It was also evident in CS' reflection on what marriage had to offer.

> I: What is good about marriage?
> P: The good thing about marriage would be for someone to get old with, someone who could take care of me.
> (CS, 34, heterosexual, woman)

We are expected to share resources with our spouses, children, parents. Beyond that, the expectation of shared resources starts to run thin and contributions to the well-being of others starts to be seen as "extra". In this way the *primacy of the monogamous sexual relationship* in structuring the distribution of goods functions to bolster the *out-grouping* of persons who are not in those relationships by rendering their needs "exceptional". They are exceptional needs because they creep outside the confines of "private" family life in which "responsible" citizens meet their needs. The pressures of this economic arrangement were most visible in the lives of participants with children, as illustrated by C.Byrd's excerpt below, and/or others whom participants cared for, as illustrated by the excerpt from Jack.

> I: How do you support yourself?
> P: I am a stay at home mother with a small business. Without my spouse, I would not be able to support myself.
> (C.Byrd, 29, lesbian, woman)

> Divorce. I would love to get a divorce, it would free me up so I can throw myself into my art and instead of just hitting the top 5-10% of contests, I could start winning some of them. The reason I stay married to her is 1. She is mentally ill and could not function completely on her own, she makes bad decisions 2. No one would take her in really. She would have no place to go and doesn't make enough money to support herself.
> So, if I get the divorce I want, she'll go to the street, which is not what I want for her or anyone. If she would just stop attacking me and my art, I could handle the situation. But she keeps on pushing me. She has thrown things at me, she has hit me and she has said that she would like to kill me. I'm

> stunned, because I try to do everything I can to make her life as bearable as possible.
> She also knows that if she does leave me, that I would not be affected by her leaving, which makes her really, really mad. That in fact, I would be happier without her than with her and she has said that makes her mad.
> (Jack, 43, asexual/heterosexual, man)

Jack's excerpt also illustrates the price at which access to resources through membership in a sexual relationship can come.

These participant experiences demonstrate that awareness of how sexuality structures the distribution of resources shaped participants' choices about fundamental aspects of living. The *sexual economy* that emerges from the *primacy of the monogamous sexual relationship* is disciplining and subjectfying in the sense that it fundamentally structures the avenues through which participants may seek desired ends and the social positions through which those avenues may be successfully navigated. The sexual economy is also empowering in the sense that it provides participants *with an avenue* for the pursuit of desired ends. The double-edged nature of the *sexual economy* was most evident in participant experiences in which sexuality acted as currency. R.B.'s description of what strain caused by sexual desire discrepancy looked like in her relationship provides one example of this. R.B., as you may recall, experiences dyspareunia and does not enjoy sex at all. R.B.'s husband does not say or do anything to indicate judgment or displeasure about their sexual desire discrepancy or the frequency with which they have sex. However, she reported that sex garnered emotional support, care, and daily labour that was not otherwise forthcoming in her relationship.

> I: Can you give me an example of what this strain looks like in your relationship? (something said or done)

P: my husband and i spend a lot of time with technology but i notice that after we engage in sexual intercourse he is more attuned to me and looks at me and smiles and is willing to make the dinner and do more things for me
I: hmm. Does he act the same way after massages?
P: he always wants the massages to lead to sex
(R.B., 29, heterosexual, woman)

Notice that physical intimacy does not access the same goods as sexual intimacy. The coin is sex. Sex as currency was discussed explicitly by Sandy when reflecting back on prior relationships. On several occasions, including the one below, she identified social and emotional support as a key good purchased through sexual relationships.

I spent most of my early life doing things I didn't really want to. My mom was crazy, on a Joan Crawford and wire coathangers level.   The words mother and monster are synonymous in my head. Both my father and I were afraid of her, he got to leave and go to work, and he was away from home as much as possible. It was my job to stay behind and protect my younger brother. There were times where I believed that she was going to kill us. My whole world for many years was figuring ways to keep her calm and keep my brother safe. Thinking about myself usually led to myself or my brother getting hurt. She had to control everything, the clothes we wore, the way our hair looked, what we did, what we ate, what we watched on TV, what we read. Things she did not approve of were destroyed or given away. I had to be the person she wanted me to be. In my teens, I got a little crafty, I began to hide things in my locker at school, at my boyfriend's house. I had a few precious hours here and there where I was free to be myself. ...
For many years, I saw sex as a tool, as a means of getting power, to get things that I wanted. Before sex, I had no friends, no one to confide in about the situation at home.   I used sex to get boyfriends, and then they became my social navigator, they gave me a place to fit in, they taught me about things I had been naive about, they took me to dinner and movies, they bought me things. I didn't like sex itself, I found it boring most of the time, but it paid off. I wonder what it would have been like had I felt strong enough and confidence in myself that I didn't need to jump from one relationship to the next. If I could have picked partners based on attraction and shared interests, as opposed to what they could do for me.
(Sandy, 46, bisexual/polyamorous, genderqueer)

Several participants identified their sexual intimate relationship as their primary means of sociality and often the only relationship in their life on which they

could rely for the types of emotional, social, and economic support that are critical

to participation in the co-construction of our shared aspiration for human living and

its associated distributive arrangements. In other words, participants' intimate

relationships were critical to their exercise of citizenship. The following excerpts

from Hannah and millie33 provide illustrations of this.

> Being with other people is simply not fun, and is not compatible with fun
> unless the 'other people' = my husband (see NOTE below)or a VERY few
> other people I have ever met. ...
> So it's been 20 years, and it's – and we get all these congratulations on, oh,
> staying together: 'You've been married such a long time.' I have to tell you,
> though, that, that it basically is a default. It's hard enough for his social skills
> or for mine to find anyone. I, for one, am not the kind of person who could
> correctly manage, you know, an affair and hide it. I don't have the social
> skills to have an affair! And either, you know, either hide it or not. I don't
> have the social skills to, to get involved in situations that might lead to
> divorce, you know?
> I made up my mind very, very early in life – and I mean at about five – that if
> and when I ever married, this would be for life, not because I think divorce or
> any of that stuff is wrong. You know, I don't think – I don't think it's wrong,
> you know. But because I d-, I know that the more people you have in your
> life and the more messes you get into, the more problems you have. Why
> should I not minimize my interpersonal problems? And in this culture, a
> good way to do that is to find one person and stick with him. And my
> husband, I suspect, feels much the same way.
> (Hannah, 49, heterosexual, woman)
>
> I: Do you prefer being in a relationship or do you prefer being single?
> P: I prefer being in a relationship. ...
> I: What makes that better?
> P: Well, uh, um, I, I don't really think it's good to be isolated all the time. It's
> not good.
> (millie33, 55, lesbian, genderqueer)

(Hetero)Sexual normativity: Normalization. Participants' access to

citizenship was not only impacted by the distribution of resources through the

sexual economy, but also, critically, to the membership offered by participation in a

monogamous (hetero)sexual relationship. The sub-theme of *normalization* was one

of the most frequently occurring themes in the data. It was also one on which

participants wrote or spoke with particular passion and insight. *Normalization*

refers to experiences in which membership in a community, and often the *human*

community, was mediated by partnered (hetero)sexuality. The profound way that

(hetero)sexual normativity structures society is demonstrated by participants'

sense that what it means to live a human life, to be part of the human community,

includes participation in *partnered* (hetero)sexuality.

The importance of the partnered aspect of this sub-theme is illustrated quite

clearly by the experiences of asexual participants. Billy Joel, for example, wrote

about how others do not grant reality to her embodied experience of asexuality

because sexuality so profoundly structures their sense of what it means to exist as

an embodied human that they cannot imagine a human with different experiences.

"I don't feel a need to change anything about it. However, I wish it were easier for

people to accept or believe that I actually do not have sexual feelings for anyone"

(Billy Joel, 23, asexual, woman).

Two overlaps with ability as a normativity are illustrated here. First, there is

reason to suspect that heterosexuality is associated with neurotypicality given the

high rates of non-heterosexuality in this and other samples of autistic adults.

Second, if we place Billy Joel's experience in the context of Hannah's story about the

classmate who commented that she must have a "human-ing" disability, we observe

a commonality between the privileging of sexuality and ability. In both cases,

persons with dominant body-mind experiences discredited and disparaged the

embodied reality of participants. Sexuality and ability are entwined, taken-for-

granted aspects of social life rooted in *particular* body-mind experiences that are taken to represent the "human" experience.

Danielle, echoing M's commentary on the marked status of singlehood for women over 30, also talked about the presumption of sexuality and an associated lack of representation of asexuality or asexual lives. Danielle places her experience in the context of her fundamentalist religious upbringing and considered the marginalization of asexuality within that culture relative to the oppression of same-sex sexuality.

> In the fundamentalist culture, asexuality is considered to be simply nonexistent, so I never even learned that it was possible. The best information I had, growing up, about my orientation, was Paul's discussion in the Bible about his own lack of desire for marriage--how he believed he could serve God better without a wife. I figured I was like that, too. But Paul's probable asexuality wasn't something that fundamentalists recognize; if you're single, you're presumed to want to get a mate, and single people are encouraged to be content with their singlehood, with the constant undertone of singlehood being second-best and a burden to bear. The worst I ever got was, "Don't give up; you'll find a man!" If I'd been sexual, I mightn't have made it out nearly as intact. If I'd been sexual and lesbian, I mightn't have made it out alive.
> (Danielle, 29, asexual, androgynous female)

Billy Joel and Danielle's experiences demonstrate that partnered (hetero)sexuality is a fundamental assumption about human life. They also demonstrate the need for alternative models of adult living and the distribution of resources to support this shared aspiration.

Currently, demonstrations of partnered (hetero)sexuality are used as measures of social integration and personal success and value. Cisco, for example, mentioned that his mother accused him of being gay (i.e. deviant) because he did not demonstrate (hetero)sexuality until after he left the United States Marine Corps.

"She accused me of being gay because I didn't have a girlfriend in high school or the first two years out of the USMC" (Cisco, 60, heterosexual, man).

Social integration was also a concern for participants who referenced peer experiences in their discussions of normalization. An example of this is given in the excerpt in *sex-ability* in which C.P. discussed how his outsider status is partially constructed through the absence of common experience. Younger participants frequently mentioned the importance of sexualized expectations, such as early relationship initiation, to social integration. Participants such as Elle found that social expectations that she perform (hetero)sexual normativity at the same age as her peers were out of step with her own needs.

> I wish that sex wasn't treated like such a shamed thing, and instead a natural part of life. There have never been adults to whom I could go with queer-identity questions, or questions about the specifics of sex, and that's just not good. I also wish I had learned later. Too much of my childhood was spent with girls "going out" with boys, from such a young age, like 10 years old. I wish I had had more of a childhood, and hadn't been aged so quickly by knowledge of this Great Big World of Sex.
> (Elle, 18, asexual/bisexual, woman)

Peer experiences as a unit of measurement for one's human normalcy were also salient in Jack's account of heteromasculine humanity, presented in *heteronormativity*, and in the following excerpts from abby normal. abby normal's account of this measurement is particularly interesting for a few reasons. First, he applies this thinking to sexuality broadly, from simulated partnered sexuality to actual partnered sexuality. Recall that abby normal started his first sexual relationship with a woman during the course of our e-mail interview. It was his first sexual relationship in decades. When we started corresponding, abby normal was a self-described "hermit" who frequently mentioned suicide.

P: "rosie palm and her 5 sisters" was my only relief of male urges until i obtained a topco cyberskin ass (it is just as what its name would imply, an anatomically correct silicone body part ranging from low back to upper thigh, in a doggy-style position, with two orifices for male satisfaction) which for me was a lifesaver, it took care of 99% of my frustration which allowed my decades of accumulated wounded misogyny to basically evaporate into irrelevance. my method of self-satisfaction is simply to view porn and then when a certain stage of excitement just below the plateau stage, where i report to my silicone appliance and finish things off. that is the long and (mostly) short of it. porn is also (with my appliance) a BIG lifesaver, a BIG safety release valve. it allows me to at least vicariously know/experience that which i perceive most normal people experience as a matter of course, and in the process makes me feel a lot less alien. ...
I: You mentioned before that it also helped alleviate your "wounded misogyny". Could you please tell me more about that?
P: because it gave me a taste of what other men were routinely experiencing with women.
I: I'm understanding that you typically use the cyberskin ass in conjunction with viewing porn. What do you get to experience vicariously through porn that other people experience as a matter of course?
P: point-of-view scenes of penetrations.
(abby normal, 52, bisexual, man)

It should be noted that "normal" and "routine" as measures of "humanity" explicitly include entitlement to women's bodies in abby normal's account. abby normal's assessment of his life and himself shifted remarkably after the onset of his sexual relationship. His description of how his first sexual experience with his new partner affected him demonstrates the second way abby normal's application of peer experiences as a measurement of human normalcy is particularly interesting. His initial application of this measurement to actual partnered sexuality privileges heterosexuality, but on consideration he decenters the hetero to focus on general sexual normativity as the key indicator of a valuable human life.

I: How satisfied were you?
P: no orgasm but at least i no longer am burdened with the V card. so now i feel somewhat more like a functional adult human being. not perfect but a helluva improvement over before. ...

I: How would you like your relationship with her to develop? (i.e. what relationship condition or progression would be ideal for you)
P: matrimony. simple as that. growing old together. that is something i've longed for for decades now, and i feel i must get on with it to avoid making my whole life a total waste. ...
I: You also mentioned that this experience made you feel "somewhat more like a functional adult human being". What are the reasons for that?
P: because i was able to nominally function sexually as a man in a normal relationship with a female where satisfaction is had from both parties. prior to this i thought i was totally sexually dysfunctional, only able to function via porn and masturbation, and tenuously at that... like my equipment was defective or something like that. but i feel whole now for the first time... close to normal at times, i guess... or what passes for normal these days.
I: What is the relationship between having sex with a woman and being a functional adult?
P: that is what so-called normal people routinely do, and i felt for decades that was totally blocked off from me to experience. i was prepared (but not enjoying it) to just be a total eunuch/hermit until god called me home, which i wished repeatedly that he would've hurried up and stuck me with a lightning bolt and gotten it over and done with. but now i have VERY good reasons to stick around and love someone special. i have all this romantic love that was trapped inside me with no proper outlet until now. it is though a great weight has been lifted from me and i feel young again. or at least younger, for somebody that has lived 5 decades.
I: You have had sex with men before. How does having sex with a woman affect your assessment of these issues (virginity and being a functional adult) differently than having sex with men?
P: with men it was an emotionally cold experience. frankly, (as henry kissenger said about politicians) "90% of men give the other 10% a bad reputation." most men IMHO [in my honest opinion] are assholes, not to put too fine a point on it. though i will admit that if a nice and attractive (to me) man had done what my sweetie (female) had done (IOW [in other words] wined and dined and fornicated with me), i would have reacted in exactly the same way. i was just waiting for somebody (of any gender) who could make the first connecting loving move, something which i'm totally incapable of doing on my own. i lack the social connecting genes, to my lifelong detriment. ...
having my sweetie makes me feel much less like a worthlessly defective quasi-human mutant and more like a normal adult human male. Not totally normal but a LOT lot better. :) love is a great elixir for what ails one :D
(abby normal, 52, bisexual, man)

abby normal's account illustrates how peer experiences were used by

participants as a measurement of their own personal value and whether or not their

life was meaningful. It also illustrates the frequent use of "adult" and "human" in participants' descriptions of personal value and meaningful life, as well as the frequent conflation of emotional intimacy with sexuality. Emotional connection is critical to the transformative nature of his experience, but abby normal pins that emotional connection on the physical act of partnered sex.

Rick's story, shared in *sex-ability*, about how he once thought he would never know love because ableist culture told him he "was little more than a walking android," is one of the few stories of *normalization* that did not exhibit this conflation. Rick identified an inability to know love as problematic because the "emotion of love seems to be a central part of us as humans". The connection between the self as capable of love and social value, or fellow citizens' judgments of your worth, motivated Rick's participation in the research, as illustrated by his response to my initial e-mail thanking him for agreeing to participate. "No problem - I think this is new territory that should be explored if we are to be accepted as a part of society, not just a burden or an affliction on it"(Rick, 26, heterosexual, male). Rick's comment illustrates the deep connection between sexuality and citizenship, perception of oneself/one's social group as sexual is requisite for social membership and perception that one can fill citizenship responsibilities.

Participants frequently assessed their own value not only through the normative lenses developed through interactions with others (i.e. social norms), but through direct comparison with what they assumed others thought of them. In other words, "I have value if/when others say I do." The following excerpt from early in R.B.'s interview, in which I follow up on her initial report that she does not enjoy

sex, demonstrates the connection between assessments of normalcy and other-

referenced assessments of personal success and value.

> I: Did you enjoy sex when you first started?
> P: i think i enjoyed it because i was relieved that i wasn't going to die a virgin
> I: lol. Why was that important to you?
> P: because i was already in my 20's and i felt like i would be considered a
> loser if i didn't lose my virginity before i reached 30
> (R.B., 29, heterosexual, woman)

Some participants emphasized how the assessment of personal value was

tied to being found valuable or desirable by another. Cisco, for example, wrote about

how he experienced the need to be desired as a physical anguish in response to my

query about why he fears pursuing sexual relationships with women other than his

wife.

> I just want to have a decent sexual relationship with someone (female). So
> the answer is I fear my reactions as well as their's. If it worked that they
> would want to join me, I might not be able to perform. Or I couldn't because
> the chaos noted above. My fantasy women seduce me. Directly give me
> permission to do with as I would like. Or tell me what they want me to do
> with them. To be approached, seduced by one of these "other women" would
> be awesome. I want to be seduced so badly sometimes it feels like physical
> anguish in my entire body. I believe I have sex and intimacy mixed up, lust in
> the place of love or friendship and intimacy. Seems I am just learning what all
> this is about, but, I'm stuck on not having enough connection with women. I
> do believe my wife would be more than enough, if she could treat me the way
> I would like to be treated.
> (Cisco, 60, heterosexual, man)

The connection between others' assessments of sexual-romantic desirability and

personal worth was explicitly articulated by both C.Byrd and Hannah. Notice that

C.Byrd also points out the resources and membership that are attached to intimate

relationships and that Hannah brings us back again to the human.

> I: Do romantic relationships make it easier for you to move through the
> world as an Autistic person? If so, could you please tell me why you think
> that is?

P: Yes, I believe it does for me because there is that comfort of someone who cares for you which in turn validates your self worth. That may sound horrible, but I wouldn't know how desirable I was unless someone desired me, and I want to be desirable. I want to mean something wonderful to someone (be it physical and emotional) and I found that in my wife. Her reciprocating my romantic feelings is a something that I have never found in the magnitude that she does and I thought it was impossible. In other romantic relationships it did make it easier for me on a more superficial way which was to have a partner, someone who could help me in my weak areas. It also made me feel like I belonged to something.
(C.Byrd, 29, lesbian, woman)

I would say that I was not even considered as a potential boyfriend/girlfriend/partner/possible partner. Okay? ... In other words, I was not someone who – that others could be interested in that way. Okay? And probably part of the ingredients for becoming a whole – you know, a whole person who has all the ingredients, so to speak, is to have people interested in you that way.
(Hannah, 49, heterosexual, woman)

Right to pleasure*.* Sexual participants also articulated a clear *right to pleasure*. A *right to pleasure* refers to participant experiences in which sexual pleasure was pursued as a desired end. Participants' sense of entitlement to sexual pleasure aligns with their sense that sexual intimacy is fundamental to a valuable human life and the World Health Organization's inclusion of pleasure in their working definition of sexual rights as human rights (World Health Organization, 2006). Based on the data, sexual participants' shared aspiration for human living included the *right to pleasure*.

