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“They didn’t believe me”: Mental Healthcare Experiences of Autistic LGBTQ+ Young Adults-A Community-partnered Study

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"They didn't believe me":
Mental Healthcare Experiences of Autistic LGBTQ+ Young Adults- A Community-partnered Study

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in Education

By

Lauren Marie Baczewski

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ABSTRACT OF THE DISSERTATION

“They didn’t believe me”: Mental Healthcare Experiences of Autistic LGBTQ+ Young Adults- A Community-partnered Study

by

Lauren Marie Baczewski

Doctor of Philosophy in Education, Human Development & Psychology

University of California, Los Angeles, 2023

Professor Connie L. Kasari, Chair

Autistic LGBTQ+ people are at a greater risk for mental health challenges than their autistic non-LGBTQ+ counterparts and experience disparities in access to healthcare (Wallisch et al., 2023). Yet, we know little about the first-hand experiences of autistic LGBTQ+ people in the mental healthcare context. This community-partnered phenomenology explored the mental healthcare experiences of Autistic LGBTQ+ young adults, including barriers and facilitators to receiving care. This study was built in partnership with 5 autistic LGBTQ adults who co-designed each aspect of the research, from development of the interview protocol through data coding and interpretation of findings. Twenty autistic LGBTQ+ young adults (18-28 years old, M_{Age}= 23.3 years) from across the United States participated in semi-structured online or written interviews about their mental healthcare experiences. Almost half of those interviewed identify as nonbinary, gender fluid, or gender expansive, and the majority identify as transgender. Eightyfive percent of interviewees reported that they have anxiety, 70% endorsed depression, and over half (55%) reported that they have ADHD. Although some participants had affirming mental healthcare experiences, the vast majority faced barriers in accessing services. Six themes emerged from participant’s descriptions of their experiences with the mental healthcare system, including: 1) disbelief & denial of autistic LGBTQ+ identities, 2) intersectional identities and multiple diagnoses complicate the road to an autism diagnosis or self-identification, 3) accessing care through existing relationships & systems I am already part of, 4) ‘reading’ potential therapists for safety, 5) providers’ lack of fluency in supporting diverse autistic clients, and 6) alternatives to the traditional mental healthcare system. After being dissatisfied with their care and at times actively turned away by providers, participants found and created their own pathways to healing through both individual practices and community care. These findings emphasize the importance of community connectedness in supporting autistic LGBTQ+ mental health. We describe several implications for provider training, addressing diagnostic disparities, and investing in avenues of community care. In the context of increasing anti-LGBTQ+ healthcare legislation in the United States, it is critical that we implement changes to make mental healthcare accessible and affirming for autistic LGBTQ+ young people.

The dissertation of Lauren Marie Baczewski is approved.

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DEDICATION

This dissertation is dedicated to my Granma, Phyllis Guzé. Your tenacity and brilliant mind inspire me. I want to shake things up like you have in your field. Watching your career has made me feel like I can do anything. Thank you for all of your support during my PhD and beyond.

TABLE OF CONTENTS

APPENDIX

LIST OF TABLES & FIGURES

TABLE Page

FIGURES Page

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Introduction

Over the course of the next decade, a half million autistic young adults in the U.S. will enter adulthood and this number is growing (Roux et al., 2015). Autism and other disabilities shape a person's life experiences at every age; however, the majority of studies focus on children, not adults. Given that individuals are adults much longer than they are children, research should focus on adolescence and adulthood in particular (National Institute of Mental Health, 2016). As studies begin to focus specifically on autistic adults, researchers are starting to recognize that autism is an aspect of identity and people hold multiple intersecting identities simultaneously. Recent work has begun to explore the experiences of autistic young people regarding multiple-held identities (i.e., race/ethnicity, sexual orientation, gender identity, and first-generation status, among others; Cascio et al., 2021). However, few studies have examined the experiences of autistic LGBTQ+ young adults, or their mental health needs and experiences.

Increasing evidence suggests an over occurrence of autism among transgender and gender diverse people (de Vries et al., 2010), and an over occurrence of gender diversity among autistic populations (George & Stokes, 2018). Autistic people are also more likely to identify with a sexual orientation other than heterosexual (Dewinter et al., 2017). LGBTQ+ young adults and autistic young people are at an increased risk for negative mental health and physical health outcomes (Jackson et al., 2018; Russell & Fish, 2016), and their interactions with the healthcare system are different from their peers (Hall et al., 2020a).

Autistic people experience substantial disparities in access to adequate healthcare, with stigmatization and other barriers contributing to poorer physical health outcomes and quality of life (Maddox et al., 2019; Nicolaidis et al., 2015). As a result of their multiple-minority status in a heteronormative and neurotypical-dominant culture, autistic LGBTQ+ individuals face an increased number of systemic barriers to accessing affirming healthcare (Lewis et al., 2020). Recent work underscores these evident disparities in care, as LGBTQ+ autistic adults report significantly higher rates of unmet healthcare needs and rates of being refused care by a medical provider (Hall et al., 2020a). Insufficient access to necessary care can lead to a myriad of health problems, including mental health challenges. In fact, LGBTQ+ autistic adults are more than two times as likely to report having a psychiatric diagnosis compared to their straight, cisgender counterparts (Hall et al., 2020a). In order to support the physical health and wellbeing of autistic LGBTQ+ individuals, it is critical that we better understand the barriers of this population in accessing healthcare services and supports.

Although recent years have seen an increase in the number of studies focused on the prevalence of intersectional autistic and LGBTQ+ identities, few studies have examined the experiences of autistic LGBTQ+ individuals in their own words. As the literature begins to highlight glaring healthcare disparities for this population, it is critical that we understand the experiences of this community as they receive or attempt to receive mental health supports. Although recent phenomenological studies have included participant voice through semi-structured interviews (Lewis et al., 2020), this is one of few studies to examine mental health that was co-designed and conducted in partnership with autistic LGBTQ+ partners. The purpose of this community-partnered phenomenology was to interrogate the following question: what are the firsthand experiences of autistic LGBTQ+ young adults in the mental healthcare system?

A Note on Terminology and Language

Many autistic people have expressed preference for identity-first language (i.e., autistic person; Kenny et al., 2016), and thus identity-first language will be predominately used here. Some variation in terminology may appear in descriptions of studies that utilize different terminology (e.g., person first language; “person with autism”). A glossary of key terms relevant to this study (e.g., gender identity, neurodiverse, trans, cisgender) is included in Appendix B.

Intersectional identities of autistic people

Recent work increasingly considers the intersectional identities of autistic people (e.g., race/ethnicity, gender identity; Cascio et al., 2021), and gives us a framework for understanding autism as a marginalized identity (Botha & Gillespie-Lynch, 2022). This intersectional lens pushes the field of autism research to focus on the diversity within the autistic community, and conduct studies that acknowledge that diversity of experience. As such, work that focuses on sexual and gender minorities in the autism community is steadily increasing.

Autistic individuals are more likely than their non-autistic counterparts to identify as LGBTQ+ (Dewinter et al., 2017; Strang, Powers, et al., 2018). The majority of early studies in this area aimed to understand and record the over occurrence of LGBTQ+ identities among autistic people, and these studies are described in the section that follows. Additionally, I highlight evident gaps in the extant body of work on the intersection of LGBTQ+ and autistic identities.

Gender Diversity in Autism

The past decade has seen a substantial increase in empirical studies that focus on the topics of gender diversity or gender dysphoria among autistic people. Between the years 2015 to 2018 alone, the number of empirical studies published on these topics more than doubled (Nordahl-Hansen et al., 2019). Many of these studies assess autistic traits among individuals who are referred to receive gender-related care (e.g. van der Miesen et al., 2018) or assess those who are referred for gender care for an autism diagnosis (e.g., Nahata et al., 2017; Shumer et al., 2016). As quantitative data on the intersection of autism and LGBTQ+ identities grow, studies more commonly report prevalence estimates. Among gender diverse individuals of multiple age groups, rates of a clinical autism diagnosis appear to range from 6-25.5% (Strang, Janssen, et al., 2018). This range in rates of autism diagnosis among gender diverse people may be in some part because available data comes from studies that pull both community and clinic-based samples. Among those who are referred to gender clinics to receive care, autism screening measures suggest that having an autism diagnosis was 3-6.4 times more common in transgender or gender diverse people than their cisgender counterparts (Warrier et al., 2020).

As a whole, this body of research suggests that there is an over occurrence of autism among those who identify as gender diverse (e.g., Glidden et al., 2016; Strauss et al., 2017) as well as an overrepresentation of gender-diverse characteristics among autistic individuals (George & Stokes, 2018). Clinically, accurately diagnosing and understanding intersecting LGBTQ+ and autistic identities can be complex. Social differences or challenges resulting from the experience of gender dysphoria can impact or complicate the diagnosis of autism (Strang, Powers, et al., 2018). Additionally, most autism diagnostic tools were developed for use with and normed using cisgender male samples, which can complicate giving a diagnosis of autism among cisgender females as well as gender diverse people (Strang, van der Miesen, et al., 2020). These factors among others can result in one's gender diverse identity being invalidated as a result of their autism, or vice versa (Strang, Powers, et al., 2018). Few studies examine the inner experiences of gender diverse autistic individuals or the nature of their gender diversity and/or dysphoria, although Strang and colleagues have produced the first papers on this topic (see Strang, Powers, et al., 2018; Strang, van der Miesen, et al., 2020). I review these papers and their contributions in sections to come. Despite increasing work in this area, there is still much to be understood regarding the firsthand experiences of gender diverse autistic people, and studies need to use interview and focus group methods to look beyond prevalence rates.

Sexual Orientation in Autism

Like work on gender identity in autism, much of the emergent literature on sexual orientation aims to assess the prevalence of non-heterosexual orientation using large samples of autistic people. A recent study examined sexual orientation among autistic adults compared to the general population using the Netherlands Autism Register and responses from a broader sexual health population survey (Dewinter et al., 2017**).** Results showed that autistic adolescents and adults (n= 675) reported non-heterosexual attraction more often than peers in a large general population sample (n= 8064). Autistic female participants in particular were more likely to report same-sex attraction than their male peers (Dewinter et al., 2017). Overarchingly, available studies suggest that autistics are more likely to identify as sexual minorities compared to their non-autistic counterparts (Lewis et al., 2020). Echoing trends seen in literature on gender diversity in autism, there are few studies that examine lived experiences of autistic sexual minorities.

The Impact of Minority Stress on Health Outcomes

Individuals who are members of minoritized groups experience a series of unique stressors, including but not limited to discrimination and harassment (Meyer & Frost, 2013). Those with multiple marginalized identities face additional stressors (Balsam et al., 2011), and recent work in the field of sexual and gender minority research underscores this point. Mallory and colleagues found that sexual minority youth of color confront intersectional stressors including racial discrimination and LGB (Lesbian, gay, bisexual) victimization, resulting in a greater risk for negative mental health outcomes including depression and suicidal ideation (Mallory & Russell, 2021).

The Minority Stress Model was originally developed to conceptualize the path to increased health risks of marginalized groups, including LGBTQ+ people. Botha and Frost recently extended the original Minority Stress Model to understand the mental health challenges of the autistic community. They argue that autistic people are exposed to additional stressors as a result of the discrimination and stigma they face as a result of their social status (Botha & Frost, 2020). This model provides rationale for the elevated rates of mental health challenges among autistic people.

Considering autistic and LGBTQ+ communities separately, each population is faced with unique stressors as a result of their minority status in a largely ableist and heteronormative sociocultural context. These stressors lead to a greater risk to develop depression, anxiety, and suicidal ideation (Cassidy et al., 2014; Layland et al., 2020; Strauss et al., 2017). LGBTQ+ youth experience significantly higher rates of emotional distress, suicidal ideation, suicidal behavior, and symptoms of mood and anxiety disorders compared to their heterosexual and cisgender counterparts (Russell & Fish, 2016). Autistic people are more likely to experience suicidality compared to non-autistic people (Cassidy et al., 2014), and their health disparities are pervasive (these disparities are described more in depth in the section that follows). Taken together, this literature on health disparity highlights the need to understand the experiences of those with intersectional autistic and LGBTQ+ identities regarding mental health and access to mental healthcare. This research is an important intermediary step that can facilitate the development of healthcare programs that improve access to and quality of mental health care.

Health Status of Autistic Young People: High Levels of Unmet Need

The health disparities of autistic individuals across ages are well described in the literature. The physical health needs of autistic people are often unmet, and this trend increases as autistic individuals age (Liu et al., 2017). Health disparities in this population are evidenced by rates of emergency department use, hospitalization, and high incidence of co-occurring mental health diagnoses. Autistic adolescents access emergency department services four times more than their non-autistic counterparts (Liu et al., 2017), and emergency department use increases across the life course for autistic individuals (Nicolaidis et al., 2013). Of those utilizing emergency department care, a large volume of cases require behavioral health or psychological services, pointing to the specificity of mental health concerns in this population (Liu et al., 2017). Rates of hospitalization are high among autistic individuals of all ages (Mandell, 2008). This data illustrates the high rates of mental health challenges among autistic individuals. Autistic individuals commonly have co-occurring mental health diagnoses (Camm-Crosbie et al., 2018) and are at a high risk for non-suicidal self-injury and suicidality (Cassidy et al., 2014).

Many apparent barriers to accessing needed mental and physical healthcare exist for the autistic population. The cost of healthcare services increase as autistic young people age (Croen et al., 2006), and the cost of services for autistic youth is approximately 3-7x greater than for non-autistic counterparts (Croen et al., 2006; Peacock et al., 2012). To identify more barriers to care beyond the financial, Crane and colleagues recently conducted a mixed method community-based participatory study with autistic young adults in the UK. Participants reported a general lack of available mental health services for autistic people and expressed general feelings of unhappiness with the available standard of services, although they were grateful to have something (Crane et al., 2019). Similar barriers were described in a 2019 thematic analysis of a large online survey of autistic adults’ healthcare experiences (Camm-Crosbie et al., 2018).

Participants expressed difficulties accessing treatment and support, a lack of understanding amongst their providers about autistic people and mental health, and noted that access to appropriate treatment directly impacted their wellbeing (Camm-Crosbie et al., 2018). Taken together, these studies demonstrate the clear health disparities of autistic individuals across the life span and challenges in accessing appropriate and affirming care. Although many studies have examined autistic experiences with healthcare utilizing a range of methodologies, much of the available work does not assess the experiences of those with additional marginalized identities within the autistic community.

Health Disparities of Autistic LGBTQ+ Individuals

Studies have only recently begun elucidating the substantial disparities in healthcare that autistic and LGBTQ+ individuals face. Using data from the National Health Interview Survey (NHIS) 2018, Hall and colleagues examined the healthcare experiences of autistic individuals aged 18-62 years who identified as LGBTQ+. LGBTQ+ autistic respondents reported significantly higher rates of mental illness and a greater number of poor physical health days per month compared to their non-LGBTQ+ autistic counterparts (Hall et al., 2020). Additionally, participants who identified as LGBTQ+ reported higher rates of both unmet healthcare need and incidences of being denied or refused care by a medical provider. Just this year a study by Wallisch and colleagues examined results from the 2019/2020 version of the same NHIS survey and found results consistent with Hall et al. LGBTQ+ autistic people had both more co-occurring mental health diagnoses and more unmet healthcare needs compared to straight/cisgender autistic people (Wallisch et al., 2023). Large-scale survey studies that collect gender identity and sexuality data alongside disability status are few and far between, and thus the Hall and Wallisch studies are an important first step towards a deeper understanding of the healthcare experiences of autistic LGBTQ+ adults.