As mentioned above, this right is connected for many participants with *normalization*. This connection is illustrated in C.P.'s assessment that he has had a "wasted life" because he "never got what other people did and take for granted". It is also illustrated in the following excerpt from Vivian in which she explains why she

identifies her dyspareunia as a concern. Notice that Vivian actively pursues the

experience of coital pleasure.

> P: It's a concern for me because I want to be able to enjoy it. The vast
> majority of people who experience sexual intercourse consider it pleasurable
> and I wanted to feel similarly. I've wondered if it's a different type of
> experience than other types of sexual pleasure I have experienced. I've
> wanted the opportunity to have it be pleasurable, yet it's always been painful
> for me.
> I: And then how does your partner, um, react to your pain?
> P: He's very concerned about it, to the point where he avoids it, and it makes
> me sad because I keep telling him (as my gynecologist recommends) the
> more you practice it, the more easier it'll become for the muscles to relax. I
> keep encouraging him to practice it more often. I think he gets very nervous
> and scared because he knows I'm in pain, and I can't withhold the truth from
> him. I'm not going to pretend it's pleasurable when it's not. So, he tends to
> avoid it. It feels weird to have to do this, but it's to the point where I would
> have to be very direct with him about it...
> ...
> If I really had to, um, rank it, um, I would say that I *want* to enjoy it is my
> main thing. Um, it's not that I should; it's that I want to. Um, and then maybe
> concern about his satis-, full satisfaction is a close second.
> (Vivian, 31, heterosexual/bicurious, woman)

The connection between *normalization* and *right to pleasure* is also evident in

male-identified participants discussion of sexual products and services. abby

normal's advocacy of his sexual appliance and pornography as a "lifesaver" because

of their provision of pleasure through simulation of peers' "routine" experiences

provides one example of this. Another example is provided by the following excerpt

from Jack's list of the supports he would like to see available for Autistic persons so

they can have a good sex life. The Q and A in brackets indicates a post-interview

clarification of Jack's story.

> 4. Embrace porn!!! Yup, provided that they understand that porn is "fiction",
> yes, people are having sex, but it's a different type of sex. It can be a useful
> and viable outlet for males.
> One Christmas morning, I think I was 20 or 21, I went to a porn shop to buy
> some videotapes. There were 1 or 2 girls left over from the strip joint next

door that hadn't gone home yet. A cute girl approached me and asked me if I wanted a private show. I paid her $40 and we went down separate hallways and ended up in two booths divided by a glass wall. She said that she would get off if I did. I didn't understand and she said to show I wasn't a cop or something, I would have to jerk off with her. So, I unzipped and watched her strip and finger herself until I came against the glass wall. She put her clothes back on and left. I do see a WHOLE lot of ways that autistic men can get into trouble in real life, so they need to be told and educated that there is safe porn and dangerous porn. [Q: Does your story about the stripper illustrate safe porn or dangerous porn? A: Well...that's a good question. On the one hand, it's dangerous to do something like that since you are out in "public", but on the grounds of a private business. On the other hand, it was a very safe way to release frustration and feel proud about doing ANY type of sex with a real woman. I would not encourage guys to do something like that, but if you're ready to go out of your mind from not having any sexual contact with a girl no matter what you do, it is something that might be considered. It would be very easy to get in trouble or get robbed.] But I still think controlled porn can be a safe and healthy outlet for guys.
5. Sex surrogates - Recently in Nevada, a politician was just elected that is a very successful business owner. Among some of the things he owns are 2 or 3 legal brothels. I don't know if you know this, but prostitution is legal in a few counties in the state of Nevada. He said and I believe him that America has the wrong impression about the people who go to brothels. He said that widowers, handicapped and damaged men go to brothels. I think they go there to feel like men, once in a while. I don't mean that in a bad way, but when you see these idiot guys screwing the hottest girls on the planet and no matter how nice you are, how hard you work or what a great guy, son, brother, father, uncle you are, if you don't have the right look and mannerisms, you will NEVER have sex. That's the greatest problem with not having legal prostitution in more places. Every man in the world gets erections, whether you want to or not. It does get a little sad masturbating by yourself, for your entire life. I think a gentle, human connection can mean the world to a lot of guys. I'm very lucky that [], my first time, was so gently and supportive of me, if she had been nasty and rude, there's no telling how that would have affected me.
(Jack, 43, asexual/heterosexual, man)

Participants' articulation of a *right to pleasure* was also indicated by their no nonsense discussion of masturbation, much of which was presented in *sensual equilibrium*. Sexual participants applied this aspiration to relationships as well, indicating that an intimate relationship must be sexually satisfying to be generally

satisfying. Cisco's sex-based dissatisfaction with his marriage provides one example

of this, as does L.B.'s description of ending her first romantic relationship.

> I: Did he stimulate your genitals in any way?
> P: No. That's part of why we broke up. ...
> I: Have you ever been in a sexually satisfying relationship?
> P: Not with a partner. It's hard for me to dissappoint myself.
> I: What are you looking for in order to be satisfied with a partner?
> P: I want someone who I can be friends with as well. Someone who is on my level intellectually. I need someone who likes affection as much as I do, and wouldn't mind having sex right away. It doesn't matter whether he's a virgin or not at this point.
> (L.B., 22, heterosexual/sapiosexual, female)

Finally, the *right to pleasure* was illustrated in participant accounts that

demonstrated how they made room for or prioritized sex in their lives. Hank's

eloquent description of accessing physical pleasure, emotional connection, and deep

acceptance through sex in the context of extreme sensory disregulation, presented

in *sexual pain/dysfunction*, provides one example of this. Gabby's rationale for

engaging in physiologically complicated vaginal sex provides another.

> I: What are your reasons for having vaginal sex?
> P: I do enjoy it. It is less physically exhausting than many other forms of sex and easier to figure out with my back and other types of pain. It also is one of the easiest ways for both of us to get pleasure simultaneously.
> (Gabby, 23, queer, woman)

It is important to note that this aspiration for human living was not,

personally, shared by most asexual participants. Asexual participants did not

question others' *right to pleasure* and some masturbated for pleasure in addition to

sensual equilibrium. However, some asexual participants did not have desire for any

genital activity and some experienced masturbation as purely physiological, rather

than "sexual".[23] This aspiration is, therefore, connected to *(hetero)sexual normativity* in the sense that it prioritizes the sexual and in that sexual pleasure is sometimes derived through participation in the hegemonic. However, pleasure as a right is not perforce attached to *(hetero)sexual normativity*. Participants' *right to pleasure* was, indeed, expressed in the context of many activities and relationships that do not fit the dominant normativity, such as those described in the forthcoming section on *alternative normativities.*

  Social support. S*ocial support* was another resource of sexual citizenship that participants discussed. *Social support* refers to experiences in which other people provided participants with emotional, material, and/or practical support outside the framework of formal institutional arrangements. Participants' pursuit of desired ends and articulation of alternative normativities were facilitated by *social support.* In addition, *social support* was itself a good of citizenship, providing participants with the emotional intimacy that is, as discussed by participants, central to a good human life. It is of note that participants' level of social support was associated with age, with younger participants reporting greater social support than older participants. I theorize that the relationship between age and social support is a result of several factors. The younger cohort benefited from access to a culture of autism that was not available to older adults during their formative years. This culture includes increased awareness of autism in general society, increased availability of services, and the availability of an Autistic community and identity. In addition, younger participants were more likely to receive on-going support from

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  [23] Asexual participants also did not talk about physical intimacy in the same way that sexual participants talked about sexual intimacy.

their family of origin and relationships formed in institutional settings (i.e. school)

due to their stage in the life cycle. The lower levels of general *social support* reported

by older adults enhanced the importance of intimate relationships for their sociality

and exercise of citizenship.

Intimate relationships were an important source of social support for many

participants. They are, as discussed in *primacy of monogamous sexual relationships*,

actually the key source of social, emotional, material, and practical support for

adults. Intimate relationships are a good of citizenship and provide one avenue for

the fulfillment of citizenship responsibilities. They also facilitate social membership.

Membership is facilitated both ideologically, as illustrated by M's observations on

coupling, and practically, as illustrated by the following excerpt from Hank.

> How do relationships make it easier for you to move through the world as an
> Autistic person?
> [My partner] in particular moves socially fairly easily, and is extroverted so is
> happy to assist with social roles. When we're in places like a party with
> people who I don't know we'elll, or a restaurant, he assists with
> communicating in many ways (with my explicit consent). If we're chatting
> with a group of people, which I find very difficult, he can introduce topics
> that I might be interested in and include me, or just smooth over potential
> social mistakes by explaining what's going on to me or other people.
> In restaurants, servers often can't hear or understand me, and with food
> allergies, its really important to get things right. With my permission (never
> without), he can say things and I can confirm.
> I've gathered a lot of tools to read people, but sometimes am not sure I
> understand emotional/social communications so I can check with or think
> through situations at work or in the world with him. I also have a friend at
> work who can help with this.
> (Hank, 33, queer, Transgender/genderqueer)

Though sexual relationships are a space in which this type of labor is

expected, it is not the only vector for such social support, as illustrated by the

following quote from Billy Joel. Billy Joel also emphasized the importance of a

supportive relationship for getting feedback on social communication skills when

asked what Autistic persons should be taught about relationships.

> They should be taught that everyone struggles with relationships. I think it's
> important to stress communication skills - expressive and receptive. The
> Hidden Curriculum (all those unstated social rules) really help, so having a
> safe place to practice those and get feedback (when you want it) from friends
> was really important from me. (But I don't do romantic relationships, that's
> just a comment about relationships in general.)
> (Billy Joel, 23, asexual, woman)

Participants spoke to the importance of *social support* for facilitating access

to other goods, such as public spaces. This is illustrated by Hank's quote above and

L.B.'s reliance on friends to get groceries. Elle, who does not have a formal ASD

diagnosis, spoke to how social support can provide (dis)ability accommodation in

formal institutions outside the framework of official accommodations.

> I have a few very good teachers who are okay with me not watching things
> that have bright flashy lights, for example, and with me not necessarily
> getting jokes or talking some days, but this is because they like me as a
> person and like how I perform in their class, not because of any officially set
> up support system.
> (Elle, 18, asexual/bisexual, woman)

Elle's socially, rather than institutionally, derived accommodations provide an

illustration of how citizenship as a framework for articulating the conditions that

enable equitable participation in the co-construction of our shared aspiration for

human living and its associated distributive arrangements can help us better

understand inclusion for persons with a range of abilities. Elle's needs did not

require framing as disabilities, nor the structural supports enabled by that label, to

be accommodated. Elle's teachers adjusted their rules for relating to students,

making their classrooms accessible to Elle, because she was perceived to be a

valuable member of that group.

Sometimes the access facilitated by *social support* was of a directly sexual

nature, as with CS' sister.

> I: Who do you go to, to talk about sex?
> Can you talk to them about concerns or questions you might have?
> P: I don't discuss sex with my mother (or sister). However, my sister is a
> Certified Nurse Midwife (CNM), and told me it was ok to go to her for birth
> control and planning.
> (CS, 34, heterosexual, woman)

This type of practical support was one way that *social support* facilitated

participants' inclusion in the community and exercise of sexual rights. *Social support*

also played a role in ensuring that this inclusion was respectful. Billy Joel

occasionally has atypical speech or loses speech. She described several instances in

which NT persons mistook communication limitations for intellectual limitations

and treated her disrespectfully. Previously, we read about Billy Joel's school nurse

patronizing her and her high school friends providing *social support* in the form of

affirmation of her status. In the following excerpt, Billy Joel's friends actively work

to (re)establish her place as a respected member of the community. Notice that they

do not patronize Billy Joel themselves by approaching the pastor, but instead

provide supports for Billy Joel's pursuit of desired ends.

> At the start of this school year or maybe some time last year I had an issue
> with the pastor in my student ministry. I play in the band during worship
> and several people brought it to my attention that she was treating me like a
> child (I didn't even pick up on it for a while). So I wrote her a letter and had a
> friend look it over. She felt really bad but I assured her that it was okay,
> people make mistakes all the time, and it doesn't help because my
> communication skills go "in and out" even though I am intellectually present
> all of the time. I told her even that if my speech doesn't sound right or I'm
> not talking she can speak to me normally as an adult, even though it may feel
> weird. We haven't had any problems since then and I am glad I wrote the
> letter even though it was hard. Because I see how people treat me when my
> communication skills falter, sometimes I elect to not talk. I have started to go
> to the dentist by myself, which is a pretty big deal to me. I hate the dentist

office. I drive myself there, go up to the desk, show an ID and give thumbs up
or down to answer questions. I follow directions when the hygenist is doing
the stuff and I don't talk until it's the actual dentist I know. That has worked
for me.
(Billy Joel, 23, asexual, woman)

Respectful inclusion in the community was associated with increased self-

esteem, as illustrated by the following quotes from C.P. and Rick in which they talk

about the positive impact of friendships and being out in the community.

Now, you've got to remember, this person that I've known, I went there with
to go there with was really good in you know kind of building my self-esteem
because you know I'm actually – you know we're actually going places and
doing things and you know doing different things, you know.
(C.P., 48, gay, male)

Now that I'm older, I have a couple of friends who openly discuss sex, and it's
actually a relief; I learn that I'm not the only one with certain issues, and how
to deal with them. I don't feel as ignorant or as isolated as I did in high school.
(Rick, 26, heterosexual, male)

Social support also functioned to bolster participants' well being during difficult

times, illustrated by Vivian's explanation as to why she returned to the site of her

boarding school after graduation. "There was a family issue, and I needed to get

away. My high school advisor (a different faculty member) and their family invited

me to stay at their home while I was sorting through my issue." (Vivian, 31,

heterosexual/bicurious, woman)

Most often, participants discussed how *social support* was key to creating and

navigating intimate relationships and sexuality. Social learning, feedback, and

affirmation were key to participants' successful pursuit of desired ends. Three

participants were introduced to their intimate partners by friends or family,

including Hannah and Rusty. Recall that Rusty had not had sex before his wedding

night. His father provided him with some concise, but sound, advice about sexual

intercourse with a woman. His father's expression of *social support* is notable

because it is explicit, thus partially adhering to the *radical honesty* communication

style, and because Rusty was in his 40's when it was provided.

> I: You wrote that your father told you about sex. What did he tell you?
> P: This was when i was about to be married at age 41, it was that I should be slow and gentle and be in her for a long time.
> (Rusty, 61, heterosexual, man)

More often participants learned about sexuality from their peers. Some

examples of this were presented in *sexuality education*, such as Billy Joel's dorm-

mates and C.P. and millie33's adult friends. Gabby and L.B. also spoke to the

experience of peer learning, with L.B. identifying how helpful it can be when that

support comes from another person on the spectrum.

> I had a lot of male friends in high school (I found social interactions with them easier) so I learned more about male sexuality from them.
> (Gabby, 23, queer, woman)

> P: I've considered online dating and have an internet friend who is doing that. She is also autistic and I'm thinking of asking her how she presents herself on there. ...
> I: Who do you go to, to talk about sex?
> P: I have friends that are more experienced than me. Especially my autistic friends who tend to be very direct. Most of them are at least a couple years older than me so they've had a longer time to get sexual experience.
> (L.B., 22, heterosexual/sapiosexual, female)

These processes were also key to participants' production of *alternative*

normativities. Dragonfly's experiences with gender identity development illustrate

how lack of *social support* can delay the production of alternative normativities.

Dragonfly presented as a gay boy in the community until puberty. When he

developed breasts, he was rejected and ostracized, told he was no longer welcome at

a community center because he "lied" about who he was. You may recall that

Dragonfly had also been told that being autistic and transgender were incompatible.

He never met anyone who was gender non-conforming nor had anyone validate his

identity until he started working with a new therapist. When Dragonfly first

received a Gender Identity Disorder diagnosis from his therapist, he worked with

what this new identity meant to him.

> I: Why don't you want to be transgender?
> P: It is awful. Never wanted to be in wrong body, never wanted to have body feel so wrong. It is wish to die level of awful. Not see any benefits to being trans at all, just awfulness.
> I: Why do you dislike the word "transgender"?
> P: Bad word. Means unhappy thing do not want to be. Means something self is forced to be, has no choice, did not want, word can not be good because of this.
> I: Do you know anyone whose body and mind do not "match" (i.e. genderqueer, gender variant, trans, etc.)?
> P: No. Just me. But am supposed to be meet people, trans-guys, soon. So might know others in future. ...
> I: Do you have information about options for physical transition (e.g. hormones, top or bottom surgery, etc)?
> P: Some, it is very confusing to me. Am planning on getting top surgery, that is not confusing. Will be hard, do not have help, intend to try anyways. Not really understand hormones but started low-dose testosterone on the 19th anyways. Therapist and doctor both think it will help and they are trusted.
> I: What do you think about using interventions to make your body look and feel more like a male's body?
> P: Not know what to think of it. Did not know it was possible a year ago so it is all very new.
> Therapist and doctor not think self crazy like everyone else did before, that at least is nice.
> (Dragonfly, 30, asexual/pansexual/polyamorous, odd)

All LGBTQ participants discussed connection with an alternative sexualities

community at some point in their lives and the support it provided. millie33, for

example, learned a lot about sexuality and felt a sense of community, or inclusion, as

a result of her visit to the Michigan Womyn's Music Festival (an annual music

festival welcoming only female-bodied persons that is well known in feminist and

lesbian communities).

> P: Oh, well hey, I went -- [My former partner] took me to a Michigan
> Womyn's Music Festival for two or three years.
> I: My goodness.
> P: Yeah, that was amazing.
> I: That is a scene.
> P: That was *amazing*. So I learned a lot there. [Laughs] But they have
> workshops that are like -- [pause]
> I: They do.
> P: I don't know if you have ever heard of Dr. Annie Sprinkle?
> I: Yes.
> P: But she put on workshops there and, yeah, that was pretty neat.
> (millie33, 55, lesbian, genderqueer)

Sandy is involved in both online (i.e. FetLife or Fet) and local BDSM

communities.

> After the local poly groups "dried up" (I was 38), I began participating in the
> local BDSM community. ...
> My parties are a bit unusual in the community. I run a Fet group for local
> geeks who are also kinky. I got irritated because no one at the dungeon
> wanted to talk about science fiction, so I started my own group. I thought it
> would be a dozen people, but membership is pushing 800. It's way more
> social stuff that I wanted to take on, but I like that we've created a little haven
> for geeky types. Our play parties have gaming and BDSM play. Sometimes
> there is more gaming, sometimes there is more play. I'm usually so busy
> hosting that I rarely get to play myself. It's hard work and costs a fair amount
> of money, so I don't host that often.
> (Sandy, 46, bisexual/polyamorous, genderqueer)

Billy Joel also spoke to the importance of *social support* for producing alternative

normativities in her concern about the availability of asexual-appropriate living

accommodations after college. For her, the dorm provided an alternative community

that supported her alternative sexuality.