Exploring the Experiences of those Under the “Double Rainbow”: Autistic & LGBTQ+

Although the healthcare disparities of LGBTQ+ autistic individuals are becoming increasingly apparent in the literature, there is a general lack of information about the experiences of this community. Two recent studies that employ focus group and interview methods begin to examine the in-depth firsthand experiences of autistic LGBTQ+ people. Hillier and colleagues asked four LGBTQ+ and autistic focus group participants about the unique benefits and challenges of holding their dual identities. Although many participants noted that their dual identities served as a connection point with others of shared experience, they also reported pervasive challenges with accessing needed physical and mental healthcare and services due to a lack of acknowledgement and understanding of LGBTQ+ and autistic identities (Hillier et al., 2020). Providers and family members often dismissed or discredited the sexual orientation and gender identity of individuals because of their autism status. “People assume when you are autistic you don’t know yourself, but even people I know with intense symptoms, know themselves” (Participant 1; Hillier et al., 2020).

Expanding on this work, Lewis et al. (2020) conducted online interviews with 67 autistic adults (aged 18-57 years) who identified as sexual minorities. Lewis and colleagues conducted the first phenomenological study of the autistic LGBQ experience, aiming to understand the experiences of queer autistic individuals with respect to their multiple identities. Six themes emerged, including “1) self-acceptance is a journey, 2) autistic traits complicate self-identification of sexual orientation, 3) social and sensory stressors affect sexual expression, 4) feeling misunderstood and isolated, 5) challenges finding mutually satisfying relationships, and

6) difficulty recognizing and communicating sexual needs" (Lewis et al., 2020). Taken together, these themes highlight the unique experiences of autistic sexual minorities and illustrate the complexity of identity formation and meaning making around those identities.

Participants in each of these studies discussed their experience with living at the intersection of autistic and LGBTQ+ identities and challenges associated with holding "double minority" identities and stressors. Overarchingly, these studies provide support for considering the multiple identities of autistic people as intersecting and interacting, rather than as separate or parallel (Hillier et al., 2020). Importantly, the vast majority of participants in the Lewis and Hillier studies were White. In examining the multiple identities of LGBTQ+ autistic individuals, we must ensure that we are learning about these experiences from samples that are diverse in terms of race/ethnicity, socioeconomic status, and education level.

The Hillier and Lewis studies represent a critical step forward in prioritizing participant voice in research conducted with LGBTQ+ autistic populations. Very few studies to date have examined the experiences of autistic LGBTQ+ individuals using community partnered research designs. These limited studies are discussed in the section that follows. The use of community partnered methods is a critical next step in developing ecologically meaningful research that is tied to the needs and priorities of the community.

Community partnered research: an under-utilized approach

Although scholars across fields of study have recognized the importance of including the community of interest in the research process for several decades, community participatory studies are rare in autism research (Croen et al., 2006). This may in part be due to evident challenges with conducting this type of research (e.g., greater financial costs to compensate partners, reliance on established relationships). Despite evident obstacles, the benefits of involving the community in research outweighs these challenges (den Houting et al., 2021). The use of community partnered methods facilitates a focus on ecologically-meaningful outcomes for the study population and works towards closing the research to practice gap (Jones & Wells, 2007; Strang et al., 2019). As research focused on autistic adults becomes more common in the field of autism research, community participatory methods are essential (Nicolaidis et al., 2019).

Community partnered participatory research (CPPR) is a form of community based research that focuses on academic-community partnership across all phases of the research process- design, implementation, and ownership of products (Jones et al., 2009). A main goal of this specific approach is to engage a range of community stakeholders with diverse experiences in a collaborative research process. While CPPR approaches have been used in autism research (e.g., Smith et al., 2017), only two studies to our knowledge have employed community-based methods to partner with the autistic LGBTQ+ community. In the first study of its kind, Strang and colleagues partnered with autistic gender diverse adolescents to characterize their gender trajectories across time and to learn about salient themes in their lives (Strang, Powers, et al., 2018). Subsequently, Strang et al. 2020 used community based methods to develop a clinical program and recommendations for gender diverse and trans autistic adolescents (Strang, Knauss, et al., 2020). These studies serve as examples for how community-based and community-partnered methodologies can facilitate a greater understanding of the autistic LGBTQ+ community and their priorities for research. As the mental health disparities of the autistic LGBTQ+ community become increasingly clear in the literature (Hall et al., 2020a), community partnered research provides a path forward to help us understand the barriers that these individuals face in accessing affirming mental healthcare and support.

Thus, a fundamental component of this study is its community partnered approach. Five autistic and LGBTQ+ adults from across the United States were recruited and interviewed to be part of an advisory group for the current study. The Autistic LGBTQ+ advisory group and I worked collaboratively on each aspect of this research study, from creating, piloting, and testing the interview protocol to coding and interpreting results. The inclusion of autistic LGBTQ+ individuals as co-researchers and collaborators allows this study to be guided by voices of the community to promote understanding of specific experiences in the mental health care system.

Positionality

I come to this work as a non-autistic queer white cisgender woman and, therefore, aim to learn more through partnership and collaboration. The paucity of literature around the experiences of queer-identifying autistic young adults in the mental health care system is what drives me to this collaborative work. Additionally, I am the family member of an autistic adult with intellectual disability and bipolar disorder. My experiences growing up alongside my family member shaped my interest in the intersection of mental health and autism. In many ways this study is a marriage of my two passions- LGBTQ+ advocacy work and autism research that centers the voices of those in the autistic community.

Current Study

To expand and build upon existing work on the LGBTQ+ autistic experience, this study aims to provide in-depth, nuanced information about the barriers and facilitators to accessing mental health care among this population. The purpose of this qualitative, phenomenological study is to answer the research question: What are the experiences of LGBTQ+ autistic young adults with regards to their mental health status and mental health care?

Theoretical & Conceptual Frameworks

Theoretical Framing: Crip Theory & Neuroqueerness

This study integrates several theoretical approaches that shape the study design, analysis, and interpretation of findings. Figure A is a visualization of the approaches that support and guide this study, and how they are situated in relation to one another. The overarching theory that guides this work is Crip Theory, which posits that autistic behavior cannot be separated from sexual and gender deviancy, as both autistic and queer identities deviate from the norm under the existing majority systems of oppression and power. McRuer writes that “compulsory heterosexuality, including the stereotyped genders that undergird it, and ‘compulsory able-bodiedness’ are interlocking and mutually-constituting systems of power” (McRuer, 2006). In this way, neurological variance is inherently intertwined with gender and sexual variance.

Scholars from queer and disability studies have expanded on these ideals in recent years, writing about the interconnectedness of queer, disabled, and neurodivergent identities. M. Remi Yergeau echoes the above musings from McRuer: “autism and queerness are implicated in one another, are mutually sustaining- even if at times radically diverging- conceptions of what it means to demi-rhetorically move and defy” (Yergeau, 2017). In 2014, M. Remi Yergeau, Nick Walker, and Athena Lynn Michaels-Dillon collectively coined the term “neuroqueer” or “neuroqueerness”, which points to the interconnectedness of queer and neurodivergent identities, which both “frustrate norms” (Walker, 2015; Yergeau, 2017). To be neuroqueer is to identify as both queer and neurodivergent, “with some degree of conscious awareness and/or active exploration around how these two aspects of one’s being entwine and interact (or are, perhaps, mutually constitutive and inseparable” (Walker, 2015). Walker and colleagues push forward and expand upon the work of McRuer and others, creating a term that embodies the intersection of neurodivergence and queerness.

Taken together, this body of disability-gender-sexuality work is foundational to this study. Crip theory and neuroqueerness give us a lens through which to view the experiences of the autistic LGBTQ young adults in this study. These frameworks emphasize that to be disabled in current society means that you are othered—your existence stands in contrast to a world that is built for people who are able-bodied and non-autistic. If you are both disabled and simultaneously queer, your existence challenges additional norms—for example, how you are supposed to dress and behave if you are born a certain sex, who you are expected to marry to become a 'successful' and 'functioning' adult in the eyes of society, how you are supposed to communicate and interact socially. To be an autistic queer young adult is to 'frustrate' multiple societal norms simultaneously, just by existing as yourself.

McRuer's conceptualization of Crip theory, whose work is continued and expanded upon by current neuroqueer scholars, serves as the overarching theoretical framework for this study. In addition to this overarching theoretical framework, I employ two smaller-scale theoretical models that help us situate the autistic LGBTQ+ person in the current sociopolitical and healthcare contexts.

Intersectionality & Minority Stress Model (MSM)

Intersectionality is a theory and tool that describes how multiple forms of inequality combine to produce compounded experiences of oppression and subsequent discrimination for those with multiple-marginalized identities and experiences. Coined by Kimberlé Crenshaw, intersectionality is grounded in Black feminism and Critical Race Theory and its application spans fields of study (Carbado et al., 2013). We can apply the theory of intersectionality to this study to acknowledge and make space for multiple salient identities that participants may describe as important to their experiences in the mental healthcare context. Semi-structured interviews were chosen as a data collection method under guidance of this conceptual framing, to make space for participants to describe their multiple identities, and how the intersection of these identities impacts their mental healthcare experiences.

The Minority Stress Model (MSM) posits that individuals in minority groups, particularly sexual minorities, experience unique stressors that are both distal (e.g. harassment, discrimination) and proximal (e.g. perceived stigma) (Meyer & Frost, 2013). Individuals with multiple marginalized identities face these additional stressors that can have a series of negative effects (Balsam et al., 2011). The Minority Stress Model, as adapted by Botha and Frost, informs why autistic LGBTQ+ young people may have more mental health challenges and different experiences within the mental health care system compared to those who do not hold the same marginalized identities. The MSM informs the lens through which I view autistic mental health struggles in this study.

In sum, Crip theory serves as the overarching umbrella theory for this study and is grounded in work that discusses the intersection of disability and queerness. Intersectionality and MSM are theoretical models that aim to help the reader conceptualize more specifically how we situate the autistic LGBTQ+ person in context. Intersectionality helps us understand the compounded forms of oppression that our participant face as a result of their social identities, while MSM helps us understand these marginalized identities in our current socio-cultural and healthcare context.

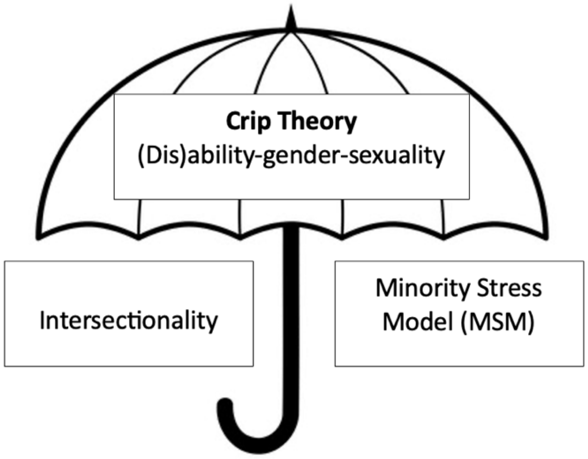

Figure A. Visualization of the overarching theoretical framework and nested models that guide this study.

Conceptual Framework

With influence from the theoretical framings discussed above, we conceptualize the autistic LGBTQ+ young person alongside their multiple, intersecting identities within the current social, political, and healthcare contexts. The conceptual framework for this study is visualized in Figure B. This framework takes into consideration the impact of dominant cultures and ideals (e.g., heteronormative, cis, white ideals and norms) and the results of deviating from those norms (e.g., experiences of oppression, discrimination, harassment). Both the physical and mental health of the autistic LGBTQ+ person is impacted. This study focuses specifically on the healthcare context, and how having multiple marginalized identities impact experiences accessing appropriate care.

Taken together, these theoretical and conceptual models influenced the way that I gathered data for this study (semi-structured interviews offered in a variety of modalities with accommodations), and how data were analyzed and interpreted (acknowledgement of multiple marginalized identities, within the healthcare context, and how oppression and harassment may shape the experiences of autistic LGBTQ+ individuals).

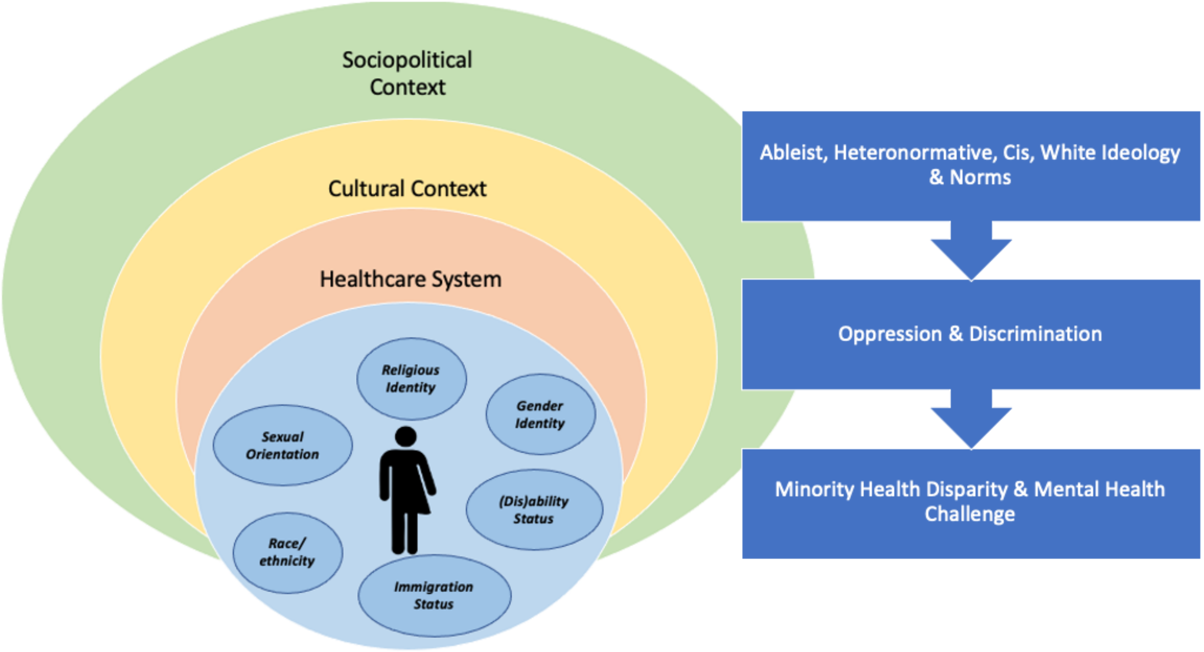

Figure B. Conceptual Framework. The autistic LGBTQ+-identifying individual alongside their multiple, intersecting identities. They are nested within the healthcare system and broader cultural, social, and political contexts.

Methods

Research Design & Methodology

This study employs a phenomenological approach, as this work aims to investigate how several individuals commonly experience a phenomenon or interest or the essence of a phenomenon (Creswell & Baez Creswell, 2015). This study spotlighted specifically the mental health care context, and the barriers that LGBTQ+ autistic young people face in accessing care. Participants who have experienced the phenomenon of interest (receiving or attempting to receive mental healthcare) were specifically recruited to take part in the study, and their accounts serve as the data (Colaizzi, 1978).

Community Partnered Participatory Approach

Five autistic LGBTQ+ adults from across the United States were recruited to be members of an advisory group for this study. To collaboratively design and execute this study, myself and the Autistic LGBTQ+ Advisory Group (referred to as AG from here on) used the community partnered participatory research (CPPR) approach developed by Jones and Wells (Jones & Wells, 2007). There are three major stages to CPPR, including 1) vision (collectively envision and articulate the goals of the research), 2) valley (work together to collect data), and 3) victory (celebrate success and disseminate agreed upon products) (Jones et al., 2009).