> I: Are there friends you spend time with?
> P: Yes. The people I spend my time with are the people in my dorms. I
> consider them my good friends and each year I have new people that I
> become friends with. Once they move out of the dorms (as most people do

after a year) I see them less. I keep in touch with some of them and a couple of them are still good friends. Many of my friends from [campus disability support/advocacy group] I met through the dorms and recruited for the group.
(Billy Joel, 23, asexual, woman)

Finally, many participants were involved in social and/or self advocacy groups for disabled and/or Autistic persons. Participants in college were involved in campus-based groups. Older adults often participated in local social groups and sometimes local advocacy and service groups. As should be expected given the recruitment method, almost all participants were active in Autistic Internet communities and/or national self advocacy organizations. Younger adults discussed how disability-Autism groups were helpful in combatting internalized ableism and providing a "safe space" where they experienced solidarity with other (dis)abled persons. Older adults more often discussed how these groups provided an important social outlet, with Autistic social groups serving as the only regular *community* contact (i.e. contact outside of work or the home) for several participants.

Autistic identity. The *social support* provided in Autistic spaces is one example of how an *Autistic identity* supported participants' pursuit of desired ends and creation of a new normativity and associated arrangements that better enable their access to citizenship. *Autistic identity* refers to understanding oneself as Autistic or Aspie and claiming that as an identity as well as (and in some cases instead of) a psychiatric diagnosis. Almost every participant spoke to the positive aspects of understanding oneself as Autistic. Participants who had been diagnosed

in adulthood frequently spoke to how it provided a way of making sense of their

biographies.

> I: Okay. Um, so what prompted you to get a diagnosis?
> P: Oh, my -- I've had, I've had, uh, two, uh, hospitalizations for depression and I, I got diagnosed with bipolar and -- which they said no. But anyways, uh, um, um, my doctor, my general doctor said she thought it was Asperger's and she sent me to a therapist who, who said it was Asperger's. ...
> Uh, I think that like when I first learned that I had Asperger's like my doctor said, "Well I think this is Asperger's." And I was like, "That's Rain Man. That's not me." And, uh, and then when I did research on it I was like, "Yeah, that's me."
> And so now I'm trying to figure out what, what all really was going on, and, and the whole, I mean, you know, I just learned about this when I was 54. And so I'm trying to figure out what all went on. But like people that I, like a couple of people at work know about this diagnosis and they're like, "There's no way that you're Asperger's; you're way to smart."
> So I don't think it's -- I think it's kind of, it's kind of like, you know, it's not like if you're missing a hand or something, you know? ...
> So, like I didn't know why I had so much trouble at work and so much anxiety and, and oh man, it was so hard. And, and I mean that's what [voc] rehab -- they should, like they should know about things like that and, um, so I think that it would be -- that's why I wanted to participate in what you're doing because I think that, um, you know, that maybe, um, you know, maybe there's, there's a, um, you know, a bridge, you know, where, where everybody can meet in the middle. ...
> I remember when I was growing up through school, um everybody thought that I would make it because I was so smart, but it didn't end up doing anything for me. Um, so I, you know, maybe, um, maybe recognizing it and doing like, you know, if I knew about, if I knew the framework -- like I felt like I had a blind spot that I didn't even know about. And now I know about it so now I know -- you know, now I know to tell people, you know, I'm overloaded or -- you know?
> I: Mhm.
> P: Knowledge is power so it's got to be knowledge.
> (millie33, 55, lesbian, genderqueer)

Enhanced self-understanding was a central aspect of the *Autistic identity*

theme. It is important to recognize that this enhanced self-understanding does not

come from the diagnosis *per se*, but from the public that has grown up around it.

millie33 did not just read the DSM and come to the conclusion, "Yeah, that's me." She

accessed blogs, websites, autobiographies, and other sources, primarily generated

by other Autistic persons, articulating the experience of being on the spectrum. This

is an important point because it demonstrates how the *Autistic identity*, and the

community and/or public that has grown up around it, was the primary source of

empowerment for participants, rather than the psychiatric diagnosis. This point is

well-illustrated by Vivian's reflections on why she was happy to have "come out" as

Autistic.

> P: There's a few reasons. I think first of all, I have learned so much more about myself since then. I always knew I was autistic, because I got the diagnosis when I was two, and, um, you know, my parents did disclose that to me when I was quite young. And so I've always known for most of my life that I was different and that I was autistic. Um, however, I didn't understand to the full extent how it plays a role in everything I do in my day-to-day life, how it plays a role in my personality, how it plays a role in why I react a certain way, why I feel a certain way. It helped me to better identify, um, certain things that I'd experience, um, whether they were sensory violations, like to help me – I always had the sensory violation – certain sensory violation issues, but I didn't identify it as a sensory violation, as a, um, characteristic of being autistic. So it helped me to learn so much more about my identity, who I am, and why I am – you know, act the way I am in my day-to-day life, how it plays a role.
> Um, also, I think it's helped a lot of people to understand me better, um, even though there's still a lot of people that don't me understand well and misunderstand me a lot, but I think, um, it's – it's definitely – feels more, uh, liberating when you're open about your life. Um. And, and, you know, fortunately, um, at least by, you know, people I know, I've received a lot of support, um, and positive feedback about it.
> I: Well, good.
> P: So yeah, that's fortunate.
> I: Um, so you said that previously you experienced sensory violations, but you didn't identify them in that way.
> P: Yes.
> I: So how di-, did you identify sensory violations? How did you understand them in your own mind prior to this self-discovery?
> P: I unders-, I understood them as, um, painful experiences or not, um, pleasant. So for instance, um, lights, lighting. Take lighting, for example. Um, I have been able to identify, Since becoming public with my disability and gaining a better understanding of how it interacts with my life, I have been able to identify why fluorescent tube lighting has often made me feel

nauseous, irritable, and mood-effecting. I've always had that issue. But I wasn't able to identify it as, um, a visual sensitivity in relation to autism.
I: Mm-hmm. Okay. Did you think that it was a personal sensitivity, or you just didn't even have a name for it, or...?
P: Um, I don't think I had a name for it, um.
I: Okay.
P: I also have a sensory sensitivity to the textures in certain foods. When I was a child, my parents would try to force me to eat a variety of foods, and it was difficult for me to adapt to all of those foods. Bananas are one example. Whenever I've tried to eat a banana, I feel like I want to gag. The texture is physically painful and displeasing. Other people around me were eating them without a problem, so I was always wondering why my reaction was different. I didn't know at the time that could be identified as a sensory issue in relation to autism.
(Vivian, 31, heterosexual/bicurious, woman)

Despite being aware of the diagnosis since early childhood, it was not until

Vivian became familiar with the community and its discourse that she began to

understand her personal experiences through this lens and name them as autism.

Beginning to see oneself through the lens of the *Autistic identity* was often

associated with increased self-acceptance and self-respect. This had understandable

impacts on participants' sex lives.

> Autistic people should be told, reassured, that maybe you're not going to feel sexual attraction (I don't know what the rate of asexuality among my peers is, but as total anecdata, it feels higher), but that doesn't make a relationship invalid or less romantic. They also need to be told that relationships are hard, that people are difficult to figure out, and that you don't have to go out with someone who doesn't make any effort to understand the way you think or what upsets you/makes you happy, just because they're willing to go out with the "weirdo".
> (Elle, 18, asexual/bisexual, woman)

> I have been seeing a counselor for the past 3 months and it was there that she and another counselor diagnosed me as having Asperger's Syndrome on October 10th and not Borderline Personality. I haven't mentioned this before because it never came up during our discussions. With a different diagnosis, it has changed some of my self-perceptions about myself and I'm likely to change even more. For 3 months now, I feel that I have a right to be happy, a thought I never had before. If there is any question that you would like me to ask my counselor, just let me know.   I do think it's far, far better to be autistic

than to have a mental illness such as borderline. Borderline has hung over my head for the past 25 years and has made me feel like I was broken. By being autistic, I have a right to be myself and that includes my sex life, as I'm still trying to figure that one out I guess. ...
I discovered instead of dating women that I was attracted to and interested in, I picked women I thought were looking for anyone in their lives. This was a very important discovery from me.
(Jack, 43, asexual/heterosexual, man)

Lots of things about my queer autistic disabled life don't match what my society values - but I have, and my partner and I together have, defined what is important to us. I have learned from disability community to not listen to the social expectations that I should feel only pleasure and ecstasy via standard definitions of "sex" in order to value a sexual experience or relationship. I am limited from doing some things that I would like to do, a few by my body itself but much more by society (dance well enough not to be ridiculed in public, work a social job and have a family without being completely overwhelmed, meet my medical needs safely without mistreatment from doctors, etc.), and have chosen not to limit myself further based on other people's definitions and expectations.
(Hank, 33, queer, Transgender/genderqueer)

Elle and Jack's comments illustrate how an *Autistic identity* increased some participants' sense of value as an intimate partner. Hank's comments illustrate how this understanding was developed by some participants to become an alternative normativity that guided the development of alternative arrangements in their relationships.

While it is important to recognize that the Autistic (or broader disabled) community/public, rather than the diagnosis was key to participants' enhanced self-understanding and acceptance, diagnosis was often required to unlock meaningful access to this community. Though the neurodiversity movement and most online Autistic spaces explicitly welcome the self-diagnosed, two barriers to accessing the community without a diagnosis were identified by participants. First, many participants never considered that they may be on the spectrum prior to diagnosis

by a health professional. Second, those who self-diagnosed prior to receiving a

psychiatric diagnosis often mentioned that they did not feel completely safe

accessing the community and its resources without a diagnosis. The following

excerpt from M, who has an autistic son, provides one illustration of this inhibition.

> I did not feel comfortable being active with ASAN before I got the official
> diagnosis, because of the enormous tension between the "autism parent" and
> autistic communities. ASAN is officially welcoming to people who are self-
> diagnosed, and I completely understand that many people either don't have
> access to or choose not to seek a formal diagnosis. I sought the medical
> diagnosis mostly because I needed to make an ADA [Americans with
> Disabilities Act] accommodations request at work, but it also freed me from
> some of my own insecurities about being accepted in the autistic community.
> (M, 39, heterosexual, woman)

M's comments also demonstrate another critical role played by psychiatric

diagnosis, access to services and accommodations. As illustrated by the first quote

from millie33, an ASD diagnosis provided participants with a way of understanding

themselves and their lives, as well as a "framework" for navigating the predicaments

associated with being atypical. The importance of the diagnosis for enhancing one's

repertoire of strategies for pursuing desired ends was echoed by many participants.

One such strategy is accessing appropriate services and accommodations, as

discussed in *service providers*. Danielle spoke to how diagnosis empowered her

through receipt of appropriate medical care, hope, and an effective framework for

navigating predicaments, as well as by opening up a new social position that better

enabled her access to citizenship.

> One day my usual psychiatrist transferred to another clinic and I was given
> an appointment with a nurse-practitioner for medication management, and
> this was an extreme stroke of luck, because the nurse-practitioner had an
> autistic son and immediately recognized the possibility that I might be
> autistic as well. Eventually I got a proper evaluation and was diagnosed, and
> my mother later admitted that she had known all along, but had not told me. I

had my diagnosis changed, was taken off all medication but an antidepressant, and as I learned more about autism and how my problems were things other people had faced and solved, I recovered from depression and started learning to manage stress, sensory overload, and executive dysfunction. ...

Regarding how I view my autism, it's important to remember that I don't think of autism as something external to me. Autism is not something I "have", but a partial description of the way my mind is structured. I have a healthy autistic brain, not a damaged neurotypical one. The distinction is crucial. It means that rather than trying to turn myself into a faux-NT, I need to find the ways to do things, to get along in the world, that work for me the way I am--to become a skilled, independent autistic person, rather than to see "normal" as the ideal.

(Danielle, 29, asexual, androgynous female)

Proactive strategies. An *Autistic identity* provided participants with a framework from which to articulate effective *proactive strategies* for managing the difficulties sometimes associated with having an Autistic body-mind and/or their social positioning as a disabled person. Participants reported using a variety of strategies for managing the individual and structural factors that produce (dis)ability. They also provided suggestions for useful supports and advice for others on the spectrum.

The most frequently reported *proactive strategy* was the practice of *radical honesty*. *Radical honesty* was not just an artifact of "autistic traits", though it may be that as well. It was a consciously deployed strategy for pursuing desired ends.

I: How have you overcome barriers that you've experienced?
P: Compromise, lots of communication, and directness, with honesty (within discretion of course).
(Rick, 26, heterosexual, male)

Intentional communication was an important *proactive strategy,* especially in the context of intimate relationships. For several participants, this included occasional reliance on the written word.

I: What strategies do you and your husband use to negotiate differences between the two of you regarding communication?
P: Often times, we will revisit fresh issues a few times throughout the day they happen, in order to full bring closure to such situations. Sometimes, when our tempers flare during verbal communications we will write to each other through text, instead.
(Ayla, 32, asexual/hetero-romantic, woman)

Several participants also talked about planning social activities, including sex, in advance.

If we don't plan for sex then chances are that we don't have it. It is really hard for us to do things on an impulse. To expect what is coming is way less stressful. Sex is very social and the more we have planned, the smoother it goes.
(C.Byrd, 29, lesbian, woman)

It should also be recognized that the strategies reported for managing *sexual pain/dysfunction* (e.g. gloves, blankets) and for producing *sensual equilibrium* (e.g. sensory regulation through masturbation) are *proactive strategies*.

Several participants had workplace and/or school accommodations. Aside from measures for eliminating background noise (e.g. noise-cancelling headsets, physically segregated work space, etc.), there were few commonalities among reported accommodations as each participant had their own unique needs. Participants also identified learning about and being involved with the Autistic community as a *proactive strategy*, often for the reasons discussed in *social support* and *Autistic identity*. However, as illustrated in the following quote from M, many also indicated that sexuality and/or relationships were "too personal" to discuss with community contacts. This contributed to participants' concern about their own sexual normality in the context of the alternative normativity of neurodiversity.

I read blogs because it is very validating to hear other people's stories when they overlap with my own experience in some way. Growing up autistic

without a diagnosis is incredibly isolating. Most autistics of my age have few real-world relationships with other autistic people. I have dozens of autistic "online friends," and I have met a couple dozen autistics IRL [in real life] through self-advocacy work, but none of them are people I am close enough with to talk about relationships and sexuality. I talk about these things with my own close friends, but none of them are autistic, or at least don't identify as autistic.
(M, 39, heterosexual, woman)

Participants also reported journaling, patience with themselves and others, research and analysis of social phenomena and issues, practicing NT social communication skills, and developing personal communication methods (e.g. communication cards) as *proactive strategies*.

When asked what Autistic persons should be taught or what supports they would benefit from having, participants often provided their responses in the form of advice they would hand down to others on the spectrum based on their personal experience. There were some clear trends in the advice given. The following excerpts illustrate these.

I think young Aspies should be taught the following.
1. Sex does NOT make you a man or a woman.
2. Society and people will tell you that everyone is having sex, that's not true. They are lying to impress people.
3. It's okay to masturbate, it's normal and healthy and everyone in the entire world does it at some time. (But you must be at home and in private)
4. It's okay to NOT want to have sex. No one says you have to ever have sex if you don't want to. It's up to you.
5. Having sex does not make people like or love you.
6. If you decide to add sex to your life, you must understand that you will have to give up time and energy away from other things to devote it to sex. So a sexual relationship will mean less time for you hobbies and other interests.
7. Sex can lead to children, which means that you will only have a little time to do what you want to, most of your time will be spent on your child.
8. Sex can give you diseases that you could have for the rest of your life and can even shorten your life if you get AIDS.
(Jack, 43, asexual/heterosexual, man)

Regarding Autism and sex, I will say that for a girl or boy , First you have to
be able to TRUST your partner and know what touch you like , Seconds have
sex when you are mateure enough to havesex and when I say MATEURE , I
mean that just because you are 18 + that does NOT mean that you are
READY!
(Laura, 30, heterosexual, woman)

I would say look for a person who values the same things you value. It is
more likely, but it's not certain, that that person is also going to be an Aspie.
But, you know, you're not going to get anywhere unless this is someone who
values the same things you value, and someone who sees things in you that
he values, and you see things in him or her that you value. You g-, you get
that, the rest, you know, there won't be too many obstacles to. The rest you'll
be able to build, if it doesn't come by itself, you know.
Don't go – you know, don't go look out of desperation, you know, if you, you
need someone or you have to have someone, because it's much worse to have
someone with whom you're not a fit than not to have someone. I would – I
would definitely say this: Don't be shy to ask for help. You could do worse
than join organizations that have to do either with being an Aspie – 'cause
you'll meet a lot of other Aspies who may share things that are important to
you – or organizations that share things you value.
Remember, I have heard of, actually, Aspies meeting other Aspies through
the same single book lovers' club, which is on the Net someplace, which is the
route I was going to take, except I was introduced to Rusty when I – right
when I was, uh, starting off with that route. I would say, try to find people
who share interests of yours. Think about what you're interested in, even if
it is an unusual interest, *especially* if it's an unusual interest, and go to a
group that has that as its purpose, and you will likely find other Aspies or at
least other people for whom it is important.
(Hannah, 49, heterosexual, woman)

I wouldn't know where to start; there's so much I think should be taught
about relationships. The volatility, the stability (and why both can exist
simultaneously in a relationship), how a relationship progresses over time,
what is important and what's not, what cues & norms should be followed,
how to date, how one knows when the relationship is exclusive, and more.
Relationships are not consistent, even if they last for decades, which makes
teaching about them incredibly difficult. However, recognizing an abusive
relationship - physical, verbal, or otherwise - is critical, along with how to
extract yourself from one if you are ever in one.
What has worked best for me in my current relationship is being very open
and honest. It isn't always easy, but with time it has made things less
complicated and more easygoing. No one ever advises doing so - but they
always say "just be yourself", which doesn't help much.
(Rick, 26, heterosexual, male)

I: Is there anything in particular that Autistic people should be taught about sex?
P: Yes, they should be taught it. Also, most descriptions of sex are of an emotional wonderful one size fits all experience with sex as penile vaginal heterosexual intercourse to mutual synchronized orgasm. This is silly. With any type of disability as well as for many many people without there are variations to this which are more fulfilling and enjoying. For autistics specifically this model can be overstimulating and a sensory overload. Viewing any other sexual model as inferior and teaching that serves as a deterrent for autistics in exploring alternative models which are more manageable for them.
I: What about relationships?
P: That they exist. That they aren't homogenous. That they aren't inferior if they don't look like in the movies. Basically the same type of stuff that I wish everyone learned about relationships. That finding the right person who fits with you is what is important.
(Gabby, 23, queer, woman)

First, notice that most of this advice would productively serve persons regardless of their neurostatus. Participants' choice of these themes and the communication style in which the advice is delivered (i.e. radical honesty) indicates that these messages were not clear to participants at an earlier point in their lives. I theorize this may be due to a combination of a) inadequate opportunities for socio-sexual learning in general; b) inadequate opportunities to engage in social learning about autistic socio-sexuality in particular; c) internalized ableism leading participants to devalue themselves or assume a greater degree of socio-sexual difference than is present; and d) the intersection of ability and (hetero)sexual normativity, through which many participants are doubly marginalized. The general dissemination of this information and its incorporation into population-targeted sexuality education programming would enhance the sexual citizenship of persons on the autism spectrum.

Second, this advice is notable for what it is lacking. Aside from occasional normalization of asexuality and Gabby's singular acknowledgment of overstimulation, participants did not address autism-specific sensory complications despite their prevalence in participants' personal lives. I think this is because, as M pointed out, most participants do not have access to detailed knowledge about other autistic persons' sex lives; they may be assuming their body-mind predicaments are unique to themselves. This represents a major gap in community knowledge about sexuality that negatively impacts sexual citizenship by limiting opportunity to pursue desired ends and/or articulate alternative normativities.

Participants were also asked what others should know about partnering with an Autistic person. Hank's response to this query covers the major commonalities in participant responses. These are simple practices in which fellow citizens can engage to produce participants' sexual rights. "The importance of planning for alone time, recovery from sensory/social overload, and honoring touch preferences. In terms of communication - direct is best, as is articulating feelings." (Hank, 33, queer, Transgender/genderqueer)

Finally, participants were asked what supports they would like to see available. Many participants noted the absence of adequate, disability-relevant sexuality education. Younger participants specifically advocated for the creation and/or dissemination of knowledge about explicit, disability-friendly, sex-positive websites. They were eager for these to be linked through trusted sources, such as governmental, health, and/or autistic advocacy or service webpages. Billy Joel explains why.

I would say whatever NT people have in terms of supports (access to medicine, clinic, being able to talk to a doctor about questions). Additionally, I would like to see a good, safe, reliable resource online that has information. A lot of questions about sex I feel like you can't google - because googling things about sexuality can bring up unwanted, inappropriate results & potentially get you in trouble.
(Billy Joel, 23, asexual, woman)

Billy Joel's answer also illustrates a common trend in responses, "whatever NT people have in terms of supports". It is important to recognize that participants mean *both*, "we're essentially the same and need essentially the same supports", and also, "current access to these supports is inequitable". Participants were highly aware of the absence of accessible service providers in general and particularly in the realm of sexuality (i.e. sex therapists, gynecologists, etc.). Participants also mentioned public education about ableism and autism, improved public transit infrastructure, and mentorship from older autistic persons as supports that would enhance their capacity to participate equitably in the co-construction of our shared aspiration for human living and its associated distributive arrangements.

Alternative normativities. Finally, participants articulated *alternative normativities*, creating arrangements that better enabled their access to citizenship. *Alternative normativities* refers to the generation of social norms that differ from dominant ones and the discourses, practices, and distributive arrangements associated with them. Alternative normativities represent the capacity of the normative framework of citizenship for accommodating fluidity. Fluidity was demonstrated in participants' understanding and performance of gender, relationships, sensuality, and ability. Sub-themes organized under alternative normativities include: *gender non-conformity*, *alternative relationships*, *alternative*

sensuality, and *neurodiversity*. Unsurprisingly, participants who were non-

heterosexual and/or genderqueer/androgynous discussed all types of *alternative*

normativities more than straight participants who identified on the binary. Older

participants discussed alternative sensuality more than younger participants, but

there was no age trend for alternative gender or relationship norms. Hank summed

up why *alternative normativities* were needed for gender and sexuality.

> I think the hetero/sexism and ableism made it take much longer for me to figure out who I was and what I wanted and needed in sexuality, gender and relationships. The overwhelming societal narrative about what sex, gender and relationships are didn't fit where I was, and it took a long time to realize that and that there were alternatives. The narrative that "you're just like everyone else" I think is harmful when our brains and bodies are not just like everyone else. It increases difficultly in reading other people and decreases our abilities to know and share ourselves. This is true about a lot of aspects of life, but particularly true in sexuality and gender because of the narrow range of experiences that are framed as normal.
> (Hank, 33, queer, Transgender/genderqueer)

Gender non-conformity. Participants' articulation of alternative gender

norms and practices was characterized by the absence of significance attributed to

gender. For some participants, this looked like innocent transgression of gender

norms as a child that later developed into genderqueer identities that were

personally significant. Hank illustrates this unknowing transgression of norms that's

not identified as an aspect of *identity* until many years later. He also enumerates key

connections between ability and gender normativity that were often expressed in

participant accounts.

> I: Do you think there is any connection between being autistic and your experience of gender?
> P: Yes, absolutely.
> I: If so, could you please tell me about that?
> P: I see several routes of connection:

- Being autistic delayed my understanding of gender roles. Growing up in the 1980s, there was a level of flexibility (statements like "girls can do anything boys can," freedom to wear pants, etc). But it wasn't until 7th grade that I understood that while there was emerging greater equality and freedom, it was not expected for girls/women to wear clothing from the boys/men's department, identify with male role models, have men's style haircuts, etc. and that there was a social expectation line which I had very strongly crossed. Further, it wasn't until that time that I realized that I was at times passing as male, other times as female, and often people were confused about my gender.

There was a particular incident. I was at a birthday party in 7th grade with friends from accelerated classes in school, who were generally social-justice minded and friendly toward GLBT people. We were looking through the yearbook. I had gotten a haircut like a popular male TV actor and wore a polo shirt for my picture. They were looking through the yearbook, and made a comment about the "cute new boy" in it – I realized they were looking at my picture. It was more friendly teasing than bullying. It was really the first time that peers (not strangers, bullies or my sister) commented about my gender presentation, and for the first time I began to realize that I was crossing a social line.

- My physical autistic features such as increased muscle tone and ability to gain muscle and discoordination, cognitive traits such as analytical and math skills are both read as masculine.

- Autistic social skills tend toward patterns often identified as masculine, such as straightforward communication.

- I think that the biggest factor is in not overvaluing social norms due to autistic priorities and perceptions around gender identity and expression. (Hank, 33, queer, Transgender/genderqueer)

Two other key connections between (dis)ability and alternative normativities were often discussed by participants, choosing not to be social with persons/in publics that do not support one's non-conformity and the insights of marginality.

P: Um, well I mean it took -- I'm 55 now and I could really just -- I don't really care anymore, you know? [Laughs] You know, I don't, I don't -- you know, I just don't, don't really -- I've always done what I wanted to do and that's how I continue to do.

I: Okay. So when you say you don't care anymore you mean you don't care about gender or you don't care what other people have to say or think about it?

P: I do not care what other people have to say or think about it.

I: Okay. And how old would you say you were when you got to that place where you didn't care anymore what other people had to say about it?

P: Well I never really much thought I was going to change because other people thought I should.
I: Okay, that can take a lot of strength, though, when you are -- you know, having interactions every day with people who do things like try to get you to dress different.
P: Well I don't have interactions with people all the time.
(millie33, 55, lesbian, genderqueer)

I think that being Autistic allows me to be more empathetic (I know, the irony) to others from marginalized and oppressed groups. Since I know what it is like to view things differently and have experiences outside of the norm, it is easier for me to [see] that there are other experiences and that there is a wide range of experiences.
(Gabby, 23, queer, woman)

Though some participants like Hank placed significance on their cis- or

genderqueer identity at the time of the interview, many did not. Or, perhaps more

accurately, did not place significance on it in the way expected under dominant

gender normativity. For some participants this meant that gender, itself, was

insignificant.

The issue of transgendered people came along quite naturally along with all of it, because I personally don't identify as very strongly female; I'm more an androgynous person who doesn't mind female pronouns because I don't care either way. Once I realized that it's entirely possible to have a mind of one gender in a body that looks for all the world like the other gender--well, what's more truly you, your body or your mind? It sure isn't this hunk of meat you use to transport your brain. ...
You indicated on the survey that you identify as an androgynous female. How would you define androgynous female?
Well, I'm physically female--the reproductive equipment, the chromosomes, the hormones. I've got no problem with that. I find boobs annoying, but mostly because they get in the way, not because they're associated with femininity. I have traits socially associated with males as well as traits associated with females.
I'm "female" in a biological sense, and in the way that others tend to relate to me, but I don't see that as a particularly important part of me. It's about as important to me as being blue-eyed, brown-haired, or 5'4"--a superficial, physical thing I wish wouldn't have such a huge effect on how the world sees me. I say "androgynous female" rather than simply "androgynous", because I don't feel uncomfortable in a female body, don't feel any emotional need to present as an androgyne (mostly because erasing all those gender cues

would be a hassle every morning). I don't mind that people call me a girl; I just think it's irrelevant that I happen to be female. My personality is smack-dab in the middle. When I took the MMPI, scale 5 (male/female stereotype) showed that I don't conform to the female gender stereotype. My reaction: "Duh." ...

One thing I'm pretty sure of is that autism affects the extent to which I absorb the cultural expectations around me. Because I don't instinctively pick these things up as quickly or internalize them as thoroughly as the neurotypicals around me, I didn't internalize the cultural expectations about gender, and that means that while I've got no problem with being female, I don't see it as an all-encompassing social role; rather, it's more of a biological fact. I do things that I like because I like them, rather than because they're part of my social role as a female.

(Danielle, 29, asexual, androgynous female)

For most participants, this meant that *social* aspects of gender were insignificant.

Danielle's assertion that she did not care about gender pronouns/labels was not

unique among participants. When asked about their preferred pronouns, two

genderqueer participants responded that they did not care what was used because,

as millie33 said, "I don't pay much attention to that". The understanding of gender

as a biological fact or personal construction rather than a social role was common.

I: What are some things you do that you see as feminine?
P: Because I am female, everything I do is "feminine," by definition, so long as I do what feels natural and organic. This is true regardless of whether it something most other females typically do, or it is something most typically males do.
I: What are some things you do that you see as masculine?
P: I don't believe that anything I do can be seen as "masculine," since I am not male, nor am I striving to be.
(Ayla, 32, asexual/hetero-romantic, woman)

One way participants practiced this alternative gender norm was through

androgynous grooming. Gabby, for example, was quoted earlier discussing her

decision not to wear make-up or shave. She, like many female-identified

participants, also frequently wore clothing marketed to men. These choices were

also related to (dis)ability for many participants because they stemmed from

sensory processing (e.g. comfort over style). Cisgender identity was primarily based

on a lack of conflict with one's body, rather than incorporation of social norms

attached to those bodies into one's sense of self.

> I: You indicated on the survey that you identify as a woman. How would you
> define that?
> P: I chose that identity based on my use of feminine pronouns and the clothes
> I wear. While I am not overly feminine, I still identify as female because I feel
> that my body parts are not in conflict with my mental sense of self. I don't
> match the stereotypes of women who are overly concerned with how they
> look, but I feel like I can be somewhat androgynous yet still female.
> (L.B., 22, heterosexual/sapiosexual, female)

Alternative relationships. Participants also articulated alternative

relationship normativities. Many participants were in relationships with persons

who were not the "opposite" sex/gender. Two of these participants had carefully

crafted marriage ceremonies with their same-sex/gender partners. C.Byrd, who was

in a registered domestic partnership with her partner in a state that did not permit

marriage, explained the significance of this ceremony.

> I: What was the appeal of marriage over simply remaining in a committed
> relationship without the legal/social recognition?
> P: To be recognized as a true committed couple in other people's eyes and
> showing celebrating our commitment to each other.
> I: Would you have proposed marriage if you lived in a state that did not offer
> any legal recognition for your relationship? If so, why? If not, why not?
> P: Yes, i would. The legal part of marriage (although having its important
> parts) is not the reason why I married her. I have always loved the idea of
> marriage and the symbology of union of two people. We got our domestic
> partnership and wrote every word and action in our marriage ceremony. It
> was something that her and I wanted to share together in the experience of.
> (C.Byrd, 29, lesbian, woman)

Hank also cited the social recognition of his relationship as more important than

legal recognition.

> I: I understand that you don't have the option of state-recognized
> partnership. Would you choose state-recognized partnership if it was
> available to you? Why or why not?
> P: Probably. We did live in a state for a year when it was legal to marry, but
> the hoopla at the officials offices and frankly being too busy with work
> resulted in not getting to it before it was no longer an option. We can and
> intend to register as domestic partners in our locality. We've also considered
> going to a nearby state (where I have pastor friends) to access a legal
> marriage -- again, daily life and work have not left much time for this. In all,
> we've been considered married by our communities for many years, and
> although the legal benefits are important, aren't a day-to-day focus.
> (Hank, 33, queer, Transgender/genderqueer)

These excerpts demonstrate the importance of legal consciousness to participants'

social membership and exercise of rights. It also demonstrates the importance of

alternative publics, or groups of people among whom the articulation of new

normativities becomes possible as a shared project. Without a group to recognize

their relationships as "true committed" couples, Hank and C.Byrd would not have

been enabled to practice this alternative normativity.

While Hank and C.Byrd sought to modify (hetero)sexual normativity by

stretching it to include committed, monogamous same-sex/gender couples, other

participants posed more radical alternatives. As with *gender non-conformity*,

alternative relationships were often articulated around the perceived arbitrariness

of dominant norms governing relationship structure.

> I: How do you define "romantic relationship"?
> P: People that love each other. Can not define love though. Do not know what
> exactly love is, but is not there in just friendships. People have all sorts of
> crazy rules about that though. So silly. Makes not much sense. Like my
> definition much better than the others have heard.
> (Dragonfly, 30, asexual/pansexual/polyamorous, odd)

The two most often articulated *alternative relationships* were consensual non-

monogamy and asexuality. We have already read about Sandy's poly relationship

and L.B.'s suggestion of an open relationship to a desired relationship partner. An

openness to openness was common.

> Let's just say that I have always told him – one of the things I asked him, and I won't say before we married, but actually very, very early in our marriage is, if you ever decide that someone else is it for you or if you ever decide to get into these swinger things, these – people were beginning to use the word 'polyamory' – I'm not going to say no; I'm not gonna say yes. I'm going to say, the minute you have any notion like that, talk to me and we'll see what's gonna happen. We'll see – we'll see what can be done.
> (Hannah, 49, heterosexual, woman)

> Sandy advocated polyamory as a relationship style that may better suit Aspie

sensibilities.

> I love [husband], [partner], my daughter and my dog very intensely, I'm very attached to them, they understand me and give me the space I need. I find that poly families are much better at this than monogamous families, I think there would be far fewer lonely Aspies in the world if more Aspies understood that that about polyamory. When I say poly families, I'm speaking of love that is outside of a sexual relationship and who we are as a family, as opposed poly relationships,   I think of us as being a tribe or a pack.
> (Sandy, 46, bisexual/polyamorous, genderqueer)

Indeed love that is outside of a sexual relationship did suit the sensibilities of many

participants.

> I define a romantic relationship as one wherein all participants like each other, and want to be close to each other quite often, whether physically or emotionally. A romantic relationship doesn't need to be a sexual relationship.
> (Elle, 18, asexual/bisexual, woman)

> I: I'm hearing that you would like more emotional intimacy with your husband. Does the sex you have now contribute to emotional intimacy?
> P: i think my husband thinks it contributes to emtional intimacy but i dont' think it affects it
> I: Why not?
> P: i feel like my husband and i could be more emotionally attuned without always referring to sex
> I: uh huh. How would you like to build emotional intimacy?
> P: i would like to spend quality time with him without distractions such as tv blasting or the computer on...maybe just go for a hike together or go out for a nice dinner ...

> I: If you could choose between [husband] being happy in your relationship
> without sex and you liking sex, which would you choose?
> P: [Husband] being happy in our relationship without sex
> (R.B., 29, heterosexual, woman)

The idea of a "tribe or pack" advocated by Sandy also aligned with Billy Joel's hope for a dorm-style living arrangement for adults and Danielle's thoughts on social support and parenting.

> I worry that I wouldn't be a good parent. I worry that I wouldn't be able to relate to an extroverted neurotypical child well enough to teach them what they needed to know about the world. I know I'm responsible enough to take care of children, but I'm not sure I would be able to take care of them alone. I believe children need at least two reliable adults they can trust. (This doesn't mean I think only married people should be parents, though; I think single parents need social support--a friend of the family, a grandparent, that kind of thing. For that matter, a married couple needs social support too, but there are two of them already and that makes a world of difference.) I'm not going to have children of my own--I don't see the point of having children if I'd have to go for artificial insemination or something like that, when there are so many children who need homes and don't have them, especially older children and children with disabilities, and children in the foster care system. If I ever find that I have enough resources, financially and psychologically, to share with a child, I'll probably go for it. But I want to either be married or have a strong social network that the child can depend on--and right now I have neither of those.
> (Danielle, 29, asexual, androgynous female)

Participants thus articulated alternative arrangements for the distribution of resources that do not rely on the *primacy of monogamous sexual relationships*.

   Alternative sensuality. The alternative normativity of committed asexual relationships is closely related to the *alternative sensuality* experienced by many participants. In *physical intimacy* I presented data on how many participants preferred physical intimacy to sexual intimacy. *Alternative sensuality* was also demonstrated in participants' demisexuality, or their propensity to be aroused only by persons whom they knew.

I have begun to identify as both asexual and bisexual, because sexuality is a ridiculously complicated issue, and labels make things easier, for better or worse. I identify as asexual because I don't actively care about sex, and don't look at anyone of any gender and say, "Oh, wow, they're attractive," if I don't know them. I am so, so much less sexual than others my age, who often seem to place sex as a Prime Concern in their lives. And there are so many other things I want to do with mine. ...

I do, however, identify as bisexual as well, because I do occasionally want sex, and so far, the people to whom I've been attracted have been either women or men. Sometimes I feel as though this is supporting the gender binary, but I don't know personally any genderqueer people, so I don't know how I would respond to them sexually.

These identities do overlap, I think, because sex is so not a thing in my life, that if I ever found someone with whom I wanted to have it, it wouldn't matter whether they were a man or a woman.

(Elle, 18, asexual/bisexual, woman)

Demisexuality is one aspect of a cognitive orientation to sensuality demonstrated by some participants. By a cognitive sensuality, I mean that participants described deriving deep pleasure, often with an embodied dimension, from cognition-led experiences. This is not unusual, cognitive sensuality drives the production of erotica and many other typical sexual practices and products. How participants described their experience of cognitive sensuality *was* particular, as in the case of Jack, whose arguably "sexual" energy was experienced as a drive to create art rather than have sex.

P: Creativity is a wonderful and terrible thing to have. I think it's possible that I took my sex drive and forced it into the engine room of my Art to power my art. That all my passion goes into my creativity. ...

When I do my art, there is no "Jack", I'm just a conduit for pure energy... ...

I: I hear how passionate you are about your art, and I wonder, have you ever felt as intensely passionate about another person as you do about your art?

P: Only the girl that I date for 2 or 3 weeks, []. I felt such raw passion for her. ...

I: What drives you to create?

P: Beauty. When I look at beautiful girls, my brain comes alive and ideas start flowing (not about the girls, other ideas) And music can also fuel my creativity.