Jones and Wells created a foundation for the application of community-partnered research in health and clinical fields. Others have followed in the footsteps of their work to create guidelines for partnership with autistic community partners. The Academic Autistic Spectrum Partnership in Research and Education (AASPIRE), founded in 2006, brings together academic researchers and the autistic community to conduct community-based research (Nicolaidis et al., 2019). We used several of the practice-based guidelines for the inclusion of autistic individuals in research as co-researchers developed by AASPIRE. The AG collaborated with me on each part of the research process- from development of measures (e.g., semi-structured interview questions), to data collection methods and accommodations, through the creation of the codebook, and discussion of key themes/findings.

Autistic LGBTQ+ Advisory Group (AG) Details

The Autistic LGBTQ+ Advisory Group is made up of 5 self-identified autistic LGBTQ+ adults from across the United States, ages 26-39 years old. The majority of the AG (3/5) identify as White, 1 person is multiracial, and 1 member is Hispanic/Latine/Latinx. The AG is diverse in terms of gender identity, as 2 members identify as women, 1 identifies as a man, 1 as nonbinary/gender fluid/gender expansive, and 1 as not sure or questioning. One member out of the 5 identifies as transgender. The AG have a variety of sexual orientations, and the majority identify as either Lesbian/Gay (2 out of 5) or Asexual/Ace/Ace spectrum (2 out of 5). They live throughout the United States, including in West, Midwest, South, and Northeast regions. The AG is made up of people from multiple fields and professions- two members work for a disability nonprofit/autistic advocacy organization, 1 member works in academia/higher education, 1 member is a clinical social worker, and 1 member is a visual effects specialist working in film. Overall, the AG is highly educated, as the majority have completed a graduate or bachelor's degree, and 1 member completed high school. All 5 AG members report having a formal diagnosis of autism from a clinician or health professional, and they were a wide range of ages when they received that diagnosis (range = 2-34 years old, M_{Age} = 14.4 years old).

This dissertation study is funded by an AIR-P Scholars Pilot and Feasibility Grant. The Autism Intervention Research Network on Physical Health (AIR-P) is an interdisciplinary research network funded by the Maternal and Child Health Bureau. More specifically, this project falls under the Gender, Sexuality, and Reproductive Health node of the AIR-P network. The Gender, Sexuality, and Reproductive Health node has its own autistic advisory board. This study was discussed at their regular meetings, and autistic board members passed along information to their contacts and friends. Additionally, I advertised the AG positions through emails to my contacts and network at UCLA. I made a purposeful effort to recruit AG members from racial/ethnic minority backgrounds but only 2 members are non-White, which is a limitation of this work.

AG Meetings

From February 2022 to February 2023, I met with the AG every 2 weeks for 1 hour (with the exceptions of holidays and other short, planned breaks). Advisory group members were paid

$50/hour to attend 18 team meetings total. Members were also paid for ad hoc work outside of formal meetings, including responding to emails, editing conference posters, authoring the semi-structured interview guide, piloting interview questions, recruiting participants through partner organizations, developing the codebook, and providing feedback on themes. During the first meeting we worked together to create shared understanding of the project's overarching goals and co-create community guidelines as well in the form of an "Advisory Group Charter" (in line with the vision stage of Jones & Wells CPPR approach). All meetings took place via Zoom. AG members participated in meetings in a variety of ways, including using exclusively the chat to type, verbal participation, or a combination of the two. One member participated predominately through written modes of communication (i.e., chat function, written emails). All other members participated through a combination of verbal and written modes. About a week before each meeting, I sent out an agenda and any materials for AG members to review. After each meeting, I sent an email with action items and due dates. I used the structured email template developed by AASPIRE for all community-related communications, including the meeting agenda, which follows the following format: purpose, actions, deadline, compensation, details (Nicolaidis et al., 2019). AG members were not eligible to be participants in the study.

Participant Eligibility

Participants self-screened for eligibility to participate in this study. Participants were eligible if they: 1) self-reported that they are autistic (including those with both formal diagnoses and those who self-identify), 2) identify as LGBTQ+ or questioning, 3) live in the United States, and 4) have received or tried to receive mental healthcare (e.g., counseling, therapy). Additionally, participants were required to have access to a device (computer, mobile phone) that can access the internet, and be able to independently communicate regarding their mental health experiences and care (through verbal or text-based modalities).

Recruitment

The AG and I recruited participants through two primary methods: 1) advertising the study on email listservs of organizations for and by autistic young adults (i.e., College Autism Network, the Autistic Women & Nonbinary Network, Autistic Self-Advocacy Network), and 2) social media. The recruitment flyer is included in Appendix A. We recruited participants through both a study-specific Instagram account as well as through postings to the research team's personal Instagram and Twitter accounts. To allow for the most equal opportunity for participation across a wide range of possible participants, the AG and I chose to do intensive recruitment postings across a 3-day period. From July 6-8, 2022, we posted to all recruitment avenues and social media sources simultaneously.

We reached our target recruitment of 25 participants within 48 hours and continued to accept survey responses until 29 participants had completed the survey and signed up for an interview. Those who were interested in participating after we reached 29 participants were directed to enter their contact information into a survey with the potential to be contacted for future related studies. 15 people over and above the 29 participants entered their contact information. These numbers demonstrate the level of interest in studies focused on LGBTQ+ and autistic identities within the broader autism community, presenting avenues for continued work in this area.

Participant Characteristics

Twenty-nine young adults self-screened for eligibility and signed up to take part in both the survey and interview. We excluded data from 1 participant after they completed the study as we were unable to verify that they were a United States resident, and the geocode location recorded from their survey submission was outside of the United States. Thus, our final sample includes 28 young adults between 18-28 years old (*M* = 23.3 years, *SD* = 2.8) who identify as Autistic and as LGBTQ+ (Lesbian, Gay, Bisexual, Trans*, Queer and/or Questioning, Intersex, Asexual, or Two-spirit). All 28 participants completed the demographic survey and consented to be contacted to schedule an interview. 20 out of the 28 participants responded to our research team's follow up communications and completed a semi-structured interview with me. Eight participants either did not respond to our attempts to schedule an interview or indicated that they no longer wanted to take part in an interview. See Table 1 (in appendix) for detailed demographic information on the full sample of 28 participants, as well as separate demographics of those who took part in interviews (n=20) and those who only completed a survey but did not complete an interview (n=8).

Almost half of the full sample (13/28 participants) identify as nonbinary, gender fluid, or gender non-conforming and over half (16/28) identify as trans. In terms of sexual orientation, our participants largely identify as queer or lesbian/gay. The majority (18/28) identify as White, and 12 out of 28 participants report having just enough to meet their basic needs (e.g., food, housing, transportation). In terms of education level, most participants completed some college (8/28) or hold a bachelor's degree (10/28). While the majority report being employed full time (12/28), 6 out of 28 participants report that they are not working (unemployed or unable to work due to disability or other reasons). Over half (15/28) report having a formal diagnosis of autism by a clinician or other health professional, 7 report being informally identified by a provider as autistic, and 4 report that they self-identify as autistic. On average, participants were adults when they received an autism diagnosis or began to self-identify as autistic (M_{Age}= 18 years, *SD*= 6.2).

Interview Participant Characteristics

Those who participated in semi-structured interviews (n=20) were largely nonbinary or gender expansive, identify as trans, and were assigned female at birth. The interview sample is largely White, have a bachelor's degree or some college, and report having just enough to meet their basic needs. Like the overall sample, co-occurring diagnoses were common amongst this group, with the most common reported diagnoses being ADHD, anxiety, depression, and PTSD (see Table 1, appendix). The vast majority were formally diagnosed as autistic in adulthood (M_{Age}=18.9 years). Many interviewees received their diagnosis or began to self-identify within the last few years, and for some this journey to autism occurred within the same year as the interview. Thus, for many interviewees, their autistic identities were salient, and they spent substantial time considering this aspect of who they are. Interviewees were on average 23 years old and therefore also in a stage of life when identity formation and development are central to one's experience (Arnett, 2000). Most interviewees reported having experiences of masking their autistic traits either presently or at some point during their lives and reflected on the impact of those experiences. The findings from the thematic analysis largely represent the perspectives and lived experiences of this group in receiving or attempting to access mental healthcare, and findings may be different for samples that are largely made up of others in the autistic community. Table 2 (appendix) includes pseudonyms and demographic descriptors to provide additional context for each interviewee.

Procedures

Participants followed a link or QR code from the recruitment flier to access a secure Qualtrics platform with information about the study. The Qualtrics home page included a list of frequently asked questions about the study (e.g., why are we doing this study? What will we ask you to do for this study?). All text on the Qualtrics platform was written in plain language. Participants then moved through the following tasks: 1) check if they qualify (answer 5 eligibility questions based on the aforementioned criteria), 2) review consent form, 3) decide/ask questions (decide if they want to do the study or if they need to ask questions before deciding), 4) survey (complete demographic survey), 5) schedule interview (choose between written or oral interview format).

In entirety, the IRB process took 6 months from submission to approval. Due to the mental health subject matter and participant population, the study was designated to be reviewed by the full board. Both a suicidality protocol and abuse protocol were developed for this study in case a participant disclosed during the interview. We obtained a Waiver of Consent for this study from the UCLA IRB and thus a signed consent form was not required.

Participants viewed the consent form through the Qualtrics platform and were able to download a copy of the consent with contact information for the study leads. After reviewing the consent form, participants were asked to confirm that they wanted to participate in both parts of the study (survey and interview), or if they wanted to talk with a research team member before deciding. Participants received a $50 electronic Amazon gift card for completing both the online demographic survey and the semi-structured interview. If participants completed only one part of the study (survey or interview), they did not receive any compensation and were given this information before consenting to the study.

Measures

Measures included semi-structured interviews and demographic surveys. All data were collected online.

Demographic Information

Participants responded to a 25 question Qualtrics survey with demographic questions (see Appendix for full measure).

Semi-structured Interviews

Semi-structured interviews are a commonly used qualitative interview method that allows the research team to ask pre-designed guiding questions but adapt and supplement the interview with follow-up questions when appropriate (Ravitch & Carl, 2019). Participants were presented with a variety of options for taking part in the semi-structured interview including both text-based and oral formats (i.e., Zoom video interview, phone interview, in person, or text-based via WhatsApp, an encrypted synchronous chat platform). Preferences among the autistic community for text-based communication options have been well outlined in the literature and other phenomenological published studies have employed similar offerings for participation (see Lewis et al., 2020 for example). Ten of the 20 interviewees chose zoom video interviews, 7 chose phone interviews (zoom with no video), and 3 chose written interviews. None of the interviewees chose to do their interview in person. Interviews ranged in length from 1 hour to 3.5 hours (average duration = 1.95 hours). The written interviews were the longest in duration (average duration = 2.83 hours). Interviews took place between July 18, 2022- January 10, 2023.

All interviews conducted verbally were audio-taped for later transcription and coding with the permission of the participant, and written interview transcripts were additionally collated. The interview framework was adapted from Seidman's 3-part framework for phenomenological interviewing (Seidman, 2006). Part one of the semi-structured interview served as an adapted form of a focused life history and included questions pertaining to the participant's identities and journeys to understanding those identities. Details on participant experiences with seeking and obtaining mental health care were elicited in part 2 of the interview (e.g., barriers and keys to accessing care). The third part of the interview asked the participant to reflect on their mental health care experiences and what they would like to tell policy makers and healthcare providers about their experiences accessing services. The areas of focus and order of questions were decided upon in collaboration with the AG. See appendix for copy of the interview protocol.

Interview Approach. I began each interview by reviewing the main points of the consent form with the participant and reminding them that they were welcome to skip any question they did not feel comfortable answering. To establish rapport and begin to develop trust, I shared my own positionality at the start of each interview during our introductions. I disclosed my own queer identity and position as a family member of an autistic person with intellectual disability and bipolar disorder. Additionally, I emphasized the community partnered study approach, highlighting the AG and their work in co-constructing this study. Following the input of the AG, I provided a list of all interview questions to participants before the interview so that they were able to review them in advance. I also used a visual aide/schedule detailing the interview parts to guide the conversation and serve as an anchor. Finally, to add to participant comfort, I encouraged participants to take breaks when needed throughout the interview.

Analysis

The AG and I analyzed interviews using a thematic analysis framework, as suggested by Braun and Clarke. Thematic analysis is a widely used process that allows the researcher to identify patterns in the data, leading to the creation of central themes (Braun & Clarke, 2006). We used an inductive approach to coding, which allows for data to be segmented into codes and themes without a pre-existing coding scheme, centering participant voice in the process (Creswell & Baez Creswell, 2015). In following this approach, the goal is to identify themes that are linked to the data itself, rather than the preconceptions of the researchers (Braun & Clarke, 2006). We employed Braun and Clarke's 6-phase approach to thematic analysis, which includes 1) transcribing and familiarizing yourself with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and 6) extracting examples and producing the report. Although described as a linear 6-phase process, in practice Braun and Clarke's approach is iterative, reflective, and involves moving back and forth between phases (Nowell et al., 2017). Our thematic analysis process is detailed in the sections that follow.

Step 1: Transcription

Interviews were audio-recorded and transcribed verbatim using a 3-step process: 1) audio files were uploaded to an automated transcription software program, Otter.ai, 2) undergraduate research assistants reviewed each automated transcript and checked the text against the audio recording for accuracy, noting questions and unintelligible segments, and 3) I checked each transcript for accuracy and generated a finalized transcript for each interview. Text-based interviews were exported from WhatsApp and transcripts were checked for accuracy.

Step 2: Generating Codebook

Two members of the AG opted into assisting with creation of the codebook. The 3 of us independently read 4 transcripts 2-3 times each, noting down initial ideas and keywords. Next, we met to discuss key ideas and generate initial codes. By the 6th meeting, we achieved consensus on a series of initial codes, which became the first draft of our codebook. Table 3 lists the primary and secondary codes. Figure C shows a visual version of the final codebook.

Primary Code	**Secondary Codes**
Identities	Identity journey, disconnect from gender, gender expression, coming out, autistic experience, my multiple identities.
Mental Healthcare	Diagnosis, Access to care, Reflections on therapy/care.

My Mental health	Mental health diagnosis as part of identity vs. condition I suffer from, alternative mental healthcare practices, impact of mental health on my life.
Community & Family	Internet/Media, in group discrimination, external oppression & discrimination experiences, advocacy & activism, support & connection, others' denial/disbelief about who I am.

Table 3. Primary and secondary codes that make up the codebook.