(Jack, 43, asexual/heterosexual, man)

The "energy" that Jack describes was mentioned by several participants, including

Vivian and C.Byrd.

> P: Communication has always been very difficult for me. I didn't start speaking until I was four years old. Even after that, as far as verbal communication was concerned, it was very difficult for me to relate to people growing up.
> I found that music became my authentic voice. Performing through the piano was my way of being able to express and articulate my emotions at its most accurate format to an audience. I started writing my own music and improvising as well, and that's my main thing now in regards to music. I have a Steinway in our home, so whenever the time allows, I love to kinda get lost in piano playing sessions, to me it's a form of meditation. ...
> I also believe being autistic affects the manner in which I see and hear the world around me. This affects the music I compose and perform. This affects the energy involved in my music and in my art. ...
> I: When you say that type of energy you feel, can you, um, explain that to me a bit more?
> P: Yeah. So, when I perform on the piano or sing, I don't feel like it's coming from me. There's some sort of creative energy or force that's connecting through me. Being autistic, I have a tendency to "lose myself" in that energy. I don't say that as a negative way. I focus on the details of things rather than the whole picture. When I concentrate on something detailed or small, I get into a trance. I believe that has allowed the opportunity for whatever this creative force or thing is to kind of flow through me when I perform music.
> (Vivian, 31, heterosexual/bicurious, woman)

> I: How has being autistic affected your experiences?
> P: It has made my personal life very colorful, vibrant and spiritual. I can feel the world around me pulsing with energy, alive and without boundary. I think in pictures, therefore my thoughts are vivid and precise.
> (C.Byrd, 29, lesbian, woman)

Another *alternative sensuality* discussed by participants was BDSM.

> My personal kinks/fetishes were pretty vanilla before I met my girlfriend, to be honest. They included stockings/hose, high heels, pigtails/braided pigtails, light role playing, and lots of oral sex. Now those have expanded to include some bondage & light BDSM; she likes to be tied up, and exploring that with her has been exciting and interesting. I'd like her to try out being the dominant one in bed sometime, and so does she; however, she does enjoy being the submissive one a lot. We'll see if I enjoy being dominated by her - I'm certainly willing to try it
> (Rick, 26, heterosexual, male)

Hank pointed out that there is an affinity between (dis)abled sexuality and BDSM even without engagement in "kinks/fetishes".

> In some ways, I consider all sex in my body as BDSM, in that it always involves difficult sensations and doesn't end in release. We've tried many different specific practices, but adding more elements is usually more overwhelming. I do use some sensory and position modification as a way to maintain position and deal with muscle difficulties, but it is very important to me to not feel trapped or restrained in any way, which increases anxiety so much to not be able to enter into it at all.
> I do some mild BDSM play with my partner when it's his turn - paddling, giving directions. I am not comfortable with not responding to "no," because my brain is very literal about language. And I do not enjoy trying the same practices myself.
> (Hank, 33, queer, Transgender/genderqueer)

These *alternative sensualities* were key to some participants' exercise of the *right to pleasure* and their facilitation of this right for others.

Sandy, who spoke previously to involvement with poly and BDSM communities, also spoke to the importance of these alternative communities for validating one's experiences when they were not intelligible under (hetero)sexual normativity. This function of alternative publics came up during her discussion of buying and using a strap-on for the first time.

> I was initially ambivalent about it. We went to the store to look, and I didn't like the way most of them looked. He showed one that was realistic-looking and I had to have it. Something lit up inside of me. Went home, put it on, walked around, and I felt different. I had no words then to describe what I was feeling. It started a hunger inside me that I didn't know I'd had. The first time I used it, it was [him] giving me fellatio. I had an orgasm from that that was different from any other orgasm I'd ever had. It was more than sexual, it was a shamanic experience, it was transformation. It was so powerful and so intense, I wound up throwing up. I had clarity, I saw for the first time, that there was a part of me that I'd never noticed, and that part had suddenly been given a voice. Over the next few weeks, I processed all this. I questioned my sanity, I questioned my reality. I was very relieved to read about others online who had had similar experiences. [My partner] was

extremely supportive. I was questioning everything I had believed about gender and I was redefining who I was. It's still a work in progress.
(Sandy, 46, bisexual/polyamorous, genderqueer)

Neurodiversity. Alternatives to the normativity of ability did not come up as

frequently as those for gender, relationships, and sensuality. This was most likely

due to the focus of the interview. However, we have seen some discussion of

alternatives to ability in the data already presented. For example, Danielle's excerpt

in *Autistic identity* on understanding her autism as a description of how her healthy

mind is structured. It was also evident in M's response to how changed

understanding of ability as a normativity affected how she felt about her own

(dis)abilities.

> I: How has this change in understanding affected how you feel about your disabilities?
> P: I find the disabilities themselves much less distressing, because most of the time I am able to talk myself out of thinking of them as defects (personality flaws, failures of character or willpower, etc.) and recognize them as a natural part of human diversity. I feel pride in my autistic identity, which comes from my extensive involvement with the autistic self advocacy and neurodiversity movements. I identify with autistics (and people with disabilities in general) as "my people," in the same way I sometimes identify with Jews or union organizers or political activists as a group.
> On the other hand, my hyper-awareness of systemic ableism tends to tie up a lot of brain-space with negative feelings about how I am perceived and treated because of my disabilities. Some of this is pretty subtle -- things I might not have even noticed in the past. Other power disparities have been there all my life, but before I understood ableism I may have previously attributed them to other "-isms," or I may have simply internalized/individualized the situation and not understood it as a part of a larger system.
> (M, 39, heterosexual, woman)

Conclusion

A deductive, latent thematic analysis of the data driven by the

conceptualization of sexual citizenship theory developed in Chapter 2 yielded

numerous, cross-cutting themes and sub-themes. I chose to organize data themes under the umbrellas of *discipline-subjectification* and *empower-fluidity* to identify those things that were experienced as limitations on equitable participation in the co-construction of our shared aspiration for human living and its associated distributive arrangements versus those that were not. Figure 1 illustrates how these two domains of experience overlap in the production of sexual citizenship. The figure also shows how social membership and its associated rights and responsibilities were produced through the entwined normativities of ability and (hetero)sexuality.

Themes organized under the umbrella of discipline-subjectification included *structural ableism, cultural ableism, heteronormativity,* and *primacy of monogamous sexual relationships*. Themes organized under the umbrella of empower-fluidity include *sexual economy, normalization, right to pleasure, proactive strategies, Autistic identity*, and *alternative normativities*. These themes interacted with each other in a number of ways, illustrated in Figure 1. They also interacted with the themes presented in Chapter 4, as discussed throughout this analysis.

Themes organized under the umbrella of discipline-subjectification illustrated how participants' access to both the literal bedroom and the figurative public square was dependent on a stretching or shrinking of their non-conforming characteristics. They were subject to the discipline of the Procrustean bed, a bed in which they were compelled to lie and in which they sometimes willingly climbed. Participants were lopped and stretched to force their differences of ability, gender, and sexuality fit the abled, (hetero)sexual bed of citizenship. At the same time, the

normativities of ability and (hetero)sexuality were sometimes used by participants

to achieve desired ends or were resisted.

The dual role of normativities was most evident with (hetero)sexuality. The

sub-themes of (hetero)sexual normativity were not exclusively organized under

either discipline-subjectification or empower-fluidity. Though the primacy of

monogamous sexual relationships was experienced as primarily disciplining and

subjectifying, the sexual economy of (hetero)sexual normativity was experienced as

both disciplining and empowering, offering a particular way for pursuing desired

ends. The normalization of (hetero)sexual normativity was experienced as

empowering by participants who could access it, offering persons chronically on the

margin a way of affirming their membership and participating in the hegemonic.

Participation in the hegemonic was one way participants experienced sexual

pleasure, which they understood as a right, or resource of membership. Another

resource of membership was social support. Social support facilitated participants'

pursuit of desired ends and articulation of new normativities. Intimate relationships

and the Autistic community were key sources of social support. Accessing the

discourse of the Autistic community facilitated participants' development of an

Autistic identity, which was associated with enhanced self-esteem and the

development of a more effective repertoire of strategies for pursuing desired ends

in the context of the personal and structural factors producing (dis)ability.

Participants reported a variety of proactive strategies for managing the difficulties

sometimes associated with having an Autistic body-mind and/or their social

positioning as a disabled person. Finally, participants worked to produce alternative

normativities that better facilitated their access to sexual citizenship, including

neurodiversity, gender non-conformity, alternative relationships, and alternative

sensuality.

CHAPTER SIX

Discussion

Sex as Social Communication

> Contact of all kinds is a form of communication. Sex can be thought of as a
> form of communication, too, though one that also has the purpose of
> reproduction.
> (Danielle, 29, asexual, androgynous female)

Several participants observed that the physical act of sex is social, or, as

Danielle put it, a form of communication. The analyses presented here suggest that

sex is communicative in at least two ways. First, it involves communication between

one's body and mind. Second, it involves communication (both verbal and contact)

between one's body-mind and (an)other(s). Participants experienced difficulties

with both aspects of sexual communication. They also experienced equilibrium and

satisfaction from these communications. Finally, the physical act of sex is oft

conflated culturally, and in participant accounts, with emotional intimacy,

desirability, or love. Participants spoke to how these things were both necessary

and simultaneously constructed as "impossible" for them as asocial "aliens" or

"androids".

Following these reflections, I suggest that sexuality may be central to the

predicaments of autism. Claiming sexuality as a source of intimacy, pleasure, and

choice is a way of pushing back against diagnostic criteria that problematize social

deviance as a diminished form of humanity. Sexuality was a critical site for

participants to access normalization and through it social membership. A central

question is whether the importance of sexuality for accessing normalization and

membership is generalizable to other denizens of the U.S., or whether sexuality is of particular importance to accessing social membership for this population because of how it speaks directly to the grounds on which they are denied full membership.

Building Knowledge on Sexual Experiences & Identities

The current study was the first to assess the sexual and romantic relationship histories of adults on the autism spectrum using in-depth interviews. As discussed in the Method, these findings describe the experiences of this sample of older, community-living adults. This description provides a foundation of understanding about the intimate experiences and identities of persons socially located as autistic, enabling the subsequent construction of comprehension of how these states of affairs come to be.

The current findings affirm previous research indicating that adults on the spectrum experience marital satisfaction (Lau & Peterson, 2011) and display typical romantic functioning (Stokes et al., 2007) once they get into a relationship, but have difficulty locating partners (Byers et al., 2013a, 2013b). As Byers et al. suggest, difficulty locating partners is a partial explanation for the finding that autistic adults who are not currently partnered exhibit atypically low levels of dyadic sexuality (2013b) that are not commensurate with the levels of dyadic sexuality exhibited by partnered autistic adults (2013a). However, the current study suggests that lower levels of dyadic sexuality among single autistic adults is also partially due to the higher levels of a- and demisexuality in this population, as well as sensory complications associated with ASD and physiological complications of co-occurring conditions that make partnered sex less desirable for some autistic adults. It is also

decidedly less "casual" since satisfactory partnered sex in the context of sensory and physiological complications requires a higher degree of negotiation and patient exploration than typically occurs in the context of casual sex.

Importantly, lower levels of dyadic sexuality among those who practice solo sexuality is not necessarily a sign of reduced sexual functioning or a direct result of difficulty locating partners. Participants in the current study reported that solo sexuality is useful for the regulation of general sensory and affective needs; some asexual participants did not even understand the physiological experiences of arousal and genital stimulation as "sexual" *per se*. They were also satisfied with the absence of dyadic sex. The current findings also contextualize autistic adults' increased difficulty locating partners, demonstrating that this difficulty is due to a variety of factors, including: inaccessible socio-sexual spaces, limited economic and transportation opportunities that further reduce and limit autistic ctiziens' control over socio-sexual opportunities, the small pool of potential partners available to citizens who experience intersecting marginalities, and inadequate sexuality education that fails, for example, to teach courtship skills. Together, these show how ability "introduces a structure of probabilities for sexual partnership, right of sexual choice, and the establishment of sexual status" (Green, 2008, p. 34).

Thus, current findings also concord with previous research indicating that while autistic adults have a typical (or, for many participants in this study, high) level of formal sexual knowledge (Gilmour et al., 2012; Stokes & Kaur, 2005; Stokes et al., 2007), they also demonstrate lower levels of knowledge about and performance of normative courtship behaviours (Sperry & Mesibov, 2005; Stokes et

al., 2007). Data from the current study help explain why. First, basic formal sexual knowledge (e.g. biology of reproduction) was explicitly taught in school for most participants. In addition, formal sexual knowledge is easily accessible through additional media such as books and websites. Participants indicated that they conducted research to fill any gaps in their formal sexual knowledge. However, courtship norms, and other *social* aspects of sexuality, were not explicitly taught in school, nor explicitly taught through available media. Participants required explicit communication and practice of socio-sexual norms due to their radical honesty communication style. Explicit and verbose communication is how they learn social information.

It is worthy of note that difficulties performing normative courtship behaviours are tied to radical honesty in two ways. First, through the need for such norms to be taught in a way that meets autistic persons' communication needs. Second, normative courtship behaviours rely heavily on indirect and non-verbal communication, superficial sociality (e.g. small talk), and "white lies", or falsities that are considered part of politesse. These aspects of (hetero)sexual normativity are in direct conflict with radical honesty. Finally, participants experienced a high degree of social ostracism during their adolescence, limiting their access to opportunities for social learning. Participants who developed later-in-life friendships were frequently able to use these relationships to gain explicit instruction in courtship and other socio-sexual norms, subsequent to which they were more successful in performing them.

This delayed access to peer-based socio-sexual learning points to another important finding of this study, adolescents and young adults on the spectrum are not unusual if they lack relationship and/or sexual experience. However, lack of experience does not necessarily indicate asexuality or life-long celibacy. Quarter-life onset of sexuality and romantic relationships should, perhaps, be viewed as typical for this population. While nearly all participants in this study were sexually experienced by their mid-thirties, participants consistently identified social pressures to demonstrate socio-sexuality, and even sexuality education, during adolescence as out of step with their personal development. Sex is social; it is communicative. It is itself and results from a complex chain of communications between body and mind and body-minds. Participants were often busy mastering more basic social communication and sensory regulation skills during adolescence and young adulthood. Mastery of the skill sets necessary to make friends and be successful in other domains of normative functioning, such as education and self care, enabled access to the relationships in which socio-sexual learning became possible and improved performance of normative desirability.

The importance of sensory regulation to sexuality for autistic adults is a critical contribution of this research. Sensory differences, conceptualized as maladaptive responses rather than atypical experiences, have only recently been included as a feature of Autism Spectrum Disorder as a psychiatric diagnosis. However, differences in sensory processing are widely acknowledged as an important aspect of the condition by persons on the spectrum and those who know them well (e.g. families). The current research indicates that while social

communication differences are important to sexuality and general life chances, sensory differences are also critical. In the context of intimate relationships and sexuality, sensory differences were implicated in reduced control over access to public and private socio-sexual spaces; use of masturbation, physical intimacy, and orgasm to manage general sensory and affective needs (providing evidence to substantiate Siebers' (2008) call for sexual needs/desires to be understood as healthcare); difficulty managing the body-mind experience of dyadic sex; difficulty achieving sexual climax; sexual pain and/or dysfunction; and increased likelihood of performing androgyny by female-identified participants, thereby diminishing their performance of heteronormative desirability.

Unfortunately, this research also suggests that the implications of sensory differences for sexuality and intimate relationships are not being adequately acknowledged or addressed. Previous sex research with this population has not addressed these experiences. Participants also did not indicate knowledge that their personal experiences with sensory difficulties were a shared or common experience produced through (dis)ability. Participants acknowledged *personal* connections between sensory experiences and being autistic, however, they did not generalize these connections to the community at large the way they did with social communication differences and vulnerability to abuse-exploitation. In other words, connections between sensory ability and sexual citizenship were not policiticized in participant accounts, nor have the barriers they present to full sexual citizenship been addressed.

Previous research with larger samples found that sexual problems among community-living adults on the autism spectrum were infrequent (Byers et al., 2013a, 2013b). Six of the 24 participants in this study reported sexual pain or dysfunction, with more reporting limitations on their sexual functioning such as overstimulation and undersensitization. It is possible that individuals experiencing sexual difficulties were more interested in participating in the current research on sexual experiences than those who were not experiencing difficulties. However, it is unclear why such motivation would have a differential impact on who chooses to participate in qualitative versus quantitative online sex research. With the male-identified participants in the current study, in particular, it is possible that their difficulties with premature ejaculation and erectile dysfunction are better attributed to the aging process and/or the psychosexual effects of unique relationship circumstances (e.g. first-ever relationship with a female after years of solo sexuality that involved regular use of a silicone appliance that could cause penile desensitization). However, the current research suggests that because difficulty accessing and regulating sensations is a common feature of autism, as is increased muscle tonicity (relevant to increased vaginal muscle tension and associated dyspareunia), anxiety, and unique relationship circumstances, it is possible that sexual difficulties (which persons may or may not define as *problems*) are more common in this population. In addition, the physiological effects of the aging process may affect autistic adults more profoundly due to their neurological differences. Further research is needed.

Further research is also needed on sexual and gender identity formation in this population. The findings of this research support previous work indicating atypical rates of non-heterosexuality (Byers et al., 2013a, 2013b; Gilmour et al., 2012) and gender non-conformity (e.g. Bejerot, Eriksson, Bonde, Carlström, Humble, & Eriksson 2012; Ingudomnukul, Baron-Cohen, Wheelwright, & Knickmeyer 2007; de Vries, Noens, Cohen-Kettenis, van Berckelaer-Onnes, & Doreleijers 2010) among autistic individuals. The most prominent line of work in this area has sought to explain gender differences through foetal hormone exposure (e.g. Ingudomnukul et al., 2007). The current findings suggest that social and behavioral explanations must be considered as well. Participants in this research reported that understanding of gender as a social role was often significantly delayed, meaning that it was not salient during the identity-formative years of childhood or early adolescence. For some participants, gender as a social role was ultimately unimportant to their sense of self. Participants' sense of personal gender more often related to the presence or absence of body dysphoria, rather than attachment to or performance of gendered preferences, interaction styles, or social roles. They also indicated that choices around gendered aspects of self-presentation were made for sensory reasons. These sensory based choices did not affect how they understood their own gender identity, but they did affect how others perceived them, thus creating social effects. Body-mind experiences also appear to be linked to higher rates of non-heterosexuality through asexuality and cognitive sensuality (e.g. mental connection with a potential partner carrying greater significance for arousal than embodied characteristics such as genitals).

Participants' unwillingness or inability to meet demands for the performance of normative gendered desirability worked to limit their pool of potential intimate partners in useful ways, if they had enough confidence in their self-value to keep looking until they found the "right fit". This is no small feat when the daily effects of ability and heteronormativity re-affirm your devalued and marginalized status. Partners who treated participants well and accommodated their needs were associated with positive experiences and relationship satisfaction. In the current study, these partners were most often from the disability community. It is possible that the disability community represents a sexual field in which participants' neurodivergent erotic capital enables access to higher tiers of desirability. Receptivity to relationships and/or sexual interactions due to a desire to be "normal" or found desirable (i.e. valuable) by another was associated with low relationship satisfaction and negative sexual and relationship experiences. In some cases these included abuse and/or exploitation. This dynamic illustrates one way struggle to access abled, (hetero)sexual citizenship had negative effects on participants' intimate lives and well-being.