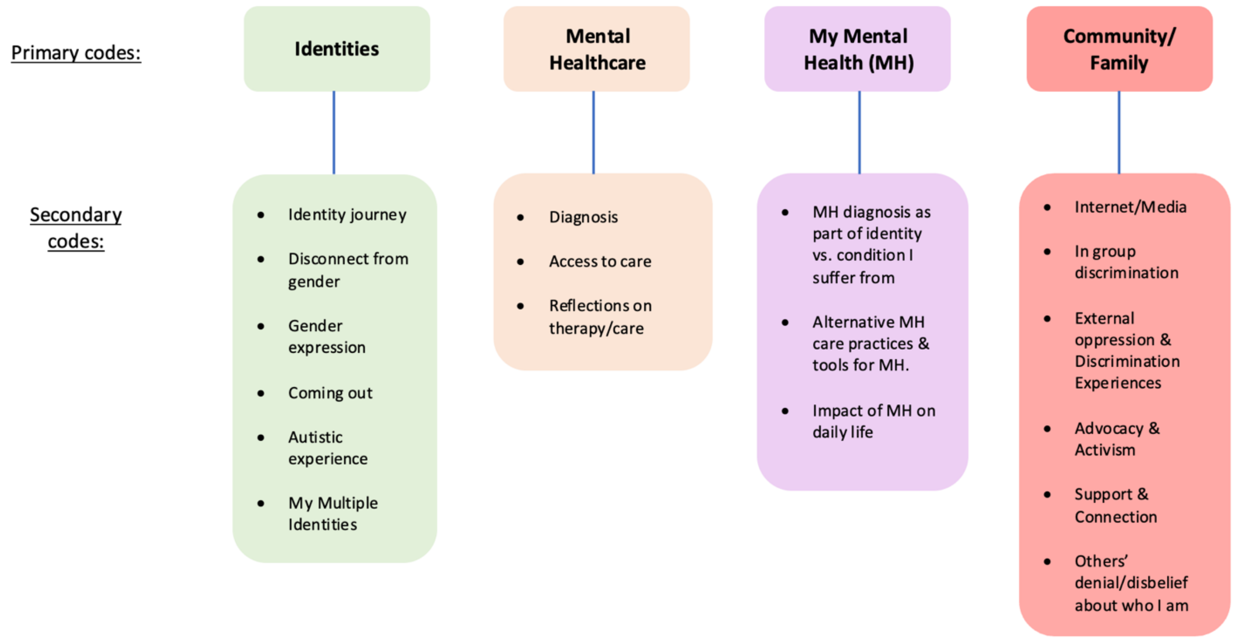

Figure C. Visual of primary and secondary codes.

Step 2 (continued): Coding & Inter-rater Reliability

Due to the volume of data, we used NVivo12, a computer-assisted qualitative analysis software program to apply codes to text excerpts in accordance with the codebook. Paragraphs were used as the unit of analysis, and thus we applied 1 code to each paragraph of interview text. A graduate student researcher (DG) and I coded the interview transcripts. To prepare for reliability coding, DG and I coded 2 transcripts together to develop a shared understanding of the codebook and coding process. We made edits to the codebook as appropriate to make codes clearer and more specific. Next, we independently coded 2 transcripts and measured reliability (practice coding round) and met to discuss discrepancies and come to consensus on all codes. Finally, DG and I double coded 6 transcripts (chosen at random), achieving substantial interrater reliability (Cohen's Unweighted Kappa = 0.69). Cohen's Kappa is a robust statistic used for interrater reliability testing with values ranging from -1 to +1, where 0 represents the amount of agreement expected from random chance, and 1 representing perfect agreement. A Kappa value of 0.21-0.40 indicates fair agreement, 0.41-0.60 as moderate, 0.61-0.80 as substantial, and 0.81-1.00 as almost perfect agreement (McHugh, 2012). Cohen's Kappa is considered a more robust measure of inter-rater reliability than percent agreement, which does not account for agreement due to random chance (McHugh, 2012; O'Connor & Joffe, 2020). After reliability was calculated, we met to discuss discrepancies and come to a consensus on all codes within the 6 transcripts.

Across the practice and final reliability rounds, a total of 10/21 (48%) of interviews were double coded by DG and I, which exceeds the 10-25% of data units that are typically double coded in qualitative research (O'Connor & Joffe, 2020).

Steps 3 & 4: Searching for & reviewing themes

Once all data were initially coded, we began the process of searching for links between the codes to collate them into potential themes. I reviewed all data excerpts within each code to draft an initial thematic map. Next, I met with the AG to review and modify the initial thematic map. Several codes were collapsed into one another, and the themes were condensed and simplified.

Steps 5 & 6: Defining themes & extracting examples

After incorporating the AG's feedback and edits, a final set of themes were drafted. We chose and collated exemplar quotes for each theme.

Reflexivity

Reflexivity is a critical tenant of qualitative research that asks the researchers to write about their biases, experiences, and values and how they impact the research process (Creswell & Baez Creswell, 2015). Throughout each step of the research process, members of our team (undergraduate transcribers and all coders) used analytic memos and reflexive journaling to document reflections. Directly following each interview, I documented my reflections in an analytic memo. While transcribing the interviews, each undergraduate researcher took detailed notes of their thoughts and reactions to the data and shared them with me. During the coding process DG and I independently wrote analytic memos, shared them with each other, and discussed reflections. In addition to writing memos, we engaged in reflexivity through zoom and in person meetings with both the AG and the student research team. During each meeting, we allotted time for collaborative brainstorming and discussion to make meaning from the data. After each interview, participants were invited to share additional thoughts and clarifications via email. No participants chose to add additional reflections or thoughts following the interviews.

Future Directions for Analysis

Thematic analysis allows us to see the breadth of ideas and concepts in the dataset and to understand and visualize connections between themes. In the future, I plan to conduct a second phase of coding using narrative analysis to cultivate a deeper understanding of individual stories present in the data.

Trustworthiness

The AG co-designed this study and gave detailed feedback on all aspects, including the drafted themes. This ongoing collaboration ensured that the data were interpreted from the perspective of a team with diverse neurotypes and life experiences.

Findings

This phenomenology explored the experiences of Autistic LGBTQ+ young adults ages 18-28 years old regarding their mental health care experiences. Interviews touched on multiple subjects and topic areas, including identities, mental health, mental health care experiences, and reflections on community connectedness and sense of belonging. The results presented here are a deep dive into participant stories and reflections on their mental health and healthcare experiences. In the sections that follow, we will: 1) briefly describe participant reflections on their mental health, 2) present the process through which many of our participants navigated the mental healthcare system and 2) describe 6 themes that emerged from the interviews that represent participant interactions with the mental healthcare system. Table 2 (appendix) includes interviewee pseudonyms and demographic descriptors to provide additional context for the quotes presented here.

Reflections on mental health

Almost 90% (25 out of 28) of our overall sample reported that they have anxiety, 80% (22/28) endorsed depression, and over half (15/28) reported that they have ADHD (see Table 1, appendix). When asked to describe their current mental health status, several participants contextualized their answer in the present historical moment (emerging from the pandemic) and described the impact of current events such as the murders of Black lives and Black Lives Matter movement. Many interviewees reflected on the impact of the pandemic on their mental health. In addition, people described that their mental health was continually impacted by past experiences of trauma during childhood (i.e., bullying in school, instances of relational trauma, therapy-related trauma via conversion therapy or being infantilized by a therapist). Many participants wrestled with the question of whether their mental health was an aspect of their identity, or a condition that they suffer from. These contrasting viewpoints on this topic are reminiscent of debates in the field around whether being “mad” [having mental illness] is a form of disability similar to neurodivergence that some may view as an aspect of their identity (McWade et al., 2015). Taken together with the high rates of co-occurring mental health conditions in this sample, these reflections underscore the salience of mental health challenges in participants’ daily lives.

Navigating the mental healthcare system

Our participants described their road to getting mental health support as a multi-step, nonlinear process. This process is visualized in Figure D (see below). We will first provide a description of this road to support for participants, followed by an in-depth analysis of themes that emerged from their experiences in the healthcare system.

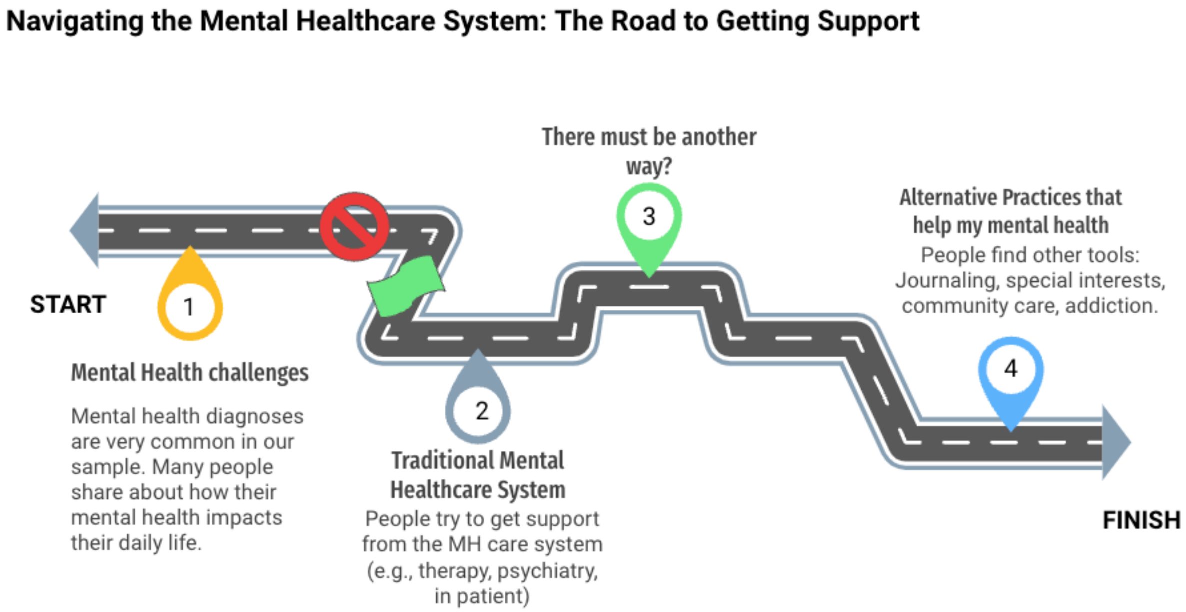

Figure D. Visual process map of participant's path in navigating the mental healthcare system.

As a starting point, autistic LGBTQ young adults described struggling with their mental health (often because of co-occurring diagnoses). The impact of their mental health on their physical health and daily lives motivated them to seek support from the mental healthcare system, which includes services such as individual therapy, group therapy, psychiatry, and in-patient programs. In attempting to access services, participants described hitting several roadblocks or barriers that made it harder for them to receive care. Most commonly described barriers include the cost of therapy and issues navigating insurance networks, as well as the substantial executive functioning burden of making and attending a medical appointment (e.g., planning out which bus route to take to the building, backwards planning the time they need to leave home to arrive on time). There were also 'green flags' or facilitators to accessing care. A common facilitator that several participants mentioned was support they received from friends and family in connecting them to vetted providers and setting up therapy appointments.

Although some participants described positive experiences with the traditional mental healthcare system, many felt that their needs were not met for a myriad of reasons (described in detail in the sections that follow). As a result of this unmet need, participants describe searching for alternative supports and ways of coping with their mental health. They describe 2 predominant forms of coping and support strategies: 1) individual practices (e.g., using special interests to regulate, using music as a tool to process difficult emotions) and 2) collective, community-based care. Although this road is depicted here as linear, in reality this was the not case for participants- they experienced many 'round-abouts' and road closures. Six themes related to participants' mental healthcare journeys emerged from the interviews (see Table 4). Each theme is described in the sections that follow.

Theme 1: "People don't believe me": Disbelief & Denial of Autistic LGBTQ+ Identities.
Theme 2: "If I was a white boy growing up in the U.S…": Intersectional Identities and multiple diagnoses complicate the road to an autism diagnosis or self-identification.
Theme 3: "College can pay for that": Accessing care through existing relationships & systems I am a part of.
Theme 4: "Mentioning my pronouns to them as a pretest": 'Reading' potential therapists for safety.
Theme 5: "I can get someone knowledgeable in autism or in the LGBT area but not both": Providers' lack of fluency in supporting diverse autistic clients.
Theme 6: Alternatives to the Traditional Mental healthcare system • 6.1: "Vectors of Autistic Joy": Individual practices & special interests that sustain me. • 6.2: Community care

Table 4. Overview of themes.

Theme 1: "People don't believe me": Disbelief & Denial of Autistic LGBTQ+ Identities.

Across contexts, and particularly in the healthcare setting, participants described experiences where others denied or disbelieved their autistic and LGBTQ+ identities. Overarchingly, interviewees told 3 types of stories around this idea of disbelief and erasure: 1) people denying or not believing that they are autistic, 2) others claiming that they don't know or can't understand their sexuality and gender as a result of being autistic, and 3) instances of providers disregarding their opinions, needs, and preferences about their medical care. Below are examples of each experience.

Sam and I met for the interview via phone. When I asked her to describe her gender identity, she shared, "for as long as I've had conscious thoughts I have known myself to be without a gender". Sam identifies with the term "genderless" but is often "typically assumed femme" by strangers. Throughout our interview, she spoke about her experience being from a Jamaican immigrant family, and how that impacted her path to discovering her queer, autistic identities. In relation to her experiences in the mental healthcare system, Sam described the interplay of her autistic, queer, and multiracial identities on her interaction with her neurologist:

> Even recently…I met with a neurologist for something entirely unrelated. But I was like, okay, it's a neurologist, and she's asked me about past things, I should just mention it [being autistic]. Like, it's a neurodevelopmental disability so like, maybe this is relevant information. So I mentioned it, and then, like, at the end of the meeting, she was like, 'Why are you so sure that you're autistic?' and I was like, 'well, like, I just know. I do also have a diagnosis, but like what do you mean by that?' And I was like, [laughs under breath] …the frustration…or she said something else about how she's had other patients who have been autistic and I'm not like them. And I was so confused, so perplexed by that. I think in medical spaces at all, I'm already a minority. I kind of don't really look like any of your patients anyways. – Sam [age 22, genderless, Black/Jamaican/Cuban/English].

Many people in addition to Sam had their autistic identities denied by people in their lives because they did not "look autistic" or exhibit stereotypical autistic traits or behaviors. Luna is an 18-year-old nonbinary person who received a formal diagnosis of autism in 2022, the same year as our interview. They described their interactions with people who have a family member on the spectrum, saying: "…their like, you're nothing like my nephew or cousin, so you must not be autistic."

Participants experienced disbelief and denial about not only their autistic identities, but many spoke or wrote about how their autism was used to negate their ability to understand their gender and sexuality. This was the case for Kennedy, a gay trans man who received a provisional diagnosis of autism as a child and then a formal diagnosis at 16-years-old. Kennedy came out as trans and queer to his parents towards the end of high school. Kennedy reflects on this coming out process:

> My parents were fine with the queer bit, but the gender piece was much tougher, they kept getting hung up on the autism piece and blaming that for my gender and suggesting that I didn't really understand my gender fully. And then they also for a while were convinced that being trans had caused the autism…- Kennedy [age 24, nonbinary/gender expansive, White].

This idea of invalidation was echoed by Amanda, who I spoke to via phone for our interview. About a year before our conversation, Amanda started seeing videos of autistic creators and experiences on TikTok, and from there, started to take self-assessments for autism and research it further. “Watching anecdotal stories” told by autistic people on social media and doing her own reading were critical parts of her journey to self-identifying as autistic. Amanda describes watching others be denied gender-affirming or reproductive health care because of their queer autistic identities, and the interplay between them:

> …I haven't experienced this because I don't really talk about my autism very much. But I've seen a lot of people get invalidated for their gender identity or their sexuality because they're autistic too. And they're just like, oh well, you are just an autistic person. You don't know what's going on…you're just mimicking someone else. And, you know, that's hurtful, and it's not correct…but that's something that I've seen other people go through…to have someone just tell you, oh you--you know, you can't be trans because you're autistic. And we don't want to help you go through your transition because you're autistic and you're disabled. And we don't want to, you know, you don't have the bodily autonomy that other people do. -Amanda [age 25, woman, White].

Participants describe being painted as a kind of unreliable self-reporter in the healthcare setting, describing instances where their opinions, wants, and needs were disregarded by providers in the context of their care. Alex is a transmasculine genderqueer 18-year-old who started to explore that he might be autistic during the pandemic through online research and received a formal autism diagnosis from his provider a year later. He is a first-year community college student and an artist of multiple modalities, including make up artistry. In describing his experiences with mental healthcare, he commented on this idea of the ‘unreliable self-reporter’, saying:

> I see so often that queer autistic people, especially queer autistic people who have a psychiatric disorder, we’re always doubted about our self-knowledge and self-understanding, which is so not fair. You know, trust the people that you’re treating to know who they are. And even if they’re questioning their identity, or they’re not totally sure that they’re autistic, they are sure that they’re questioning so then they have understanding. The lack of understanding is, in and of itself, self-understanding. So being able to just listen and understand and acknowledge when you don’t get something…that’s super important, because it will happen. -Alex [age 18, genderqueer transman, White].

These experiences of erasure led to some participants feeling less comfortable coming out as queer and/or autistic to providers and family members. Aidan and I had our conversation via zoom video, and he shared his thoughts as both an autistic queer person and as a healthcare provider, as he works at a psychological testing clinic. Aidan describes the preparation that many autistic people do to try to 'prove' their autism in the healthcare setting, and to counteract this narrative of the 'unreliable reporter'. He describes how this fear of being disbelieved can deter people from seeking and accessing care that they desperately need.

> I have a friend who's about to get evaluated for autism who's going in with five pages worth of history notes of her childhood and things she's experienced just to make sure that she's coming in with everything she needs and she isn't going to be gaslighted or demeaned in her experience as an autistic woman. Because there are so many stigmas against folks like us. It's just…it's definitely been my own experience. And I've heard endless experiences of my friends and clients I've worked with of just having so much reservations, skepticism of receiving care, because they know that people might not understand those intersections [of identity] going in and dismiss them because of it. -Aidan [age 23, Man, White].

Across contexts, participants shared experiences of one or more aspects of their identities not being recognized or actively denied and disbelieved by providers, family members, and others. Ryan describes this in relation to her experiences walking through the world as a nonbinary person on the spectrum:

> Sometimes people don't believe me when I tell them because I am high functioning, uh, and I don't really like that and I don't really want to have that conversation, um, where I'm trying to convince somebody else- of the way that my brain works. -Ryan [age 26, Nonbinary/gender expansive, White].

Jasmine, who was diagnosed with ADHD and OCD before receiving a formal autism diagnosis after graduating college, echoed this experience with both acquaintances and in coming out as autistic to her family:

> I've had people tell me, 'Well, autism is not a disability' and I'm like, really though? Or like, 'you're not like my autistic cousin, niece, whatever' and I'm just like okay, well, all

> right. Now I know, [this is a] off limit topic, you know because I think…I've always felt like I've had to convince people, even my parents when I found out I was [autistic]…it took 2 months before I finally told them. I told them first like, I just have an ADHD diagnosis. And then I wrote them an email because I knew if I told them on the phone they were gonna think it's a debatable conversation, and that was not what I was for. It was more like, 'I had a doctor give this to me, it is not up for debate. This was their outcome. My therapist has always thought this." -Jasmine [age 26.5, Woman, White].

Theme 2: "If I was a white boy growing up in the U.S…": Intersectional Identities and multiple diagnoses complicate the road to an autism diagnosis or self-identification.

Most interviewees were diagnosed as autistic or began to self-identify in early adulthood, and many described the path towards discovering their autistic identity as nonlinear and complex. Disparities on the basis of race/ethnicity, location, gender, and access to resources were mentioned as major barriers to getting an earlier diagnosis. This was the case for Luna, who is an 18-year-old Latinx nonbinary international student here in the United States. They received their autism diagnosis earlier in the year of our conversation. They reflected on their experience as an undiagnosed autistic child growing up in a South American country:

> If I was a boy, if I was a white boy growing up in the United States, I would have easily gotten my diagnosis as a baby. Because I was a nonverbal toddler. I didn't speak, I didn't have friends…I stimmed a lot…I would have had a completely different childhood. Latinas are the most under diagnosed demographic when it comes to autism. A lot of barriers come with 1) not having resources in our home countries in Latin America, but also social barriers. Latino families are more likely to blame everything except a neurodivergence on the struggles of their children. Like their like, 'It is because our family is struggling as well.' You know, it's a behavioral problem, or it's a religious problem. It's everything except autism.- Luna [age 18, Nonbinary/gender expansive, Latinx].

Others described how being LGBTQ+, and specifically a trans person who was assigned female at birth, made them question whether they would be able to receive an official autism diagnosis:

> Then in the fall of 2021, I received an official diagnosis, which I sought for the sake of accommodations for school. And…I knew for a fact that I was autistic before I was diagnosed- after that full year of being able to reflect and learn about it. But it was nice to have that confirmation. Like, 'yes!'…especially being trans, you know, assigned female at birth, being hyperlexic at an early age, being able to speak, being able to mask…the

> fact that I could get diagnosed at all was like, alright, even though a lot of doctors wouldn't say you're autistic, this one does, which definitely helped solidify my identity a bit. We did a lot of research…I met with an autism and ADHD specialist who specializes in autism in adults and people who are assigned female at birth. They're autistic themself."- Alex [age 18, genderqueer transman, White].

In addition to disparities due to intersecting identities, many people felt that their road to autism was complicated by the fact that their providers attributed their early autistic traits to their other diagnoses or disabilities. Lucia is a 25-year-old Lesbian woman who received an autism diagnosis when she was 20 years old. Throughout the interview, she described her experiences as an autistic queer person, mental health provider, and disability justice activist. She told stories of growing up with a severe skin condition, which impacted and ultimately delayed her road to an autism diagnosis:

> …as a child I had a lot of health conditions. Specifically, I had a form of dermatitis, just like a skin condition that was very, very severe. So I had like a 504 plan, and I had in school accommodations, and I was very much like, experiencing disability from birth. And so I think that a lot of things that could have been, perhaps, signs of autism were attributed to my skin, because they were seen as behavioral things, they were seen as me reacting to the discomfort of my skin, sensitivity against skin. I recently was reading a neuropsych eval that I received when I was 6, which I got for my 504 plan. And it's fascinating to read, especially as a clinician, they are naming sensory seeking behaviors, lack of eye contact, but they're attributing lack of eye contact to visual problems…so I was formally diagnosed [as autistic] when I was like, 20. And that was something I sought in college. -Lucia [age 25, Woman, White].

Several participants were diagnosed with another neurodevelopmental disability before eventually receiving an autism diagnosis. Jasmine describes being diagnosed with OCD as her "first journey in the mental health sphere" before receiving ADHD and autism diagnoses years later. For her, "…there were just a bunch of things that kind of evolved to those diagnoses but were harder to get because they were…being a female, you know- less textbook, in some ways." Over half of the interviewees (11 out of 28) report having ADHD in addition to autism, and several spoke or wrote about the overlap in ADHD and autistic traits, and how that complicated the road to an official diagnosis or self-identification with autism. Aidan was, "very hesitant to self-diagnose myself [as autistic]…I didn't feel comfortable taking that label when it had not actually been bestowed on to me because there's such a big overlap in ADHD and autism and the way that trauma plays into that can be super complex and I didn't want to take a seat at the table that wasn't mine, essentially." In these cases, the overlap in traits and behaviors associated with co-occurring conditions and disabilities complicated the road for many to an autism diagnosis.

Theme 3: "College can pay for that": Accessing care through existing relationships & systems I am a part of.

Participants described several facilitators to accessing care or a diagnosis, including getting connected to services through existing relationships and systems that they are already part of. The college campus health system is one avenue through which several interviewees were able to access 1) an autism assessment/diagnosis and 2) free individual or group therapy services. This was Aidan's experience:

> And [college] has this program called Engage- it's an academic support services for neurodivergent students. And so I was involved in that. And I found- my service coordinator let me know, she was like, 'We can give you updated diagnostic papers and you don't have to pay', because I mentioned I was like, 'I'm interested in getting diagnosed…so expensive.' And she was like, 'Well, [college] can pay for that, actually.' And so I was like, 'Oh, sick!' So I got booked for a psych evaluation with them completely free for me, which was awesome. -Aidan [age 23, Man, White].

Sam also pursued an autism diagnosis in college and was, "only able to do that in the first place because I applied for a grant from [university] …so I was able to get the grant to pay for the assessment, since it didn't take insurance as it was like a teaching school."

Although the college campus healthcare system helped connect people to care, participants lamented that they wished they had more sessions than the small number provided by their university as part of the short-term covered care.

Another system that Alex was a part of was his local LGBTQ+ community health center, or "Pride Center", where he found a therapist that felt like a good fit:

> Yeah, I had heard that the [state of residence] Pride Center had, you know, therapists, and I was like, 'well, I've had some queerphobic therapists in the past, we'll give that a shot….' Just kind of a coincidence that she ended up being so like, accidentally neurodiversity affirming, you know, even though she never used that word or brought up anything like that. -Alex [age 18, genderqueer transman, White].

Being already connected to or embedded within a system that includes mental health services allowed many participants to access diagnostic and care services, often for the first time. In addition to these systems, several participants got connected to care through existing relationships with family members or colleagues. Ryan describes how her mom, who is a psychologist, made it easy for her to get into therapy:

> Yeah she was the best therapist that I've ever seen…that felt like a really really good time and I hadn't really had many experiences that felt so helpful, um, this—so my mom being a psychologist, um, and knowing me very well, uh, she knew a lot of people working in the area and she- she knew of this woman and since she was the one kind of having an intervention with me being like, 'you need to go to therapy,' um, she was like, 'listen, I'll hook the whole thing up and you just go.'…so yeah that was great, it- that's she's always made it very accessible for me, I feel like if it was just up to me to try and find somebody, that would suck. But to like have the privilege of you know, a doctor in my house, who has known me forever being able to just set it up for me…very cool. -Ryan [age 26, Nonbinary/gender expansive, White].

Others had a similar experience, where existing relationships or connections acted as a facilitator to accessing mental healthcare. This was the case for Kris, a transmasculine nonbinary queer person. Kris pursued and received and autism diagnosis several months before our conversation but in reflecting on his childhood noted that he, "always knew I was different". Kris and I spoke about our shared passion for bringing queer inclusivity into research and medical spaces, and the importance of mental healthcare access for autistic people. Kris reflected on his own mental health and past experiences of trauma, describing that ultimately their relationship with their colleague led them to get support for PTSD:

> Oh, and then my colleague actually connected me with the psychologist. So I, we were literally in a booth at [hospital of employment]. I'm like, 'I think I have, I think I have PTSD.' And she's like, 'Why do you think that?' I'm like, I like pulled out my phone. I'm like this, this this. I'm like, experiencing all of these. And she was like, 'Okay, let's like, let's go.' So she helped me like, pull up, you know, Psychology Today and comb through people. She was like, I want to make sure they have the certifications that will specifically treat this. And then she taught me about CBT therapy. -Kris [age 28, transmasculine nonbinary, White].

In addition to the examples above, countless other interviewees described being connected to care through family members or colleagues who served as supports for them in navigating the mental health care system.

Theme 4: "Mentioning my pronouns to them as a pretest": 'Reading' potential therapists for safety.

Many described challenges in finding a therapist that felt like a good fit, and that they deemed "safe" to hold and meet both autistic and LGBTQ identities and experiences. Participants found themselves 'reading' their potential therapist; looking for clues that show how the therapist views autism, how they relate to neurodivergent people, and their understanding of LGBTQ+ identities. This was the case for Jamie, who uses the uses the pronouns 'per/per/pers', which originates from the word "person". Jamie and I had our conversation over WhatsApp, a synchronous text-based chat platform. Per identified as asexual "before anything else" and "internally knew that since middle school". Jamie was diagnosed with social pragmatic communication difficulties earlier in life. During graduate school, Jamie spoke with per therapist about a potential autism diagnosis and eventually switched to another provider who specialized in autism, who gave per a formal diagnosis. Jamie described this process of 'reading' or testing a potential therapist:

> Lots of therapists will claim to be LGBT friendly as a marketing thing but then will have no idea what anything means. I try to ask people in advance on the phone how they feel about me being transgender and mentioning my pronouns to them as a pretest. It can be

> exhausting trying to educate someone while also trying to receive help, even if they have the best intentions. -Jamie [age 23, Nonbinary/gender expansive, White].

Amanda described a similar process of trying to sense or ‘read’ whether potential providers are LGBTQ-affirming in this excerpt from our conversation:

> Amanda: It's not necessarily about like, oh, are you able to just provide, you know, the help for me. It's like, 1) are you able to provide the right help for me, but 2) do we just have mesh-- you know personalities that mesh. Are we--you know, do I feel comfortable with you? Do I feel like you will understand, at least to some degree, what I'm going through. Like if I talk to a therapist, and they're like, yeah, I'm not LGBTQ but my brother is or, you know, my best friend is or something. It's like, okay, so I know you're fine with that.
>
> Lauren Baczewski 1:00:13
> Yeah, absolutely. Like just kind of wanting to get to know that person, it sounds like, so you have a sense of where they stand. And if you're aligned in similar sort of viewpoints of the world.
>
> Amanda 1:00:24
> Yeah. And it's like, it's--it feels very taboo to talk about politics, in that sort of sort of situation, but like, I'm sure you are probably on the same page of if you're going to a therapist, and they are super pro Trump, it's like uh no [both laugh]. You're-- we're not on the same page here [chuckles]. This is not gonna work.

Participants described trying to understand the political, moral, and in some cases religious beliefs of their potential therapists, in an effort to ensure their safety during sessions and consider the possibility of unmasking or not having to mask during therapy. Kim is a nonbinary queer person who was raised in an Evangelical Christian household and describes that they have “religious trauma…[that] was exacerbated by the fact that I am autistic” because they took the words of the Bible “literally”. They describe a childhood where they “told my parents that reading the Bible made me so bored I wanted to cry, and they were like, ‘That’s Satan influencing you.’ I was like okay, guess I’m a permanent sinner.” Kim describes how they try to gauge a potential therapist’s religious leanings when screening them:

> And then, just for me also, I usually like to specify that because I did have that religious upbringing. I have a lot of religious trauma, and so I'm like, “I don't want any praying or

> God stuff like. I don't want you to mention this stuff, I don't want to, like I don't want to talk about it. It's really disserving for me and overwhelming. And so it's really important that my therapy not be faith-based," which is harder to find than you might expect [chuckles]. -Kim [age 26, Nonbinary/gender expansive, White].

Several participants were able to find therapists that felt 'safe'. Those providers were often queer and/or neurodivergent themselves or disclosed early on that they have personal relationships with neurodivergent and/or queer people, signaling some degree of respect, understanding, and/or care. Lucia's therapist is an example of this:

> I was able to find a therapist, she actually is in Seattle, but she's licensed in Washington and New York, whose partner was autistic. And she herself is identifies as neurodivergent has ADHD. And that was really good for me. Because I could trust that this is someone who sees autistic people as peers, you know. But it, yeah, it was really, really hard to find. -Lucia [age 25, Woman, White].

These personal relationships with queer and/or autistic people signaled to participants that the potential provider has some degree of respect, understanding, and/or care for autistic or LGBTQ+ identities. This process of looking for signals, clues, or indicators of safety in potential therapists was a taxing but necessary part of the process of finding a therapist.

Theme 5: "I can get someone knowledgeable in autism or in the LGBT area but not both": Providers' lack of fluency in supporting diverse autistic clients.