There is little research on the prevalence of sexual and/or intimate partner violence experienced by persons with cognitive disabilities, let alone ASD. The current research suggests these may be common experiences, particularly for older persons. Experiences of abuse and exploitation were conflated for some participants with betrayed expectations. Both types of experiences left participants feeling vulnerable. These personal experiences were not typically articulated by participants as a product of (dis)ability, i.e. a condition produced through the

interaction of personal and structural factors, but were instead understood as a personal idiosyncrasy or a reflection of the vulnerability inherent in cognitive impairments. The current study cannot speak to whether there is an increased likelihood of experiencing abuse or exploitation for persons on the autism spectrum in comparison with the general population. However, data on the context of participants' experiences and their socio-legal positioning suggest that whatever "vulnerability" autistic persons experience is largely attributable to marginalization created through the entwined normativities of ability and (hetero)sexuality. It should further be understood as a structural challenge to (dis)abled citizens' right to bodily autonomy.

Understanding How Experiences Are Shaped by Normativities

Participants' experiences were heavily shaped by the normativities of ability and (hetero)sexuality. An examination of their operation helps us understand how participants' experiences came to be and how these experiences demonstrate their socio-legal status. Participants experienced structural ableism in many ways. Their access to material wealth and the goods it buys were limited by restrictions on their economic opportunities. The material strain caused by this structural inequity had a number of effects, including inequitable access to health care and intimate relationships. These effects illustrate how ability structures access to citizenship through the capitalist economy, as well as state laws and policies. Participants also experienced structural ableism in the realm of laws and policies, experiencing inequitable access to additional goods of citizenship, such as the justice system. This violates their 14th Amendment right to equal protection under the law. Ableist laws

and policies also interfered with participants' fundamental rights (i.e. rights subsequent to constitutional rights to privacy and autonomy) to marry and procreate, have custody of their children, and refuse medical treatment. These effects illustrate how ability and abled heteronormativity structure access to citizenship through state intervention in, or failure to support equitable access to, the pursuit of desired ends. Structural ableism was further evident in participants' receipt of inadequate and disability-irrelevant sexuality education, as well as the dearth of competent and respectful service providers.

Structural ableism existed in a reciprocal relationship with cultural ableism, representing its uptake and reproduction through institutions, making ability and its deleterious effects on sexual citizenship more intransigent. The arguable base of cultural and structural ableism was NT privilege, or the privileging of neurotypical body-mind experiences and priorities. NT privilege was often experienced by participants as misunderstanding, inaccurate assumptions, paternalism, and being treated as if one's needs were exceptional demands. These manifestations of privilege contributed to participants' experience of out-grouping, as did experiences of harassment and social ostracism.

The manifestation of cultural ableism in the sex-ability discourse demonstrated the profound links between ability and (hetero)sexual normativity, as well as their role in constructing dominant understandings of meaningful participation in the human community and structuring one's opportunities to so participate (i.e. citizenship). The sex-ability discourse was characterized by perceptions that sexuality was inappropriate for persons with cognitive

(dis)abilities, that cognitively (dis)abled persons are inherently vulnerable to abuse-exploitation, and that these citizens are undesirable for and/or incapable of partnering and/or parenting. This discourse, evident in participants' experiences with those whom they live alongside, exists in reciprocal relationship with state regulation of access to sexual activity, marriage, and parenthood for persons with cognitive disabilities through both laws and policies (Carey, 2009).

Heteronormativity also restricted participants' access to sexual citizenship in key ways observable through the discipline-subjectification of traditional gender roles and LGBTQ discrimination. Participant experiences in these areas demonstrate further breaches of their right to equal protection under the law. The higher than typical rates of sexual and gender non-conformity expressed by participants in the current sample are produced, at least in part, through their atypical neurology and the social effects of an ableist society. In other words, their gender-sexual non-conformity is produced in much the same way as (dis)ability, through an interaction between personal and structural factors. Participants' experience of heteronormativity as a limitation on citizenship is, therefore, deeply abled, as is the primacy of monogamous sexual relationships in social organization. Participants' asexuality and singlehood are also partially produced through their atypical neurology and the social effects of an ableist society. The primacy of the monogamous sexual relationship in structuring the distribution of goods functions to bolster the out-grouping of persons who are not in those relationships by rendering their needs "exceptional". A shift in economic distribution to support the creation of asexual collectives or "adult dorms" may effectively re-"privatize"

(dis)abled/asexual citizens' needs by placing them in relationships of mutual care with those whom they live alongside. The primacy of these relationships as *the* mode of valuable adult living also marks single adults as "damaged" or "not quite whole" persons. This perception leads to enhanced scrutiny that can further enhance limitations on sexual citizenship for (dis)abled persons as their disabilities become visibilized as a ground for devaluation and discrimination.

Access to monogamous sexual relationships is key to accessing full sexual citizenship in a society structured by these relationships. Participants sometimes paid for access to these relationships and the material, emotional, social, and practical resources they offer with sex that they did not otherwise desire or enjoy. Sometimes this included unwanted pain and/or degradation. At the same time, experiences of (hetero)sexual normalization gave sexual participants a sense of membership in the human community and a way to display that membership to others, shoring up demands for the rights associated with community membership and assertions of value to the community (i.e. capacity to dispatch responsibilities of membership). It was also a profoundly meaningful way of demonstrating to themselves that they were *persons* of value.

Sexual participants' deep-seated conflation of sexuality with humanity was consonant with their articulation of a right to pleasure. This right was often accessed through participation in the normativities of ability and (hetero)sexuality that in other ways confined and constrained their lives. Participants' articulation of this right is also an assertion of what it means to lead a good human life and their entitlement to participate in that vision; it is a citizenship practice. In addition to

pleasurable participation in the hegemonic, participants, particularly LGBTQ

participants, enacted their right to pleasure at least in part through alternative

sensuality, gender, relationship, and ability normativities. Whether participants

sought to enact their rights through dominant or alternative normativities, social

support was key. Social support, both within and outside the framework of intimate

relationships, was also key to identity formation, respectful inclusion in the

community, and access to other goods of citizenship. It is a key resource for sexual

citizenship.

One avenue for the development of social support was participation in the

neurodiversity movement and/or Autistic communities. Though these spaces

formally welcome self-identified autistic persons, psychiatric diagnosis with an ASD

was typically requisite for gaining meaningful access (as discussed in *Autistic*

identity). Psychiatric diagnosis also provided access to treatment options and

supports that facilitated participants' sexual citizenship. It should be noted,

however, that access to supports that facilitate inclusion and pursuit of desired ends

is only dependent on psychiatric diagnosis as long as these supports are dependent

on government enforcement rather than community members' willing alteration or

application of rules for relating to one another. In addition, adoption of an Autistic

identity and accessing the associated public, i.e. the community and its associated

media products (Warner, 2002), was a transformative experience for participants,

leading to new ways of understanding their biographies and structuring their lives

(including their relationships) going forward. One aspect of this transformation was

enhanced self-esteem and respect, which positively impacted their sexual and

intimate lives. Another aspect was the articulation of proactive strategies for managing the difficulties sometimes associated with having an autistic body-mind and/or social positioning as a disabled person. Participants' use of proactive strategies represents labour to contribute and produce within the current disadvantaging framework and as such should be understood as an example of fulfilling citizenship responsibilities. The proactive strategies that participants used and suggested for others indicate the importance of accessible, disability-relevant sexuality education and socio-sexual support for their exercise of sexual citizenship.

Finally, the data provided evidence that sexual citizenship as a framework for emancipatory social change can accommodate some fluidity. With citizenship conceptualized as a framework for articulating the conditions that enable people to participate equitably in the co-construction of our shared aspiration for human living and its associated distributive arrangements, the articulation of alternative normativities can be understood as citizenship practice. It is both a right and a responsibility of citizenship. Shotwell (2012) argues that to dismantle oppressive norms, we must be in the process of assembling new ones. This process must be communal, or happening in a public. Abandoning attempts to develop a shared aspiration for human living in a bid to avoid closing down any of the endless potentialities for a good human life only leaves one "out of the game" so to speak, as people are left without the ground for political action (Shotwell, 2012).

Participants in the current study were actively involved in assembling new norms, new visions for valuable modes of human existence. The new normativities that participants were articulating in conjunction with their communities were

those that better facilitate their well-being, pursuit of desired ends, and equitable participation in public life. In addition, the alternative normativities articulated by participants could provide ground for broad-based coalition building, rather than pursuing change based on Autistic identity alone. Asexual collectives and polyamorous families as alternative relationship arrangements (including legal mechanisms for establishing privileged access to resources and decision-making outside the bonds of marriage or other "kinship" relationships), for example, might also appeal broadly to those who are consensually non-monogamous and/or LGBTQ, asexuals, singles (perhaps particularly single parents), widow(er)s, and those with (dis)abilities. Understanding social change, and citizenship, this way, I believe that the citizenship framework can organize social change efforts that answer the call of critical disability scholars, queer studies scholars, and other radical visionaries for the removal of impediments to the "evolution of equitable conditions of possibility" (Shildrick, 2009, p. 2) and provision of "access to a newly imagined and newly configured public sphere where full participation is not contingent on an able body" (McRuer, 2002, p. 96). It does so, however, incrementally through the development of alternative normativities and publics.

With the foregoing discussion in mind, I can now answer the three questions that guided this examination of sexual citizenship on the autism spectrum, though these answers are restricted to persons with legal membership. As discussed in the *Limitations*, the participants in the current study all had legal membership and few experienced legal barriers to citizenship. The most salient ways the state restricted citizenship for participants were through restrictions on same-sex marriage, lack of

adequate anti-discrimination laws or social provisioning, and its participation in the production of legality surrounding sexual consent, marriage, and parenting. How are social and legal membership dependent on sexuality? First, sexuality is a marker of personhood, or as participants (and the WHO definition of sexuality given in Chapter 2) articulated it, humanity. Assessments of personhood (traditionally based on demonstration of the ability to autonomously pursue one's rational self-interest) are the basis of rights extension in the U.S. and other liberal democracies. Second, sexuality is a hub of material distribution. Third, sexuality is a hub of social (emotional & practical) support for adults. In other words, sexuality marks one as a moral equal and enhances access to resources that enable one to maintain their standing in the community. The social membership and resources (i.e. social rights) enabled by sexuality subsequently facilitate one's exercise of civil and political rights.

How is sexuality dependent on social and legal membership? One's opportunities to be sexual depend on access to public space, as well as material and social resources. From a cultural standpoint, full social membership also entails value to the characteristics of one's social group (e.g. Autistic "traits", identities, and/or labels) that contributes to one's erotic capital. Opportunities to be sexual also depend on the legal consciousness of fellow citizens regarding one's right to sexual consent. Finally, one's opportunities to be sexual depend on legal enfranchisement (e.g. legal rights to privacy and bodily autonomy).

What sexualities and intimacies are made possible (and what are not) for persons socially located as "autistic" in U.S. society? Participation in (hetero)sexual

normativity was possible for participants in this study who benefited from the freedoms and opportunities associated with living in the community and, for many, the ability to "pass" as typically abled in general society. However, access to this sexuality and intimacy was inequitable in comparison with the neurotypical majority. Participants faced personal and structural obstacles to participating in desired relationships and experiencing sexual satisfaction that were tied to their disability status and/or disabled characteristics. The relative possibility of participation in (hetero)sexual normativity was stratified by intersecting social characteristics, most strikingly by age and perceived ability. Participants perceived to be incapable of autonomous self care, whether permanently or for a particular time period, experienced profound legal, structural, and social barriers to participation in any type of sexuality or intimacy. Participants who experienced intersecting marginalities also faced higher barriers to the construction of a desired intimate and sexual life. The intimacy of asexual adult living is particularly difficult to achieve under current arrangements giving primacy to monogamous sexual relationships. Polyamory is a precarious sexuality and intimacy as well, as is same-sex couplehood, although to a lesser degree. Finally, the intimacy of being known as oneself was more difficult to achieve for participants with alternative gender and sexual identities.

Implications of Ability for Sexuality-Citizenship

One contribution of the current research was an expansion of the embrace of empirical sexual citizenship projects to include persons with cognitive (dis)abilities. The two foregoing sections illustrate the utility of this concept for describing and

explaining the conditions of existence for the sexual citizenship of persons on the autism spectrum. To make this empirical contribution, the dominant structural and legal focus of sexual citizenship work was integrated with other strains of citizenship theory emerging from feminist and queer scholars (Carey, 2009; Correa, et al., 2008; Lister, 2003, 2007; Seidman, 2001), as well as those examining the shifting nature of citizenship under contemporary conditions of globalization (Benhabib, 2007; Krause, 2008; Maher, 2002; Sassen, 2005). These works turn our focus to the relations in place through which the effects of structural and legal forces are manifest, as well as the active way people negotiate the workings of power in institutions (Moon, 2008). As discussed above, one important aspect of these processes for participants in this project was their use, disregard for, and development of alternatives to dominant normativities. This observation was enabled by the emphasis of the synthetic understanding of sexual citizenship developed here on the normativity of citizenship, including normativities other than heteronormativity. These two theoretical maneuvers, emphasis on normativities and relations in place, are interrelated and directly tied to the empirical project.

Feminist citizenship theorists have long emphasized the importance of relationships of mutual care for citizenship (see Lister, 2003 and 2007), as well as the relational and context-dependent nature of rights. These insights are particularly germane to the project of understanding citizenship for persons with cognitive (dis)abilities, given that limitations on autonomy are salient for this population and that these very limitations serve as rationale for marginalized citizenship status through the normativity of ability (Carey, 2009). Focusing on

normativity enabled adequate integration of ability as a normative axis of social

stratification, both in its own right and in its entwinement with (hetero)sexuality.

The focus on normativities also enabled the perception of sexuality as a normative

axis of social stratification, both in its own right and in its entwinement with

heterosexual culture. Sexuality and heterosexuality, as normativities shaping

citizenship, are not indistinguishable. This is particularly evident when examining

the lives of asexual persons, as was necessary in this project due to the production

of asexuality through the internal and structural factors of (dis)ability in the lives of

participants. A second contribution of this research, therefore, is the development of

the sexual citizenship framework to improve its utility in explaining the experiences,

identities, and life chances of a social group differentiated by ability.

Sexual participants in this study shared in the collective aspiration of U.S.

society that human living include sexual pleasure and intimate sexual relationships.

This is an important aspect of the conduct of a valued life for most. However, for

asexual participants, a valued life does not require sexual pleasure or sexual

relationships, but does include emotionally intimate relationships and some degree

of physical intimacy. The shared understanding of a good life therefore includes

emotional intimacy and the use of the body to communicate that intimacy. If this is

our shared aspiration for human living, then the question becomes what rights and

responsibilities of membership enable this condition for those whom we live

alongside.

Shuttleworth's (2007) call to focus on "the construction of

access/obstruction to the sociocultural contexts in which desire is evoked and

sexual negotiations become possible" (p. 174) points to important rights and responsibilities for fellow citizens on the autism spectrum. The obstructions to access enumerated by Shuttleworth (2007) were affirmed in the current study. In addition, persons on the spectrum experience obstruction of their access to socio-sexuality via inaccessible public spaces designated for courtship; inaccessible transportation limiting control of when, how, and with whom to be sexual and/or intimate; limited economic opportunities; and the dominance of abled (hetero)sexual normativity, which includes particular gender embodiment norms, preference for sexually monogamous mixed-sex couples, and demands for a high level of (often oblique) communication (both social and sexual). These obstructions are not relevant only to those on the spectrum, but limit sexual expression and citizenship for persons with a range of (dis)abilities. The Internet and an Autistic identity were important avenues of access to the "sociocultural contexts in which desire is evoked" for participants in this study, with Autistic communities representing an alternative sexual field where their characteristics were more highly valued.

Not all citizens experience desire, however. The body-mind experiences of participants in this study place into question the equation of arousal and genital stimulation with "sexuality" as it is culturally understood. The pervasive and sometimes exclusive use of genital stimulation to serve physiological rather than sexual purposes pushes us to ask: what makes a sensation or behaviour "sexual"? An examination of ability's role in constructing sexual citizenship indicates that the dominant understanding of sexual desire and "sexual" stimulation is an abled one

produced through particular rather than universal neurology. It also indicates that

consensual and even desired "sexual" behaviours are not sensed or experienced as

universally pleasurable and can, in fact, be painful and unsettling. The performance

of sexuality and our understandings of it are abled.

The abled performance of sexuality was key to accessing full sexual

citizenship through (monogamous) sexual relationships. Access to these

relationships was also regulated, to a lesser degree, by the abled production of

gendered desirability through the performance of normative gender. Participants'

(dis)ability characteristics were often read as gender transgressive. This finding

points to how ability participates in the construction of gendered sexuality. Of

arguably greater significance is the finding that participants did not place a typical

level of importance on gender as a social role or, in many cases, as an aspect of

personal identity. This finding indicates that dominant understandings of gender

identity development and the importance of gender to self-understanding and socio-

sexual organization may be produced through ability as well.

As illustrated by the foregoing analyses and discussion, sexual normativity is

about the performance of the human. It is a demonstration of social membership

and the potential for social contribution (i.e. citizenship responsibilities). At the

same time, access to sexuality and intimate relationships, as rules for relating

among members, are rights of membership. Citizenship is en-abled by sexuality.

Ability facilitates access to sexuality and citizenship, both separately and in their

entwined aspect. The abled relationship between sexuality and citizenship points to

broader questions about the role of sexual relationships in social organization. What

else is normalized by sexual relationships and their halo effect? In other words,

what behaviours/characteristics among the sexually partnered are or would be

considered aberrant or irresponsible if they occurred among asexual and/or

unpartnered persons?

Sexual normativity as the performance of the human (i.e. a demonstration of

personhood) that acts as a basis for social inclusion and resource distribution also

has implications for how we understand the motivation for and right to sexuality for

other social groups. In particular, I think of other groups that are sexually

disenfranchised, such as youth. Youth are also civically disenfranchised, pointing yet

again to the connection between sexuality and community status. This connection is

also on display among the most privileged groups in society, such as cisgendered

(white) men, whose rights of sexual access and pleasure were at one time as

uncontested as their exclusive endowment with legal citizenship status and its

entailed rights and resources. It is also illuminating when considering the

positioning of social groups that retain the legal right to sexuality (unlike youth and

many persons with cognitive disabilities) but are discouraged from exercising it,

such as the poor. They too are discouraged from participation in the electoral

process and face a host of other structural and cultural inequities. There is a

fundamental connection between social status, sexuality, and the perception of

ability. The cultural intertwinement of these aspects of citizenship is taken up in

formal and informal institutions such that they become structural barriers to

equitable participation in public life.