In searching for providers, interviewees described difficulty in finding therapists who were skilled in supporting them around both their autism and queerness, and the intersection of those identities. Jamie describes this challenge, writing, "when choosing a therapist, it ends up being a lot of picking and choosing. Like, I can take someone knowledgeable in autism or knowledgeable in LGBT area but not both." Some providers explicitly decline working with autistic or neurodivergent clients due to lack of training, and this is what Lucia experienced during her search for a new therapist after moving to a new state prior to graduate school:

> I mean, so when I, when I first tried to find when I when I first moved back to the city after college, and I tried to find a therapist in the city it was incredibly difficult to find anyone who was even open to working with an autistic adult, I had- multiple therapists write back and just say no, I'm not comfortable. It's not my area of expertise. Um, and that was really hard. -Lucia [age 25, Woman, White].

Overarchingly, participants described instances of feeling like they had to educate their therapist on one aspect or another of who they are. They tell stories and give examples of providers who are lacking fluency and training in supporting autistic clients from diverse backgrounds and identities. Lucia, who was a student in a Master of Social Work program describes the lack of training she received in disability as a mental health provider herself:

> Um, you know, I think there's also just like a, a definite lack of awareness. Like, I mean, oh my god, there was not a single mention [of autism] within my program…I also think there's this lack of awareness amongst clinicians of kind of how autism can manifest. And, and then I think, because of that lack of awareness, there can be an over attribution of symptoms to mental health disorders. Rather than understanding them potentially as connected to autism symptoms or maybe for other people ADHD or things like that, that could be specific to that. -Lucia [age 25, Woman, White].

Interviewees had a clear vision of what 'fluency' in supporting autistic and LGBTQ+ identities looks like in provider, describing either positive experiences they have had in therapy or things they wish providers would do. The goal is to find someone who is neurodivergent and LGBTQ-affirming. Interviewees gave examples of neurodivergent-affirming care they experienced, which includes taking actions like incorporating special interests and other autistic traits and preferences into the care or therapeutic space. Alex shared a story from childhood when he worked with a therapist who incorporated his special interest into sessions to build rapport, safety and comfort following a traumatic event:

> I did also have a really good experience with a therapist…I had been sexually assaulted at a very early age and so processing that with a therapist and all of that. He let me use my special interests in sessions. And you know, I was not diagnosed at the time, we did not know that I was autistic, but I was really into you know like princesses, Disney, all of that stuff. And also Hot Wheels, those toy cars. And he, I think it was something like he attended monster truck rallies. And he'd talk about that because that's a fun thing, it

> lightens the mood. And so I decorated- I got like a hot wheel monster truck—I decorated with like, glitter and rhinestones, and I painted it pink. And I called it the ‘princess monster truck’. And I gave it to him, and he loved it and like put it on his shelf. And that’s just such a really precious memory to me. Like I want to get a princess monster truck tattoo…that’s so important to let autistic people not just talk about their special interests, but use it as a form of healing, because they are the things that we are most passionate about and that we hold closest to our hearts. -Alex [age 18, genderqueer transman, White].

Additionally, providing a sensory-friendly environment can make the therapy space into a safe haven for neurodivergent clients:

> …One of our clinicians in the office…she has these beautiful twinkle lights, she has little subtle rainbows everywhere to let her queer clients know they're affirmed, even if they have like parents coming in who aren't. There's squish mallows. There's lots of very like, there's, there's weighted blankets, there's soft pillows, like there's the-- she always asked like, how's the lighting for you. There's like…lots of different options for sensory input and regulation that we add in. And that is always like regardless of neurodivergent status, even neurotypical people are comforted by that. It's such a green flag, to know that someone's going to realize how much the environment plays into how you're going to be able to process your feelings. So that's always a green flag for me. -Aidan [age 23, Man, White].

Fluency was also described as having an understanding of queer identities, doing the work to self-educate, and acknowledging the systemic oppression that autistic LGBTQ people face walking through the world (and how added components of identity such as race/ethnicity play a role in people’s experiences). On this point, Luna shared, “They have to understand that thing that hurts you isn’t being autistic, it’s the fact that the world is really ableist.” This was echoed by Quinn, who I spoke to via Zoom video. Quinn is a 19-year-old college student who pursued a formal autism diagnosis during the pandemic. He is very engaged with disability advocacy on their college campus, and initially started to learn about and identify with autism through watching the TV show “Community” which has an autistic character who uses scripted language from media and TV. They spoke about how Cognitive behavioral therapy (CBT) “has never worked for me”, and that CBT techniques do not address that fact that, “The things that I deal with that cause my anxiety…are pieces of structural oppression.” He described wanting a therapist who understands the structural oppression that autistic people face, and who wants to help them adapt to and feel more comfortable getting through the day. Lastly, in thinking about an autistic LGBTQ+ ‘fluent’ provider, participants wanted to be asked for their feedback in building the care plan, acknowledging their agency as a collaborator in the therapeutic process:

> And then what I thought was very interesting is both of the good therapists I've had during the first meeting were like, you know, “This feels like a good fit for me. How are you feeling? I would like to continue treatment, but you know I want to check in with you and make sure that you also feel like this is a good fit.” And it was the first time [chuckles] anybody, any therapist, had asked me that. I was like, “Yeah, actually, yeah, I think this is a good fit!” -Kim [age 26, Nonbinary/gender expansive, White].

Theme 6: Alternatives to the Traditional Mental Healthcare System

In reflecting on their mental healthcare journeys, participants expressed frustration with a system of care that was often inaccessible to them or that had caused them harm in the past. Several participants described experiencing trauma in past interactions with the healthcare system, in settings such as group homes or inpatient hospital programs. When interviewees recalled memories of these experiences, their discomfort was apparent. Many used humor to deflect, noted that they had “artfully skipped over” that part of their healthcare story or “blacked it out”, and in some cases the speed of their speech increased noticeably. As a result of these harmful experiences and other barriers to care, many participants searched for alternative practices and tools to help them cope with their mental health, outside of more traditional forms of care (e.g., therapy, psychiatry). These alternative practices tended to take two forms: 1) individual practices and tools, and 2) community healing and care practices. Each are described below.

Theme 6.1: “Vectors of Autistic Joy”: Individual practices & special interests that sustain me.

Participants described the discovery of individual practices or tools that helped them to access and process their emotions, and cope during times of stress. These practices are person-specific, individualized and tailored to the person's preferences and interests, the things that motivate and feel comforting to them. Amanda shared how she uses music to sit with and access her emotions:

> And listening to music for me sometimes can be like…it can bring up so many different emotions and it can be really like cathartic. And honestly sometimes I've sat and listened to music for like 2 hours and just kind of thought through everything and like, felt so much better after. And yeah, I was sitting there crying for half the time and going through it just like listening to music…and you know, music is never branded as something to help you process your mental health issues or help process your trauma, but it helps for me. And so it's kind of like one of those things that I've just figured out throughout the years…and if I don't do that for a long time, then I kind of feel the effects of not really processing things as much as I should. -Amanda [age 25, woman, White].

Many of these individual practices have threads of connection to autistic traits or experience, and using existing special interests, modes of stimming, or sensory experiences to bring comfort and joy. Luna described these experiences as "vectors of autistic joy", saying:

> …There's a lot of things that I call vectors of autistic joy. For example, as much as our hypersensitive senses can bring us discomfort and distress, they can also give us a lot of happiness. Like I wish that I could lend my non autistic friends my autistic ears, so they could experience music the way that I do….my special interests as well. I also wish that I could give my non autistic friends the ability to be so invested in something the way I am with my interests. - Luna [age 18, Nonbinary/gender expansive, Latinx].

Several others echoed this idea of engaging with special interests as a healing practice, including Alex, who said, "…nearly all of my coping mechanisms revolve around a special interest I currently have or had at some point." Sam shared on the importance of crocheting as a coping mechanism, reflecting how it provides both sensory input and serves as an autistic comfort item that she prefers to bring with her wherever she goes:

> …with crochet and knitting, I have been doing that since childhood. And so they were both things I've done on and off throughout my life and then really started doing again in 2020. It just brought me a lot of peace. And then I think as far as like an outlet for coping

> and experiencing the world, my attention shifted from music to crochet…I noticed that like, I think I stim with crochet…I like the specific movement of it. It's just very, like, it's just exactly what my hands need sometimes. It's also become my, I know that there's a term that people use, but like the thing of autistic people often having an object that they just carry with them even if they're not using it. -Sam [age 22, genderless, Black/Jamaican/Cuban/English].

Coping mechanisms were not always "positive" or health-promoting, as some participants described using distraction or in some cases, turning to substances to cope. When asked about things that help her mental health, Jasmine shared:

> I don't know. Sometimes I always struggle with this, but like I mean, I love Korean dramas. So it's like, usually- and that sometimes is my coping strategy, which is really just avoiding [chuckles]. It's not really solving my problems. But like you gotta do what you gotta do. -Jasmine [age 26.5, Woman, White].

Luna described needing to be hospitalized for their mental health during the pandemic, but not being able to be admitted. She describes grappling with her mental health during the pandemic while attempting to recover from addiction, saying:

> I would say the pandemic was a big thing for autistic people everywhere. But especially for me, mostly because both my parents were healthcare workers, like frontline workers, during the pandemic. So I would say that was something that really affected me, especially my access to healthcare. During that time, I definitely needed to be hospitalized for my mental health, but I couldn't be…I was also suffering with addiction, which was a horrible…even worse than bipolar I would say, recovering from addiction. Because with bipolar, I just had to take medication and I was fine…I was 18 years old and trying to recover from an addiction by myself too. I don't have siblings, both my parents were working like crazy people so I was alone a lot. - Luna [age 18, Nonbinary/gender expansive, Latinx].

In the case of substance use or distraction/detachment, some of these individual practices or coping mechanisms may result in participants returning to the traditional healthcare system for support or treatment despite their efforts to cope outside of it.

Theme 6.2: Community Care

In addition to individual practices, participants described their connection to others, in particular the autistic LGBTQ+ community, as an alternative method of mental health support. Alex articulates this:

> A really overlooked form of mental healthcare is community care. And not just community services, but people who are not professionals—friends, family, etc., providing the support that they are comfortable providing, that has been huge for me as well. Finding people who understand it…autistic people, you know, queer autistic people…that has been just massive in improving my mental health. Community care is also mental healthcare and should not be overlooked or seen as lesser than professional care, it is just different. -Alex [age 18, genderqueer transman, White].

This sentiment was echoed by Lucia, who views mental healthcare as more expansive than the traditional forms of care:

> Therapy is not the only form of mental healthcare. Psychiatry is not the only form of mental healthcare. Mental healthcare can be community care, it can be having peers who relate to you, it can be giving yourself permission to have a sensory space. I think we have this idea of mental healthcare as exclusively a medicalized thing. But caring for mental health can be so much more than that. Therapy can be really great. Therapy is also not always great. Harm can be done, and I think mental healthcare is much more expansive. -Lucia [age 25, Woman, White].

One way people cared for community members was through the sharing of community-authored knowledge, resources and supports. Aidan describes his experience with this, and his passion for connecting others through his queer and neurodivergent advocacy work:

> A lot of it [finding a good provider] is through the grapevine. Like that's also why I think community is so important...like I'm in several Facebook groups. I have this one…it's for trans men in the [state] area. There's always questions of like, what gynecologist do you guys go to like, what therapist do you guys see? Do you know of any housing that's affirming that I'm not going to feel like scared about?...Pooling resources is such a big thing…I even have like a specific list for that intersection of neuro queer of like here are people who know about that, who are educated on it…whether it's a support group, just a meet up group, whether it's actual mental health professionals. I think community can play a big role in accessing that as well. -Aidan [age 23, Man, White].

Several participants who had positive experiences in therapy found their providers through recommendations from other autistic LGBTQ+ people, including Kennedy:

> …they [therapist] were recommended to me by my access consultant at school (the person working in the disability accommodation office), who was himself trans and autistic and so he knew a lot about autism-affirming services in the area. -Kennedy [age 24, nonbinary/gender expansive, White].

There were many complexities to the idea of community care, because not all participants felt that accessing community and being connected to others was easy for them. In fact, there may be barriers to accessing community care, too. Kim began self-identifying as autistic a few years prior to our interview. They named having a hard time "feeling like I'm allowed to participate in social situations", which is a "significant barrier" for them to meet others and access community. Thus, the internet and social media were very common paths for people to connect to autistic queer community and see other visible queer autistic people. Participants shared complex reflections on what parts of the autistic and/or LGBTQ+ communities feel like home to them, and which do not. Often this had to do with the intersectional identities autistic queer participants brought to queer or autistic environments. Sam reflects on this:

> I have a lot of politicized identities. And there are many intersections between them. And so now I tend to interact with lots of [social media] content that is already within some kind of intersection. So like, I don't just interact with women, like I might specifically interact with Black queer women or like, autistic queer people. So it's easier now in that way that I found people who are already within intersections that start to make me feel closer to them…but I know if I were to step outside of the bubble I've kind of created for myself, that there isn't space generally made for autistic people in queer spaces. Not even for disabled people in general, I don't think. – Sam [age 22, genderless, Black/Jamaican/Cuban/English].

Despite the complex nature of community connectedness and belonging, community care was described as a critical alternative form of mental health support for many. These alternative methods of healing were born out of necessity in the face of closed doors and inadequate care within the traditional mental healthcare system.

Discussion

The aim of this study was to conduct an in-depth exploration of the mental healthcare experiences of autistic LGBTQ+ young adults in the United States. Interviews with 20 participants resulted in the generation of 6 primary themes: 1) disbelief and denial of autistic LGBTQ+ identities, 2) intersectional identities & multiple diagnoses complicate road to an autism diagnosis, 3) accessing care through existing relationships and systems I am a part of, 4) ‘reading’ a provider for safety, 5) lack of provider fluency in supporting diverse autistic people, and 6) alternatives to the traditional mental healthcare system. Participants had diverse experiences within the mental healthcare system. Some people were able to access affirming mental healthcare and were satisfied with their support, while many others struggled to find and access quality care and some experienced harmful and discriminatory interactions with providers.

Every participant in this study (N=28) reported that they have at least 1 co-occurring mental health condition or disability in addition to autism, with ADHD, anxiety, depression, and PTSD as the most endorsed diagnoses. The high rates of psychiatric diagnoses reported by our sample are consistent with other, larger-scale studies of autistic LGBTQ+ adults. Hall and colleagues found that autistic queer and trans adults are twice as likely as their autistic non-LGBTQ+ counterparts to have a psychiatric diagnosis (Hall et al., 2020b). Although studies focused on healthcare disparities of autistic LGBTQ people are relatively few, interest in this area is rapidly growing. Extant studies show that compared to autistic non-LGBTQ people, autistic queer and trans people experience greater disparities in both physical and mental healthcare, and have more unmet healthcare needs (Wallisch et al., 2023). This study adds to existing literature by providing an in-depth look into the experiences of autistic queer and trans people within the mental healthcare system in the United States.

Interviewees (n=20) expressed disappointment and frustration with their difficulty finding mental healthcare that met their needs, and creatively reimagined what their mental healthcare could look like. As a result of being dissatisfied with their care and at times being actively turned away by providers who do not feel comfortable working with the autistic community, interviewees looked for other forms of support to cope with their mental health. Many participants developed alternative coping strategies, some of which were individualized and tailored to their specific needs and preferences, and another major form of coping was to connect with and receive support through community care. In this way, participants adapted to their reality of often inadequate care, taking agency in finding other pathways to healing.

There were complexities to these alternative practices of care. Several participants engaged in individual coping practices that were less “positive”, including substance use or distraction/detachment—which may ultimately result in people needing to seek support or treatment from the traditional mental healthcare system again, creating a kind of feedback loop. Some participants felt that their individual practices/tools could take the place of working with a therapist or other mental health provider. These strategies may be adaptive for many. However, viewing these individual practices as a replacement for traditional care could impact people’s openness to engaging with the mental healthcare system again in the future, should they need additional levels of support.

In examining participant experiences while in the mental healthcare system, those who had positive experiences with their care often had family and/or friends help them get connected to care. These family/friends often referred and/or encouraged the participant to seek out mental healthcare, and sometimes served as a form of care coordinator, scheduling appointments and searching through insurance databases. Several participants told stories of positive experiences with their providers, describing therapists who viewed their autistic traits and special interests as strengths and incorporated them as tools in therapy (e.g., using special interests as ways to build rapport and process emotions). Providers felt 'safe' to participants when they acknowledged the structural oppression and ableism that participants face. Additionally, these affirming providers actively encouraged the participant to be a collaborator in their care plan, asking upfront about communication style and preferences, and soliciting their feedback throughout the therapeutic process. Many interviewees with positive experiences in care had providers who were neurodivergent and/or queer themselves, or who were strongly allied with the community. Although some participants had queer and autistic-affirming experiences with mental healthcare, the vast majority faced barriers of some kind accessing services. Most of this sample received a diagnosis of autism or began to self-identify as autistic in adulthood, around age 18. This later age of diagnosis may in part be explained by 1) a complicated diagnostic landscape due to the participant having multiple different diagnoses and/or disabilities, many of which have overlapping traits and behaviors and 2) disparities in accessing a diagnosis due to cultural stigmas about autism and presentations across genders.

Across the six themes that emerged from the interviews, participants emphasized the role of community connectedness on their mental health and healthcare experiences. Having relationships with other autistic LGBTQ+ people (either in person or online) made it easier for many participants to get connected to affirming care (e.g., through referrals to vetted providers). Furthermore, seeing and hearing stories of other autistic LGBTQ+ people acted as a powerful counter to participant's experiences of feeling erased, invisibilized, or disbelieved by providers and others in their lives. This idea of belongingness cultivated through seeing oneself represented in someone else is one important aspect of autistic community connectedness, as conceptualized by Botha and colleagues (Botha et al., 2022). Connecting to the autistic and/or LGBTQ community was not always easy for participants, and some participants shared experiences of in-group discrimination, or internalized ableism or homophobia. Future research should conduct a more in-depth examination of autistic LGBTQ+ people's experiences in relation to barriers to connecting to community. Overarchingly, participants' community connection (or disconnection) had great impact on both their mental health and mental healthcare experiences.

Limitations & Strengths

The demographics of this sample may not be reflective of the diversity within the broader Autistic LGBTQ+ community across the United States, particularly in terms of race/ethnicity. The overall sample was predominately White (64.3%, 18/28), and of those interviewed, 75% (15/28) identified as White. Although participants were from a variety of states across the U.S., the majority were college educated, reporting that they have completed some college or a Bachelor's degree. Another possible limitation is that this study did not include a measure of autistic traits, which may have allowed us to characterize our sample further and contextualize our results accordingly. Our sample is inclusive of those with a formal diagnosis of autism and those who self-identify as autistic, as it can be difficult to access a formal diagnosis due to financial and other reasons (Lewis, 2017; Mandell et al., 2009). We did not require our participants to provide proof or documentation of their autism, which may be seen as a limitation by some. However, the results of this study emphasize the importance of believing autistic queer people and underscore the importance of self-identification for many who face numerous barriers to accessing a formal diagnosis.

In terms of strengths, this study highlights the perspectives of autistic LGBTQ+ young adults who identify as non-binary, gender expansive, or gender fluid. The experiences of those who do not identify with a binary identity (man/woman) are oftentimes less represented in research, even within research inclusive of trans identities (Matsuno & Budge, 2017). Many of the themes that emerged from this study are in line with others who have conducted research with gender expansive autistic people about their lived experiences (e.g., Maroney & Horne, 2022). For the majority of our participants, their diagnostic journey or self-identification as autistic was recent, during the young adulthood years. This study is unique in that it provides an in depth look at the experiences of late-diagnosed queer autistic people and highlights the barriers and access challenges that may have contributed in some part to their later diagnosis.

Although increasing, community partnered studies are still not commonplace in autism research. Each part of this study was built though intensive collaboration with the advisory group, but we faced challenges to this partnership at numerous times in the research process. University Institutional Review Boards (IRBs) and other governing bodies are often not familiar with community partnered research, and there are significant barriers to getting autistic partners listed on IRBs, restrictions on what they are able to do in their roles on the project, and challenges in getting them paid through grant funds. Thus, there are many opportunities for future research and institutional-level work to advocate for change in this area.

Implications

Diagnostic implications

Several studies, including this study, have found high rates of co-occurring conditions and disabilities among autistic LGBTQ+ people. Over half of our sample reported that they have ADHD, and the vast majority endorsed anxiety and depression (90% and 80% respectively, see Table 1, appendix). Our findings suggest that the complex psychiatric and medical profiles of autistic queer and trans people may contribute to delays in receiving an autism diagnosis, and/or self-identifying. Overlap in characteristics and behaviors can complicate differential diagnosis, and we need to equip providers with both training and measures that support them in this area. There are several examples of new measures that are designed to aide clinicians in identifying autism among populations that are often underdiagnosed, including gender diverse people and those who were assigned female at birth. One example is the Self-Assessment of Autistic Traits (SAT), which is a self-report measure of autistic characteristics designed in partnership with autistic people (Ratto et al., 2023). Self-report tools such as the SAT and others may support clinicians in understanding their patients' internal experiences on a deeper level. Additional tools and measures that aide clinicians in differential diagnosis with this population are needed.

Additionally, it is essential that care providers working with autistic and/or LGBTQ people conduct holistic diagnostic evaluations that look at physical health needs, past experiences, and psychiatric profiles. Our findings also point to the importance of culturally competent clinicians who are educated on LGBTQ+ identities and experiences. Clinical practices will strengthen their ability to serve diverse autistic clients by employing and investing in clinicians from a variety of cultural and neurotype backgrounds, particularly those who are racial/ethnic and sexual/gender minorities.

Training implications

Our results show that many providers are not equipped with the training they need to support autistic LGBTQ+ clients. As a result, some providers may choose to decline working with autistic adults because they feel ill-equipped to meet their needs. These findings are consistent with other studies of autistic adults, which show that the most commonly reported barriers to accessing mental healthcare are therapists' lack of knowledge of autism and unwillingness to work with autistic clients (Lipinski et al., 2022). Lipinski and colleagues examined 498 adult-patient psychotherapists on their knowledge of autism and self-perceived competency to diagnose and work with autistic adults. Despite the fact that psychotherapists were interested in additional training on autism, they reported very low autism expertise and often had misconceptions and outdated understandings of autism (Lipinski et al., 2022).

Several of our participants were either current mental health providers or in training to become providers themselves. They report that their programs do not have any explicit training in autism and lack a diversity of training in disability more broadly. Institutions and programs that train future mental health providers have a responsibility to provide disability-specific training to their students. Others have written about the dearth of disability-specific curriculum in medical schools and professional programs nation-wide and provide concrete suggestions for ways to incorporate this training (see Ratakonda et al., 2022; Rosa et al., 2016). Our findings underscore this work and show that there is a clear need for disability and autism-specific curriculum to be developed and embedded in medical and professional schools in the United States. This training should be led by and/or built with neurodivergent queer providers and subject-matter experts.

Rather than developing novel training approaches for use with autistic LGBTQ patients in therapy, we may find useful existing models and frameworks from LGBTQ-affirming care and those used with other minority populations that account for the impact of minority stress. Lucia, who is a mental health provider herself, shared an example of how this might look in practice:

> So when we think about like, treating disabled or autistic people, we can't just think about it as like a clinical or medical condition. It's also a social identity. And there's a level of oppression that comes in with that and so, like, that's when we need to bring those like oppression-based trauma focuses, right, and like, consider that and how, how we're thinking about clients and I think that's really missing. I'm just thinking back to the challenges of like, pushing against the model of assimilation, like, 'oh, stop doing that behavior, because that's why you're getting bullied' versus building self-confidence, strength in community, where that individual can continue using that if it's an adaptive

> behavior, like stimming-- they can continue doing that and feel safe. I think there's so much overlap with that and like, LGBTQ youth, like we don't want to tell them, 'No, stop wearing the nail polish that's why you're getting bullied. We want to build their strength, resilience, and build community for them so they can wear the nail polish. So, I think taking a little bit of that model and applying it to working with neurodivergent people would be helpful. -Lucia

Investing in Community

Our findings suggest that a clear strategy for reaching autistic LGBTQ+ populations is to invest in existing community spaces and institutions where they are most likely to gain access to mental healthcare. Many of our participants were able to access an autism diagnostic evaluation and/or therapy for the first time through their college campus counseling services or mental health program. Many of our participants were not diagnosed as autistic until young adulthood, emphasizing the critical importance of embedding mental health services into the college setting and other institutions that these young people interact with on a regular basis. In addition to college campuses, another major opportunity to increase access to care is to partner with existing community health clinics that predominately serve LGBTQ+ populations. A sizeable proportion of the patients served by LGBTQ-health clinics like Fenway Health, Callen-Lorde, and the Los Angeles LGBT Center are likely autistic and/or neurodivergent. Thus, partnering with these organizations to implement neurodivergent-affirming tools and strategies could be a viable way to improve mental healthcare access for autistic LGBTQ+ people of all ages.

Research Implications

The themes and findings from this study may serve as a framework for the development of curriculum or a competency training for providers around supporting autistic LGBTQ patients. In addition to provider-focused trainings, our team hopes to develop tools to equip autistic LGBTQ young adults and youth in their search for a therapist. The themes and findings could additionally be used to inform the development of a larger-scale survey of autistic LGBTQ mental health and healthcare experiences.

A methodological contribution of this study is its community partnered participatory approach. Each phase of this research was co-constructed with the Autistic LGBTQ+ Advisory Group- from the creation and piloting of the interview protocol through data coding and interpretation of findings. Our goal in implementing this approach was to ensure that the priorities of autistic LGBTQ+ people were centered and prioritized in this research. Community partnered methods often require additional time and funds to adequately compensate partners, which can present additional hurdles for early investigators and students who want to do this work but lack access to those resources. Future studies can continue to interrogate the question of how to partner with diverse autistic community partners representing a range of lived experiences in autism research. Our team is willing to share materials and/or reflections with other researchers who are interested in using a collaborative model.

Context and Importance

Fifty-one anti-LGBTQ+ bills have been passed into law this year in the United States, many of them restricting access to healthcare (American Civil Liberties Union, 2023). This legislation has and will have a direct and clear impact on the mental health of queer and trans youth across America. The Trevor Project, a nonprofit institution focused on decreasing suicidality among LGBTQ+ youth conducts a yearly survey of LGBTQ+ youth across the nation. According to their 2022 survey of nearly 34,000 queer and trans youth (13-24 years old), 93% of transgender and nonbinary youth report being worried about transgender people being denied access to gender-affirming medical care due to state or local laws (The Trevor Project, 2022). The same report provides a comprehensive picture of the mental health challenges of LGBTQ+

youth, reflecting high rates of seriously considering attempting suicide (45%) and depression and anxiety (58% and 73%, respectively). Eighty-two percent of LGBTQ youth surveyed wanted mental healthcare support, but 60% of them were not able to get it due to a variety of reasons, including fear of discussing mental health concerns, concerns with obtaining parent/caregiver permission, and fear of not being taken seriously (The Trevor Project, 2022).

The mental health landscape of autistic LGBTQ+ young adults is similarly dire, with high rates of unmet healthcare needs. No large-scale studies have yet examined rates of suicidality, depression, and anxiety among autistic LGBTQ adults. Yet, due to high rates of mental health challenges and suicidality among autistic and LGBTQ populations separately, it stands to reason that autistic LGBTQ+ people are at an increased risk for negative mental health outcomes. Recent research shows that state healthcare laws that are protective of LGBTQ+ rights result in more healthcare needs being met for autistic LGBTQ adults (Wallisch et al., 2023). These findings suggest that state policies that prohibit discrimination of LGBTQ people in the healthcare setting may act as a protective factor, and make a meaningful difference in limiting healthcare disparity, and in turn, may lead to better healthcare outcomes.

On the day that I write this discussion section, Florida has passed two new bills designed to restrict the rights of trans and nonbinary children and youth. Although these interviews were conducted months ago, this is the climate and context that these participants, and LGBTQ+ people everywhere are living in. More than ever, it is critical that we understand avenues to increase access to mental healthcare for autistic LGBTQ+ young adults. Additionally, these interviews illustrate the importance of mental health support that exists outside of the traditional healthcare system, and how participants are already finding and creating their own networks of healing and support. While these findings point to pivotal ways that we may decrease barriers and increase access to care for autistic queer and trans people, they also underscore the importance of building more opportunity for community care and connection.

At the close of the interviews, I asked participants what advice they would have for their younger selves or for other queer and trans autistic young people who are trying to get mental healthcare. In reflecting on this question, participants repeatedly encouraged other autistic queer and trans young people not to settle—to 'shop around' for a therapist that feels right and that you can be your authentic self with, and to lean on the power and knowledge within the autistic LGBTQ+ community. In the face of numerous barriers to finding support and experiences of discrimination in the healthcare system and beyond, participants found strength in community and were overwhelmingly proud of who they are. I close here with the words of a participant that exemplify this resilience and pride:

…if I was to be born again, I would choose to be autistic in every lifetime. - Luna

Table 1.