Finally, this study demonstrated that ability has implications for our understanding of the relationship between sexuality and citizenship in the context of privatizing need within the "family". As we become adults, and especially as our parents age and die, the "family" context for the "responsible" fulfillment of needs is a (monogamous) sexual relationship. Access to these relationships is abled-sexualized. This arrangement renders (dis)abled/asexual[24] citizens as abnormal both culturally and economically. They cannot responsibly meet their needs in the framework of the private "family" and therefore become objects of care from the state and "goodnatured" fellow citizens. Becoming an object of care renders one subject to increased surveillance and regulation. The privatization of need within monogamous sexual family life therefore works to marginalize and disenfranchise those of atypical sexuality-ability. This discussion of the implications of ability for the relationship between sexuality and citizenship demonstrates that for autistic difference, or neurodiversity, to be seen as a valid possibility for the conduct of life, the primacy of monogamous sexual relationships in socio-economic organization will need to be challenged.

Concluding Comments

   Limitations. The scope of this study of sexual citizenship on the autism spectrum was restricted to persons residing in the U.S. who had private access to the Internet, were in some way involved with Autistic Internet communities and/or

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   [24] I conscientiously use a slash rather than hash here. It is not my intention to reproduce the oppressive desexualization of disabled people by conflating these two categories. For participants in the current study, however, these two identities are produced through the same embodied experiences. The structural barriers to sexual (dis)abled persons developing satisfying sexual relationships also place these two social groups in common cause on this issue.

the neurodiversity movement, and had moderate literacy levels. Individuals who chose to participate were all living in the community with legal citizenship status at the time of the research. When this research began, I anticipated that a greater proportion of participants would live in more highly supervised and regulated settings, such as supported living environments and parents' homes. I also anticipated greater reliance on formal supports, such as Social Security Income/ Social Security Disability Insurance or state-regulated services. Participants' relative independence from formal supports and supervised environments meant that a more nuanced analysis of the impacts of these settings and state relations on sexual citizenship was not possible. I have pointed to participant experiences that shed some light on these processes throughout the analysis.

In addition, most participants were diagnosed with an ASD in adulthood, had some post-secondary professional training or education, and identified as white. The findings of this research should be understood within this scope. Though it is difficult to predict how these characteristics shaped the findings of the current research, aside from the relative eloquence and independence already discussed, it is quite possible that younger generations of individuals on the spectrum, for whom diagnosis was culturally and medically available from a young age, would have experiences more heavily shaped by early childhood interventions, on-going services, and a radically different cultural milieu surrounding autism, including the existence of a positive Autistic identity and associated community. Some findings from the current research support this speculation, such as higher degrees of family

support among younger participants. It will be important in future research to attend to such potential cohort differences.

Despite these limitations, the current research nonetheless made several contributions to the scholarly literature. In addition, the findings presented here suggest important directions for future research and have implications for public policy and service provision. I will conclude by highlighting these.

Contributions.

Methodological. This research integrated data from three different formats of Internet mediated in-depth interviews: video-cam/streaming audio, chat (e.g. instant messenger), and e-mail. The selection and variety of interview formats was critical to facilitating the participation of a population of participants defined by social communication differences. Previous research on this population has most frequently been conducted through secondary informants, such as parents and caregivers, on the grounds that direct assessment would be too difficult. One contribution of this research, therefore, is demonstration that assessment of the experiences of persons with communication differences can be done directly when appropriate accommodations are made. This has scientific merit, in that it enables the production of knowledge from primary rather than secondary sources. This distinction, always important, is particularly salient when assessing "private" experiences such as sexuality and intimate life on which secondary sources are less likely to be competent to report. The collection of primary data is also meritorious from a social justice perspective. It facilitates inclusion in public life. In particular, it includes the voices of a marginalized social group in knowledge produced about

them. The discussion of the benefits and challenges of the primary format of Internet mediated interview, e-mail, extends this methodological contribution by detailing the ins and outs, as well as pros and cons, of this method of data generation. This discussion will be useful to researchers interested in a variety of populations.

Theoretical. An additional contribution of the current research was its expansion of the embrace of empirical sexual citizenship projects to include persons with cognitive (dis)abilities. To make this empirical contribution, the dominant structural and legal focus of sexual citizenship work was integrated with other strains of citizenship theory emerging from feminist and queer scholars, as well as those examining the shifting nature of citizenship under contemporary conditions of globalization. This synthetic understanding takes sexual citizenship as a framework for articulating the conditions that enable equitable participation in a public struggling to realize shared aspirations for human living. These aspirations importantly include aspirations for intimate life. This conceptualization of citizenship is explicitly normative and firmly grounded in lived experiences and the concrete social locations where they occur. As such, the conceptualization developed here emphasizes the relational nature of citizenship. Another contribution of this research, therefore, is the development of the sexual citizenship framework to improve its utility in explaining the experiences, identities, and life chances of a social group for whom ability is a central axis of social stratification. Finally, these theoretical developments enable me to further scholarship on sexual citizenship and (dis)abled sexuality by demonstrating how ability inflects our

understandings of intimacy and sexuality and how these entwined normativities shape the social and legal membership of people with (dis)abilities, i.e. persons with a range of abilities.

Empirical. The current study is the largest to examine the relationship experiences of adults on the autism spectrum based on first-hand, qualitative data. It is also the only study to examine sexual experiences in this manner. This study makes a unique contribution to our knowledge about the sexual and relationship experiences of this population, adding depth and perspective by documenting these experiences through in-depth interviews with individuals on the spectrum. This contribution lays a critical foundation for our understanding of autistic persons' sexual citizenship, as we must have a base of understanding about experiences before seeking to explain the conditions of their existence. It also enables the contribution of a variety of policy and programming applications for this research.

Implications for service provision and public policy. Participants in the current study consistently indicated that they did not have a base of knowledge about autistic sexuality and do not have frank discussions about sexuality with their Autistic community contacts. There is a need for autism service agencies and organizations within the neurodiversity movement to explicitly address sexuality and intimate relationships for persons on the spectrum. In addition to asserting this population's right to be sexual and providing disability-relevant sexuality information and/or resources, agencies and organizations should address self-esteem in the context of dating and mating. The current research suggests that there may be a profitable link between the esteem generated by an Autistic identity and

determination to find a partner whom one values and who demonstrates that they value you in return.

One of the resources that should be linked through autism agencies and organizations is a disability-friendly, sex-positive, sexuality education website (such as www.scarleteen.com). In addition, funding for and provision of evidence-based, population-targeted sexuality education is needed for autistic persons. These programs should be tailored to adolescents, young adults, and adults respectively, given findings that socio-sexual development continues into the third decade of life for some persons on the spectrum and that different age cohorts deal with different issues specific to their stage in the life cycle.

As a matter of public policy, care facilities, service agencies, and other institutions that house and/or provide services for persons with disabilities should be required to have a sexuality policy on file to receive federal/state funding or approval. These policies should support chosen sexuality (e.g. provision of privacy and sexuality education), with any potential restrictions carefully justified and their application in specific cases documented. There is also need for improved structural supports for child rearing, such as state-provided quality child care and/or respite care services for parents with (dis)abilities, and transportation, such as improved infrastructure and/or stipends. The current research also suggests the need for investment in communal adult living arrangements, such as supported apartment housing. Importantly, the goal of such housing is not to supervise or care for the adults living there, but to provide an economically and socially viable alternative to monogamous sexual relationships. Policy guidelines should reflect this. Finally,

inequitable access to the justice system needs to be addressed through mechanisms such as streamlining the process for reporting crimes and providing advocates for (dis)abled persons who are involved in legal proceedings.

Directions for future research. Rich and detailed discussion of autistic participants' sexual and relationship histories revealed many gaps in our knowledge about this population. No known research addresses the sexual-sensory experiences of autistic individuals. We need to know more about these experiences and strategies used to manage them, as well as research into new effective supports and strategies for their management. This gap in knowledge is related to our ignorance about autistic individuals' experiences seeking sexual health care and barriers to accessing sexual health care. Access to competent gynecological health care and treatment for sexual pain and dysfunction were areas of particular concern for the participants in the current study.

Further investigation into autistic persons' experiences with the legal system, and family law in particular, is warranted. Experiences with family law are one potential aspect of parenting experiences for autistic persons about which we have a dearth of knowledge. Five of the 24 adults in this study were parenting, four of whom were parenting children who were also on the spectrum. Scholarly information about these experiences is absent.

Though it was not designed to assess these experiences, data from this study also indicate that sexual and intimate partner violence may be common experiences for persons on the spectrum. However, conclusions cannot be drawn due to the sampling method and size. Future research is needed that addresses the prevalence

of sexual and intimate partner violence in this population (as well as the broader

cognitively (dis)abled populace to which it belongs) and how these experiences may

be different for, or have different effects on, (dis)abled persons. A focus on the

creation of vulnerability to intimate violence through structural inequities rather

than essential characteristics is suggested by the findings of the current research.

Finally, further research on sexuality and citizenship in the lives of autistic adults is

needed with persons living in more highly supervised and regulated environments,

such as the home of a natal family member (e.g. parents, siblings) or care facility.

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APPENDIX

Appendix A

Demographic Survey

Sexual Citizenship on the Autism Spectrum

This brief survey is for primary autistic participants who would like to be in this study. If you have been referred to this study by a romantic partner or someone with whom you have a supportive relationship (whether or not you are autistic yourself), please exit this survey by closing the browser window or tab. The study webpage has a separate link for secondary participants, or those who have been referred by a primary participant in their role as romantic partner or support person. Thank you.

1.   How did you find out about the study? (name of website)

_____

2.   Did someone refer you to this study?

Yes   No

a.   If YES, what is the *first name or screen name* of the person who referred you?

_____

Referrals for Follow-up Interviews

For this study, you are being asked to refer a romantic partner for me to interview later on. In this context, romantic partner refers to someone with whom you currently have an intimate relationship and/or an on-going sexual relationship. The purpose of this follow-up interview is to learn your partner's perspectives and experiences on the topics of sexuality and autism and to better understand

important social relationships in your life. If you do not have a romantic partner

right now, or if you don't want to refer me to someone, you may leave this question

blank.

3.   What is the *first name only* of the romantic partner you will be referring for a

follow-up interview?

_____

You are also being asked to refer a support person for me to interview later on. In

this context, a support person refers to someone with whom you have an on-going

relationship that involves them providing you with some type of support on a

regular basis, such as social or emotional support, financial support, or support with

the tasks of daily living. Examples of support people include siblings, parents,

friends, and paid workers. The purpose of this follow-up interview is to learn your

support person's perspectives and experiences on the topics of sexuality and autism

and to better understand important social relationships in your life. If you do not

have any support people in your life right now, you may refer someone who has

been a support person in the past; or you may leave this question blank.

4.   What is the *first name only* of the support person you will be referring for a

follow-up interview?

_____

Demographic Information

5.   How old are you (in years)?

_____

6.   How many years of school have you completed?

_____

7.   What's your highest degree?

I don't have any degrees.

GED

High school diploma

Associate's degree

Bachelor's degree

Master's degree

Doctoral degree

Other _____

8.   What are your race and/or ethnicity? (Black, White, Latina/o, etc.)

_____

9.   What is your gender? (woman, transgender, man, genderqueer, etc.)

_____

10.   What is your sexual orientation? (Check all that apply.)

Asexual

Gay

Bisexual

Heterosexual/straight

Lesbian

Queer

Polyamorous

Other _____

11.   What state do you live in?

_____

12.   Who do you live with? (Check all that apply.)

No one, I live alone.

Romantic partner(s)

Roommate(s)

Parent(s)

Children

Group home/supported living shared with a few others

Other_____

13.   What type of work do you do?

Student

Unpaid housework/child care

Paid housework/child care

Hourly wage job

Salaried professional job

Sheltered workshop

Job training

Volunteer for non-profit organization

Other _____

14.   What is your approximate *personal* yearly income?

This should include any government benefits you may receive, but not financial

support from family or friends.

0-15,000

15,001-30,000

30,001-45,000

45,001-60,000

60,001-75,000

75,001-90,000

90,001-100,000

100,001 or more

Prefer not to answer

15.   What's your relationship status? (Check all that apply.)

Single

Dating

Living with romantic partner(s)

In serious romantic relationship(s), not living together

Married

Divorced

Separated

Widowed

Other _____

16.   Do you have any children?

Yes   No

a.   If yes, what are their ages? (in years)

_____

Disability and Identity

17.   Do you have an official/medical diagnosis on the autism spectrum?

Yes

No

Don't know

a.   If yes, at what age did you first get diagnosed?

_____

If yes, what is your medical diagnosis?

_____

If no, at what age did you first self-identify as someone on the spectrum?

_____

18.   How would you like me to refer to your disability identity? (autistic person,

aspie, autie, person with autism, on the spectrum, etc.)

I will refer to your disability identity this way in our future interactions. I will also

use this identity in any reports that are generated from this study.

_____

19.   Do you have any other disabilities?

Yes   No

a.   If yes, what are they?

_____

20.   Reports created from this study will not use participants' real names.

Pseudonyms (nicknames) will be used to protect people's privacy.

What pseudonym would you like to be called by in reports created from this study?

_____

21.   I will be contacting you via email to schedule our interview. Please provide

an email address at which you feel comfortable discussing personal matters.

Please provide an address at which I may contact you.

_____

Appendix B

Interview Guide

Interview Key

    This email interview format of the primary informant interview guide indicates the questions that will be sent to participants who select the email format and the sections or chunks in which questions will be sent. Please see the full interview guide for potential follow-up questions. As with synchronous questioning, questions will be deleted if they have already been answered or obviated. Follow-up questions regarding a section will be sent prior to sending the next standardized section of primary questions.

Hello,

Thank you for taking the time to talk with me. I appreciate it.

I want to learn about the role of sex and relationships in the lives of autistic people. I also want to understand how sexuality is related to being a respected member of our communities. A goal of this study is to find ways to help people have satisfying personal lives and be respected in the community.

I'm going to ask you some questions and take a few notes as you talk with me. This conversation will be recorded. Your answers are confidential. Reports created from this study will use your chosen nickname. If I ask a question that you're uncomfortable answering, you can say, skip it or ask me later. We can end our conversation at any time.

I'm going to be sending you sets of questions. Some sets contain a lot of questions, and others only a few. Please record your responses in-line with (i.e. right after) each question so I can keep straight which question you're answering. When you're finished with a set of questions, please Respond to my email rather than sending me your answers in a new email. I will keep our whole email conversation together as one long email chain. That way, we can both refer back to things we have said in the past.

Please feel free to ask me questions at any time. Please let me know if I send too many questions at once or ask questions in a way that is difficult to understand.

Do you have any questions before we get started?

[answer questions] *Let's get started...*

Let's start by telling me about yourself so I can get to know you...

Section 1

What do you like to do for fun when you're alone?
What do you like to do for fun when you're with other people?
Are you involved in any structured activities such as a class, recreational group, training program, etc?
You found me on X, what other websites do you visit frequently?

Section 2
In your daily life, how do you feel being Autistic affects you positively? (sensory, processing, treatment by others)
What about negatively? (sensory, processing, treatment by others)
Do you have a case worker or social worker?
How do you support yourself?
Do you get any help? (SSI or SSDI, family, partner)
Do you think financial constraints inhibit your sexual freedom?
What supports or help do you have for schooling/work? (job coach, classroom accommodations)
How do you get around, from home to school/work for example? (use the bus, have some one to take you places, or anything like that)
Has there ever been a time when you felt that limited transportation options resulted in you missing out on a sexual or relationship opportunity? If so, could you please describe that for me?
Do you get any help at home? (financial management, cooking, other ADLs)

Section 3
   Thank you. I'd like to switch topics now. I want to talk about how you learned about sex and relationships.
How do you define "romantic relationship"?
What about "sex"?
Do you remember when your parents first talked to you about sex?
What did they tell you?
Is there some other way they taught you about sex?
How did you feel about that at the time?
How do you feel about that now as an adult?
Could you please tell me about the sex ed you got in school?
How did you feel about that at the time?
How do you feel about that now as an adult?
What kind of an experience was that? (good, bad, confusing)
What are some other ways that you learned about sex? (friend, tv, books)
Are there things you wish you had learned that you didn't?
Did you try to get more information?
If so, how?
Is there something that you wish had been done differently? (learn sooner, different way)
Based on your own experiences and stories that you've heard from other Aspies, is there anything that Autistic people should be taught about sex?
What about relationships?

Section 4
How do you define "gender"?
You indicated on the survey that you identify as X. How would you define X?
Have you ever identified differently? If so, can you tell me more about that? (why different, how things have changed)
Do people read your gender the way you want them to?
What are some things you do that you see as feminine?
What are some things you do that you see as masculine?
(If they don't do typical feminization, ask about why – sensory, time, irrelevant?)
Do you think there is any connection between being autistic and your experience of gender? If so, could you please tell me about that?

Section 5a/6a
(ordering of sections, sex to relationships or relationships to sex, will be determined on a case-by-case basis)
Now I'd like to talk a bit about your sexual history.
Have you had sex?
Have you wanted to have sex?
Why?/Why not?
Could you please tell me about the last time you had sex and what that experience was like for you?
What it with a casual or committed partner?
How long had you known this person?
How did you meet?
Were you able to use a condom or birth control if you wanted to?
Did you end up doing anything you didn't really want to?
Was there something you wanted that you didn't get?
How satisfied were you?

Section 5b
Could you please tell me about the last time you had sex with a casual/committed (whatever not discussed above) partner and what that experience was like for you?
How long had you known this person?
How did you meet?
Were you able to use a condom or birth control if you wanted to?
Did you end up doing anything you didn't really want to?
Was there something you wanted that you didn't get?
How satisfied were you?

Section 5c
Tell me about the first time you had sex and what that experience was like for you.
Have you been sexual or intimate with only men, only women, or both?
Do you prefer one to the other?
Are there certain qualities a person should have to be allowed to have sex? (age, ability to consent)

What kind of things do you do to feel sexy?

What sexy or intimate things have you done with your current/most recent partner? (hold hands, kiss, touch each other, sex)

Section 5d

How do you define sexual arousal?

What do you do when you're aroused and don't have a partner available?

How often do you feel aroused?

Would you like to feel aroused more often? Less often?

How often do you desire sex or intimate touch?

Would you like to feel that way more often? Less often?

Is there anything about your sex life you have had trouble with or see as a problem? (impotence, unable to find partners, trouble maintaining relationships, difficulty orgasming)

Thinking about your most recent/current relationship, how *sexually* satisfied are/were you in the relationship?

What are the things you like about it?

What are the things you would change?

Have you ever been in a sexually satisfying relationship?

When?

What was happening that made you satisfied?

What are you looking for in order to be satisfied?

Now I'd like to know how satisfied you are with your *personal* sex life. By your personal sex life, I mean your sense of your own sexuality and your sexual activity whether you are with a partner or not; it could include things like intimacy and masturbation. Thinking about your *personal* sex life, how sexually satisfied have you been in the last month?

What are the things you like about it?

What are the things you would change?

Has there been time in your life when you were more sexually satisfied?

When?

What was happening that made you satisfied?

What are you looking for in order to be satisfied?

Section 5e

What barriers have you experienced to being sexual with a partner?

What about barriers to being sexual with yourself?

What about barriers to sexual satisfaction?

How have you overcome X (indicated barriers)?

Who do you go to, to talk about sex?

Can you talk to them about concerns or questions you might have?

Section 6a/5a

Now I'd like to talk about romantic relationships you've had.

Have you had a romantic relationship?

Have you wanted a romantic relationship?

Why?/Why not?

Could you please tell me about your relationship with X (current/most recent romantic relationship) and what that experience was like for you?
How long have you been together?
How did you meet?
How did the relationship end?
How satisfied are/were you overall with the relationship?
What are the things you like about it?
What are the things you didn't like about it?
Have you ever been in a satisfying relationship?
What are you looking for?

Section 6b
Tell me about your first romantic relationship and what that experience was like for you.
How did you meet?
How long were you together?
How did the relationship end?
How many romantic relationships have you had?
Any long-term or serious relationships?
What made the relationship serious to you?
How long was your longest relationship?

Section 6c
Have you ever considered getting married?
What about raising kids?
Are there certain qualities a person should have to be allowed to get married? (age, ability to consent)
Are there certain qualities a person should have to be allowed to raise children?
What barriers have you experienced to having a relationship?
What about getting married?
Raising children?
How have you overcome X (indicated barriers)?
Who do you talk to about your relationships?
Can you talk to them about concerns or questions you might have?

INFORM PT THAT WE ARE NEARING THE END OF THE INTERVIEW

Section 7
   We have talked about your relationships and sex life. We have also talked about your satisfaction with these things.
How has being autistic affected your experiences? (service or benefit regulations impeding sex/dating/marriage, relationship 'bargaining power' or sexual marketability, etc.)
Can you give me an example of a relationship event that you identify as impacted by your autism?

Can you give me an example of a relationship event that you identify as impacted by ableism (social expectations that everyone 'function' a certain way and negative judgments against those who do not conform)?

How do relationships make it easier for you to move through the world as an Autistic person?

How does being autistic influence what you do in relationships?

How does being autistic influence your sexuality?

What does being autistic bring to sex and relationships?

What are the benefits of being autistic for sex and relationships?

What are the challenges of being autistic for sex and relationships?

How has being treated as an "autistic person" affected this part of your life?

Section 8

Do you think relationships in which someone is autistic are different from NT relationships?

Do you think sexuality is different for someone whose autistic than it is for someone whose NT?

What should others (autistic or NT) be taught about having a relationship with an autistic person?

What supports could help you have a good sex life, in the past or currently? (i.e. What would you like to see available?)

What about supports for good romantic relationships?

How would you like to see this research used?

Is there anything specific you would want me to do or create with what I learn here?

Is there anything I haven't asked about that you think is important to understanding your experience of gender, sexuality, and relationships?

Section 9

You found out about this study through X.

•   How many people do you know through this website/organization? (communicate with personally, have ongoing conversation)

I would appreciate it if you would tell other people you know through X about this study. I am looking for more people to talk to. Feel free to pass along my email and the study web address.

Email interview Thank you/Resources post-interview email

Thank you so much for your time and willingness to talk with me about these things. I enjoyed our conversation and learned a lot. I have attached a Resource List for your information. It lists resources that you or others may find helpful in regard to sexuality and relationships on the spectrum.

As I mentioned in my last email, you will be receiving an email from me to forward on to [follow up referrals]. You will also be receiving your Amazon gift card via email. I will send those emails tonight. I would appreciate it if you would forward the study information to [follow up referrals] as soon as possible.

I would also appreciate it if you would tell other people you know through [recruitment site] about this study. I am looking for more people to talk to. Feel free to pass along my email and the study web address.

After I have had time to transcribe and review our interview, I will send you the transcript. That will be your opportunity to add, clarify, or change anything from our interview so that your meaning is clearer or so you are more comfortable with the final text. When the study is completely finished, I will post a brief synopsis of the results and any plans for a community product on the study website. I will email you this information as well.

Please let me know if you have any questions or concerns. Thank you again for your participation.

Appendix C

CONSENT TO PARTICIPATE IN RESEARCH

Sexual Citizenship on the Autism Spectrum (Primary participant)

You are asked to participate in a research study conducted by Jessica Penwell Barnett, MA, from the Department of Sociology, Anthropology, & Criminology at the University of Windsor. The results of this research will contribute to the completion of my doctoral work.

If you have any questions or concerns about the research, please feel free to contact Jessica Penwell Barnett at 519-253-3000 ext. 3978 (barnettj@uwindsor.ca) or Eleanor Maticka-Tyndale, the Faculty Supervisor, at 519-253-3000 ext. 2034 (maticka@uwindsor.ca).

PURPOSE OF THE STUDY
This study has three primary goals.
1) Describe the sexual experiences and identities of people on the autism spectrum.
2) Demonstrate how commonalities among sexual experiences and identities are shaped by social and legal context.
3) Contribute to conversations about relationships between sexuality, ability, and being a respected member of one's community.

PROCEDURES

If you volunteer to participate in this study, you will be asked to:

1) Complete a brief online questionnaire regarding basic information about your life. This questionnaire should take about 5-10 minutes.

As part of this questionnaire, you will be asked to identify a romantic partner with whom I have your permission to seek an interview. You will also be asked to identify a support person (parent, sibling, friend, paid worker, etc.) with whom I have your permission to seek an interview. Your referrals must be at least 18 years of age to participate in this study. If you do not have a romantic partner or support person, or if you don't want to refer me to someone, you may leave this part of the questionnaire blank. Finally, you will be asked to provide an email address for further contact. I will use this email address to contact you about all future study-related matters. For example, I will email you to schedule our interview. Please provide an email address where you feel comfortable discussing personal matters.

2) Participate in an online interview.

In this interview I will ask you about your social life, supports you may receive, your sex education, your romantic and sexual life, and your views about autism and sexuality. You may select one of three online interview formats: audio streaming via Skype, instant messenging via an instant messenger network (Yahoo, GTalk, Skype, Facebook, MSN, Jabber, AIM/ICQ, Steam, VKontakte, Hyves, or Myspace), or email. The length of the interview will vary widely depending on your personal story and the interview format chosen. Audio streaming interviews will be audio-recorded for later transcription. Instant messenger and email interviews will be exported and saved as a text file. If you do not respond to my initial invitation to schedule an interview, you will receive up to three (3) weekly email reminders.

3) Forward an invitation to participate in this study to the romantic partner and/or support person whom you have designated.

I will NOT contact your romantic partner or support person directly. I will ask you to forward an email to them inviting them to participate in this study. Since one goal of this study is to demonstrate how experiences are shaped by social and legal context, it is very important that relevant members of your social network are included in this research. You will receive one (1) email reminder about this matter if your romantic partner and/or support person has not contacted me within one week of their initial invitation to participate.

4) Review our interview transcript.

I will email you a copy of our interview transcript once it has been produced. This will be your opportunity to make any clarifications, additions, or redactions to our discussion. I will ask you to affirm that the interview transcript represents the information you would like to share as part of this research process. If you do not respond, you will receive up to two (2) weekly email reminders. If you have not responded after the second reminder, I will proceed with the original interview transcript.

POTENTIAL RISKS AND DISCOMFORTS

This research is not expected to present a risk of loss of personal privacy any greater than that which is encountered in everyday life when sending and/or receiving information over the Internet. All reasonable efforts have been undertaken to minimize any potential risks but you should know that any form of communication over the Internet carries a minimal risk of loss of confidentiality. Due to the personal nature of the topics covered in the interview, you may experience both positive and negative feelings. Sometimes these topics may bring up emotions about upsetting experiences you have had in the past. If, after completing the interview, you want to talk to someone about the issues, you may locate a counselor in your area by searching for one on www.autismsource.org You may also contact the Rape, Abuse, & Incest National Network at 1-800-656-4673 or www.rainn.org for assistance.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

This research is not expected to benefit you directly. This research will contribute the opinions and perspectives of people on the autism spectrum to ongoing academic and activist conversations about Autism Spectrum Condition/Disorder and sexuality, sexual rights, and disability rights. This contribution will benefit science by adding to the body of sexualities research literature that is inclusive of the voices of people on the spectrum. This contribution may also benefit activists and advocates in their social justice efforts. The results of this research will be made available to you and the autistic/autism community on the study website [give address].

COMPENSATION FOR PARTICIPATION

If you choose to participate in this study, you will receive a $25 gift card to Amazon.com. I will email you this gift card after the completion of our online interview. If you decide to terminate our interview early, you will still be compensated. If you complete the brief online questionnaire, but do not participate in the interview, you will not be compensated.

CONFIDENTIALITY

Email communications about this study will not identify the subject of the study in the email subject line. They will simply refer to a "Research Study".

Any information that is obtained in connection with this study that can be identified with you will remain confidential and will be disclosed only with your permission. The researcher will conduct interviews from a private location with Internet access. All data pertaining to the study, including survey responses, contact information, and interview transcripts, will be stored on a password-protected computer or encrypted server. All reports generated from this study will use your chosen nickname and will not identify you personally or include any identifying information. All identifying information will be redacted from interview transcripts. When this study is over, files containing your identifying information will be destroyed. Data that is only identifiable by nickname will be retained. Study data may be used in future studies.

Participants who choose audio streaming via Skype for their interview will be audio recorded. These recordings will be stored on a password-protected computer or encrypted server until the end of the study. At that time they will be destroyed. Audio recordings may be transmitted to a professional transcription

company. This company and its employees are bound by a confidentiality agreement. The transcription company will not store audio files.

PARTICIPATION AND WITHDRAWAL

You may choose whether or not to answer any question asked of you as part of either the brief survey or interview. You have the right to withdraw from this study at any time. If you choose to withdraw after completing the brief online questionnaire, you will not be compensated. If you choose to end our interview early and do not complete the interview, you will still be compensated. The investigator may withdraw you from this research if circumstances arise which warrant doing so. Your data will remain in the study even if you choose to withdraw. You will have the opportunity to review and modify the interview transcript following completion of the interview. If you do not respond to this opportunity, or withdraw from the study prematurely, your data will remain in the study unaltered.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

A summary of the findings from this study will be posted on the study website LINK and emailed to all participants. It is expected that study results will be available by January 2014.

SUBSEQUENT USE OF DATA

These data may be used in subsequent studies, in publications and in presentations.

RIGHTS OF RESEARCH PARTICIPANTS

If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario, N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: ethics@uwindsor.ca

I understand the information provided for the study *Sexual Citizenship on the Autism Spectrum* as described herein. I agree to participate in this study.

Please remember to PRINT THIS PAGE for your records.

- o   I agree

Appendix D

CONSENT FOR AUDIO RECORDING

Participant's Name:

Title of the Project: Sexual Citizenship on the Autism Spectrum

I consent to the audio-recording of interviews.

I understand these are voluntary procedures and that I am free to withdraw at any time by requesting that the recording be stopped. I also understand that recordings will be kept confidential. Recordings are filed by number only and stored in a password-protected file on a password-protected computer.

The destruction of the audio files will be completed after transcription and verification.

I understand that confidentiality will be respected and that the audio recording will be for professional use only.

_____

(Signature of Participant)

Appendix E

Initial E-mail to Schedule Interview

Hello,

Thank you for agreeing to participate in my study, Sexual Citizenship on the Autism Spectrum!

I am looking forward to speaking with you. I would like to schedule an online interview at your earliest convenience. We could have an oral interview via Skype, a text-based interview via instant messenger, or an email interview. The choice of format is up to you.

I expect that oral interviews will take about 1-2 hours. Instant messenger interviews will take a little longer, about 2-3 hours. Email interviews will involve a minimum of 15 exchanges of short sets of questions. The exact length of any interview, regardless of format, will vary greatly depending on your personal story.

I would appreciate it if you could suggest 1-3 different times in the next week when we can "get together." As you consider what times may be good for you, please keep in mind that we will be discussing personal matters, including sexuality and relationships. Please ensure that you can access a computer privately during the interview times that you suggest.

Please respond to this email with your preferred interview format. If you prefer the email format, we can get started right away. If you prefer an oral or instant messenger format, please let me know 1-3 different times in the next week when you would be available and able to access a computer in private for about two hours.

Once again, thank you for your interest in my study. I look forward to speaking with you!

Hope this finds you well,

Jessica

Jessica Penwell Barnett, MA
Doctoral Candidate
Department of Sociology, Anthropology, & Criminology
University of Windsor

Appendix F

Study Adverts

Short Version

Recruiting participants for a study on sexuality in the lives of autistic adults living in the US. Participants receive a $25 gift card after completing a brief online survey and online interview. Visit http://www.uwindsor.ca/people/barnettj to learn more! Cleared by the University of Windsor Research Ethics Board.

Long Version

Sexuality and Citizenship on the Autism Spectrum

Hi, I am Jessica Penwell Barnett, a PhD student at the University of Windsor. I am recruiting participants for my dissertation study on sexuality in the lives of adults on the autism spectrum. http://www.uwindsor.ca/people/barnettj

This study will build knowledge about sexuality from the perspective of Autistic people. It will also contribute to discussions of sexual rights. Participants will receive a $25 gift card to Amazon. Participants must be 18 years or older and live in the United States.

If you decide to participate in this study, you will complete a brief survey and an online interview. You will be asked to refer your romantic partner, if you have one, for a follow-up interview. You will also be asked to refer your main support person (friend, parent, paid worker, etc.) for a follow-up interview. Follow-up interviews are intended to provide information about important relationships in your life and how people close to you think about autism and sexuality.

Please go to http://www.uwindsor.ca/people/barnettj for more information about the study's aims and to get started!

Jessica Penwell Barnett barnettj@uwindsor.ca is conducting this study. I have received clearance from the University of Windsor Research Ethics Board.

Appendix G

Study Website Landing Page

Sexual Citizenship on the Autism Spectrum

Welcome to the web home of *Sexual Citizenship on the Autism Spectrum*, an exploration of sexuality and citizenship as experienced by people on the spectrum. To learn more about this project's aims, read on below.

Click here to get started!

Primary (autistic) participants click here to participate.

Secondary participants (those referred by an autistic person with whom they have a relationship)
click here to participate.

There has not been much academic research on the sexuality of people on the autism spectrum. As a scholarly community, we are fairly ignorant of its unique features. Many of the studies that have been conducted use parents, teachers, or caregivers as sources of information about the sexuality of autistics, rather than getting information from autistic people themselves. The studies we do have show that many people on the spectrum desire sexual expression and romantic relationships. These studies also show that autistic people face some group-specific barriers to the development of a satisfying sexual and romantic life. They also suggest that there may be some differences between how autistic and neurotypical people think about and experience gender, sexuality, and romantic relationships.

One goal of this study is to document the sexual identities and experiences of people on the spectrum in their own words. Further, I will see if there are any themes or commonalities in the personal accounts. Are there common or shared experiences among autistic people with regard to sexuality and relationships?

Next, I will look at how those identities and experiences are shaped by people's social and legal context. The Disability Rights Movement has called attention to how disability oppression and marginalization have an impact on sexuality or have a sexual dimension. Not much has been written in the scholarly community about rights and respectful treatment when it comes to sexuality from the perspective of the autistic community. The term "citizenship" in the study title refers to this part of the study, to how laws and the way people treat each other as members of the community impact sexuality.

The second goal of this study is to find out what aspects of the social and legal environment impact sexuality and romance for people on the spectrum. What are

barriers? How do autistics already overcome these barriers? What systemic changes or additional supports would be helpful?

Finally, I will use these analyses to think about how ability, sexuality, and citizenship are related to and impact each other. What does our treatment of a person's sexuality say about their standing in the community? What are the roles of sexual expression, partnership, and procreation in constructing a person's relationship to the state and other's in their community? How do beliefs about ability affect judgments about sexuality and citizenship?

If you would like to be a part of this study, please click on the appropriate link at the top of the page. Thank you!

This study is being conducted by Jessica Penwell Barnett, MA. Please contact me at barnettj@uwindsor.ca or 1-519-253-3000 xt.3978 if you have any questions or concerns about this study. Alternatively, you may contact my faculty supervisor, Dr. Eleanor Maticka-Tyndale, at maticka@uwindsor.ca or 1-519-253-3000 xt. 2200.

Appendix H

Resource Handout Provided to Participants

Resources
Sexuality and citizenship on the autism spectrum

Sexuality and relationships: information and support

The Asexual Visibility and Education Network www.asexuality.org

Autism Women's Network www.autismwomensnetwork.org
A "Relationships" forum and a "Gender and Sexuality" forum are both available for discussion.

Scarleteen http://www.scarleteen.com/

American Association of Sexuality Educators, Counselors, and Therapists
Certified sex therapists can be located by state through their directory
http://www.aasect.org/directory.asp

Through the Looking Glass http://www.lookingglass.org
This San Francisco-based organization serving families with disabilities provides some national services, including legal advocacy in custody and child welfare cases, trainings for parents and professionals, and publications.

Sex, sexuality, and the autism spectrum by Wendy Lawson

Life and love: Positive strategies for autistic adults by Zosia Zaks

The Journal of Best Practices: A Memoir of Marriage, Asperger Syndrome, and One Man's Quest to Be a Better Husband by David Finch

Advocacy, organizing, and networking

Autistic Self-Advocacy Network www.autisticadvocacy.org

GRASP www.grasp.org

Autism Society of America www.autism-society.org

Appendix I

Research Ethics Board Clearance

Office of the Research Ethics Board

University
of Windsor
thinking forward

Today's Date: November 12, 2012
Principal Investigator: Ms. Jessica Barnett
REB Number: 30351
Research Project Title: REB# 12-167: Sexual Citizenship on the Autism Spectrum
Clearance Date: November 12, 2012
Project End Date: January 01, 2014
Milestones:
Renewal Due-2014/01/05(Pending)
Renewal Due-2013/10/01(Pending)

This is to inform you that the University of Windsor Research Ethics Board (REB), which is organized and operated according to the Tri-Council Policy Statement and the University of Windsor Guidelines for Research Involving Human Subjects, has granted approval to your research project on the date noted above. This approval is valid only until the Project End Date.

A Progress Report or Final Report is due by the date noted above. The REB may ask for monitoring information at some time during the projects approval period.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the REB. Minor change(s) in ongoing studies will be considered when submitted on the Request to Revise form.

Investigators must also report promptly to the REB:
a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

Forms for submissions, notifications, or changes are available on the REB website:
www.uwindsor.ca/reb. If your data is going to be used for another project, it is necessary to submit another application to the REB. We wish you every success in your research.

Pierre Boulos, Ph.D.
Chair, Research Ethics Board

c.c. Dr. Eleanor Maticka-Tyndale, Supervisor, Sociology/Anthro/Crim

This is an official document. Please retain the original in your files.

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VITA AUCTORIS

Jessica Penwell Barnett was born in 1982 in Findlay, Ohio, USA. In 2000 she graduated from Goshen High School. She completed her Bachelor of Arts (with distinction) in Psychology from Indiana University in 2003 and her Master of Arts (with a specialization in sex & gender) in Sociology from the University of Windsor in 2009. She will be receiving her Doctorate in Sociology (with a specialization in social justice) from the University of Windsor in June 2014.