Demographic Characteristics of Participants

Characteristic	Survey Only (n=8) n (%)	Interviewees (n= 20) n (%)	Full sample (N= 28) n (%)
Gender			
Woman	2 (25.0%)	5 (25.0%)	7 (25%)
Man	1 (12.5%)	1 (5.0%)	2 (7.1%)
Nonbinary, gender fluid, gender non-conforming	4 (50.0%)	9 (45.0%)	13 (46.4%)
Not sure or questioning	0 (0.0%)	0 (0.0%)	0 (0.0%)
Not listed/ I use other terms	1 (12.5%)	5 (25.0%)	6 (21.4%)
Sexual Orientation (select all that apply)			
Bisexual	2 (25.0%)	6 (30.0%)	8 (28.6%)
Lesbian or Gay	4 (50.0%)	7 (35.0%)	11 (39.3%)
Pansexual	1 (12.5%)	4 (20.0%)	5 (17.9%)
Asexual/Ace/Ace spectrum	1 (12.5%)	6 (30.0%)	7 (25.0%)
Queer	4 (50.0%)	11 (55.0%)	15 (53.6%)
I am not sure/questioning	0 (0.0%)	2 (10.0%)	2 (7.1%)
Not listed/ I use other terms	0 (0.0%)	0 (0.0%)	0 (0.0%)
Identify as Transgender			
Yes	3 (37.5%)	13 (65.0%)	16 (57.1%)
No	5 (62.5%)	7 (35.0%)	12 (42.9%)
Sex Assigned at Birth			
Female	7 (87.5%)	19 (95.0%)	26 (92.9%)
Male	1 (12.5%)	1 (5.0%)	2 (7.1%)
Intersex	0 (0.0%)	0 (0.0%)	0 (0.0%)
Age (M, SD)	23.0 (3.3)	23.4 (2.7)	23.3 (2.8)
Age Range (years)	18-28	18-28	18-28
Race/ethnicity			
Hispanic/Latine/Latinx	2 (25.0%)	2 (10.0%)	4 (14.3%)
Black/African American	2 (25.0%)	1 (5.0%)	3 (10.7%)
Asian/Pacific Islander	1 (12.5%)	1 (5.0%)	2 (7.1%)
Native/Indigenous	0 (0.0%)	0 (0.0%)	0 (0.0%)
White	3 (37.5%)	15 (75.0%)	18 (64.3%)
More than 1 identity	0 (0.0%)	1 (5.0%)	1 (3.6%)
Not listed	0 (0.0%)	0 (0.0%)	0 (0.0%)
Autism Diagnostic Status			
Self-diagnosed/self-identify	1 (12.5%)	3 (15.0%)	4 (14.3%)
Formally diagnosed by clinician/health professional	4 (50.0%)	11 (55.0%)	15 (53.6%)
Informally diagnosed by clinician/ health professional	3 (37.5%)	4 (20.0%)	7 (25.0%)
Not listed	0 (0.0%)	2 (10.0%)	2 (7.1%)
Age of Autism Diagnosis/ Self-identification (M, SD)	15.6 (8.8)	18.9 (4.9)	18 (6.2)
Highest Level of Education			
Some high school	0 (0.0%)	1 (5.0%)	1 (3.6%)
Completed high school	2 (25.0%)	0 (0.0%)	2 (7.1%)
Some college	1 (12.5%)	7 (35.0%)	8 (28.6%)
Bachelor’s Degree	2 (25.0%)	8 (40.0%)	10 (35.7%)

Associate’s degree	1 (12.5%)	1 (5.0%)	2 (7.1%)
Graduate Degree or Professional Degree	2 (25.0%)	3 (15.0%)	5 (17.9%)
Employment Status (select all that apply)			
Full-time	3 (37.5%)	9 (45.0%)	12 (42.9%)
Part-time	2 (25.0%)	7 (35.0%)	9 (32.1%)
Freelance/consulting/self-employed	0 (0.0%)	2 (10.0%)	2 (7.1%)
Internship/other apprenticeship	0 (0.0%)	1 (5.0%)	1 (3.6%)
Not working (unemployed/unable to work)	2 (25.0%)	4 (20.0%)	6 (21.4%)
Not listed	1 (12.5%)	2 (10.0%)	3 (10.7%)
Current Student			
Yes	4 (50.0%)	9 (45.0%)	13 (46.4%)
No	4 (50.0%)	11 (55.0%)	15 (53.6%)
Income (missing= 1)			
I have less than enough to meet my basic needs	2 (25.0%)	3 (15.0%)	5 (18.5%)
I have just enough to meet my basic needs	1 (12.5%)	11 (55.0%)	12 (44.4%)
I have more than enough to meet my basic needs	4 (50.0%)	6 (30.0%)	10 (37.0%)
Region of Residence			
West	1 (12.5%)	8 (40.0%)	9 (32.1%)
Midwest	1 (12.5%)	2 (10.0%)	3 (10.7%)
South	2 (25.0%)	4 (20.0%)	6 (21.4%)
Northeast	4 (50.0%)	6 (30.0%)	10 (35.7%)
Co-occurring diagnoses (select all that apply)			
ADHD	4 (50.0%)	11 (55.0%)	15 (53.6%)
Anxiety	8 (100.0%)	17 (85.0%)	25 (89.3%)
Depression	8 (100.0%)	14 (70.0%)	22 (78.6%)
PTSD	3 (38.0%)	11 (55.0%)	14 (50.0%)
OCD	0 (0.0%)	4 (20.0%)	4 (14.3%)
Bipolar	0 (0.0%)	3 (15.0%)	3 (10.7%)
Intellectual disability or Learning disability	0 (0.0%)	4 (20.0%)	4 (14.3%)
Not listed	2 (25.0%)	2 (10.0%)	4 (14.3%)

Table 2.

Interviewee pseudonyms and descriptors from demographic self-report survey (n=20).

Pseudonym	Age	Gender	Identify as Transgender	Sexual Orientation (choose all that apply)	Race/ethnicity	Age range of diagnosis/self-identification
River	23	Woman	Yes	Bisexual	Black/African American	Childhood
Jamie	23	Nonbinary, gender fluid*	Yes	Asexual/Ace, Queer	White	Early adulthood
Ryan	26	Nonbinary, gender fluid	No	Bisexual, Pansexual	White	Early adulthood
Quinn	19	Nonbinary, gender fluid	Yes	Bisexual, Queer	White	Early adulthood
Gaby	26	Woman	No	Asexual/Ace, Questioning	White	Childhood
Aidan	23	Man	Yes	Queer	White	Early adulthood
Kris	28	Transmasculine, nonbinary	Yes	Queer	White	Early adulthood
Kennedy	24	Nonbinary, gender fluid	Yes	Lesbian or Gay	White	Adolescence

Luna	19	Nonbinary, gender fluid	No	Lesbian or Gay	Hispanic/Latine/Latinx	Early adulthood
Jasmine	26	Woman	No	Pansexual, Asexual/Ace, Queer, Questioning	White	Early adulthood
Lucia	25	Woman	No	Lesbian or Gay	White	Early adulthood
Amanda	25	Woman	No	Bisexual	White	Early adulthood
Alex	18	Genderqueer transman	Yes	Lesbian or Gay, Queer	White	Early adulthood
August	23	Nonbinary, gender fluid	Yes	Lesbian or Gay, Queer	White	Early adulthood
Kai	23	Nonbinary, gender fluid	Yes	Lesbian or Gay	Asian/Pacific Islander	Early adulthood
Ollie	21	Nonbinary man	Yes	Lesbian or Gay,	White	Adolescence

				Asexual/Ace, Queer		
Sam	22	Genderless	Yes	Bisexual, Pansexual, Asexual/Ace, Queer	Black; Jamaican, Cuban, English	Early adulthood
Angel	22	Nonbinary, gender fluid	Yes	Bisexual, Pansexual, Queer	Hispanic/Latine/Latinx	Early adulthood
Kim	26	Nonbinary, gender fluid	No	Queer	White	Early adulthood
Andie	25	Autigender	Yes	Asexual/Ace	White	Childhood

Age range of diagnosis/self-identification: Early childhood (0-5 years), childhood (5-12 years), adolescence (13-17 years), early adulthood (18+ years).

Formal diagnosis = those who received a diagnosis from a clinician/health provider, Informally identified= those who were informally identified as autistic by a clinician/health provider, Self-identified = those who self-identify or were self-diagnosed as autistic.

*This category of Nonbinary, gender fluid also includes those who are gender nonconforming/gender expansive.

Note: Additional details about participant demographics have been redacted to respect participant comfort/preferences.

APPENDICES

APPENDIX A. Recruitment Flyer

Are you Autistic & LGBTQ+?

We want to hear about your mental healthcare experiences!

We are looking for people who:

- Are Autistic (self-diagnosed or formally-diagnosed)
- Are LGBTQ+
- Are 18-28 years old
- Live anywhere in the U.S.
- Have gotten or tried to get mental healthcare (e.g. counseling, therapy)

Scan the QR code or go to https://bit.ly/3NJl7Te to find out if you can take part in the study!

If you can take part, you will:

- Complete a short online survey about you
- Participate in an in-person, online, or written interview about your mental health status, coming out experiences (if this has happened to you) , & experiences getting mental healthcare

You will get a **$50 Amazon gift card** for completing the survey & interview!

Any questions? Contact Lauren (she/her):

✉ **autisticlgbtqstudy@gmail.com**
☎ (818) 724-4255

This UCLA study was developed by the study's Autistic LGBTQ+ Advisory Group & Lauren Baczewski, M.A.

Protocol ID:IRB#21-001676 UCLA IRB Approved Approval Date: 5/27/2022 Committee: South General IRB

APPENDIX B. Glossary of Key Terms

Neurodiverse: The term “neurodiverse” refers to a group of people with “atypical neurological development,” which is regarded as a normal human difference or variation (Jaarsma & Welin, 2012). The term neurodiverse is often used in reference to the autistic community but can include a wide spectrum of individuals who identify with the term. Notably, there is substantial variation in the neurodiverse and autistic community, including those who are nonverbal/nonspeaking and those with intellectual disability, among others. The neurodiversity movement challenges the cause and cure-oriented medical model of autism and aims to celebrate it as an aspect of one’s identity (Gillespie-Lynch et al., 2015). The term “neurotypical” will be used to as an analog to “neurodiverse” throughout this proposal.

LGBTQ+: The term “LGBTQ+” is an umbrella term that refers to a spectrum of sexual orientation and gender identities, including but not limited to those who identify as Lesbian, Gay, Bisexual, Trans*, Queer and/or Questioning, Intersex, Asexual, or Two-Spirit, among others. Sexual minority is another term used to describe Lesbian, Bisexual, gay, and queer individuals, while gender minority describes transgender or gender-nonconforming individuals. The term “LGBTQ+” is used interchangeably with the terms “sexual and gender minorities” in this proposal.

Sexual Orientation: Refers to emotional, sexual, and/or romantic attraction (Stokes, 2021). One can be emotionally, sexually, and/or romantically attracted to individuals of many different gender identities and sexual orientations.

Gender Identity: An internal and psychological identification of oneself as a woman, man, both, in between, or neither. Gender identity is fluid and can change across time, across development, and from day-to-day (Stokes, 2021).

Cisgender: A person whose gender identity and/or expression is the same as the sex they were assigned at birth (Strauss et al., 2017).

Trans: Umbrella term that describes a person whose gender identity and/or expression are not the same as the sex they were assigned at birth. Trans includes specific gender identities, including but not limited to trans woman, trans man, genderqueer, non-binary, genderfluid, or simply male or female (Strauss et al., 2017).

Gender diverse: Umbrella term that describes one's gender identity and includes individuals who identify as trans, transgender, gender questioning, gender fluid, and all gender identities and expressions that are different from the sex assigned at birth (Strauss et al., 2017).

Gender dysphoria: Distress that people can feel due to incongruence between their gender identity/expression and sex assigned at birth or sex characteristics (Strauss et al., 2017).

APPENDIX C. Demographic Survey Questions (via Qualtrics)

1. Name:
2. Pronouns (optional):
3. Email address:
4. Phone Number:
5. Preferred contact method: Email, text, or call.
6. Can we contact you about other studies like this one in the future? Yes/no.
7. Age:
8. Race/ethnicity:
    - More than one identity
    - Hispanic/Latine/Latinx
    - White
    - Asian/Pacific Islander
    - Black/African American

- Native/Indigenous
- Not listed, please share here:

9. Income
   - Have more than enough to meet basic needs (e.g., food, housing, etc.).
   - Have just enough to meet my basic needs
   - Have less than enough to meet my basic needs
   - Prefer not to answer

10. Education level
    - Some high school
    - Completed high school
    - Completed some college
    - Bachelor's Degree
    - Associate's Degree
    - Graduate degree (e.g., Masters, PhD) or professional degree (e.g., MD, PA, MSW)
    - Not listed, please share here:

11. Employment status (you can choose more than 1 answer).
    - Employed full-time
    - Employed part-time
    - Freelance/consulting/self-employed
    - Internship (paid or unpaid) or other apprenticeship
    - Not working (e.g., unemployed or unable to work)
    - Not listed, please share here:

12. Are you currently a student (part-time or full-time)?
- Yes
- No

13. What state do you live in currently?
    - [text box/free response]

14. Sexual Orientation (you can choose more than 1 answer):
    - Lesbian or Gay
    - Bisexual
    - Pansexual
    - Asexual/Ace/Ace spectrum
    - Queer
    - I am not sure/questioning
    - Straight/heterosexual
    - Not listed, please share here:

15. Gender Identity

- Man
- Woman
- Nonbinary, gender non-conforming, or gender fluid
- Not sure or questioning
- Not listed, please share here:

16. Do you identify as transgender?
    - Yes
    - No

17. Sex Assigned at Birth
    - Female
    - Male
    - Intersex

18. What words do you use to describe your autism/ autistic identity (e.g., “on the spectrum”, Asperger’s, autistic, etc.)?

    - Autistic
    - On the spectrum
    - Asperger’s
    - Not listed, please share here:

19. Tell us about your Autism Diagnosis (if applicable):
    - I was self-diagnosed or self-identify as autistic/on the spectrum
    - I was formally-diagnosed by clinician or health professional
    - I was informally identified as autistic by a health professional/clinician
    - Not listed, please share here:

20. How old were you when you got a diagnosis of Autism (this includes both formal diagnosis by a professional or self-diagnosis)?:

[text box entry]

21. Do you have any of the following co-occurring diagnoses or disabilities (formally-diagnosed or self-identified)?
    - ADHD
    - Anxiety
    - Depression
    - PTSD
    - OCD
    - Bipolar
    - Intellectual disability or Learning disability
    - Not listed, please share here:

22. Do you agree or disagree with the following statement: “I feel like I belong in the autism community”.

1= Strongly disagree
2= Disagree
3= Neither agree nor disagree
4= Agree
5= Strongly Agree

23. How important is it to you to belong in the autism community?

1= Not important
2= Somewhat important
3= Neither important nor unimportant
4= Important
5= Very important

24. Do you agree or disagree with the following statement: “I feel like I belong in the LGBTQ+ community”.

1= Strongly disagree
2= Disagree
3= Neither agree nor disagree
4= Agree
5= Strongly Agree

25. How important is it to you to belong in the LGBTQ+ community?

1= Not important
2= Somewhat important
3= Neither important nor unimportant
4= Important
5= Very important

APPENDIX D. Interview Protocol

Interview Questions

Interviewer:	Date:	Time Start:	Time End:	Interview #:
Participant ID:				
Location/format:				
Other Notes:				

Below is a list of questions that we will ask you in the interview.

- **We may not ask you all of the questions on this list.**
- **We might ask you these questions in a different order than what you see here.**
- **We also might ask you a few more questions that are not on this list to learn more about your experiences.**
- **You don't have to answer any questions you don't want to, and you can take as much time as you need to think about your answer.**

Part 1:

1. What is your sexual orientation?
    - How did you discover or realize your sexual orientation?
    - Did you have a 'coming out' experience in regards to your sexual orientation?
        1. If yes, what was that experience (or experiences) like? Can you tell me a bit about it?

2. What is your gender identity?
    - How did you discover or realize your gender identity?
    - Did you have a 'coming out' experience in relation to your gender identity?
        1. If yes, what was that experience like? Can you tell me a bit about it?

3. What words do you use to refer to your autism diagnosis (e.g., "neurodivergent", "autistic", etc.)?
    - Do you have any other neurodivergent identities in addition to autism?
    - When and how did you know or find out you are neurodivergent or autistic?
    - Did you have a 'coming out' experience in regards to your autistic/neurodivergent identity?

**Note to interviewer: If not brought up, ask:

a. Did you diagnose yourself as being neurodivergent or autistic?

b. Did someone else diagnose you as being neurodivergent or autistic?

c. Both?

4. Some people think about mental health as a part of their identity.
   - Is this true for you?
   - Why or why not?
   - Can you tell me a little bit about your current mental health status?

5. Is there anything you would like to add about who you are and/or your identities?

Part 2:

1. Tell me about a time you got mental healthcare.
   1. What went well about it?
   2. What could have gone better?
   3. Did you feel comfortable talking to your doctor about being autistic? Why or why not?
   4. If so, did you feel like the doctor(s) understood autism?
   5. What made you try to find mental healthcare?
   6. How did you find mental health care?
   7. How hard or easy was it to find what you needed?
2. Have you ever tried to get mental health care, but couldn't?
   1. If so, what got in the way (e.g., insurance, cost, transportation, etc.)?
3. How do you think being autistic affected or contributed to your experiences getting mental healthcare, if at all?
4. How do you think being LGBTQ+ affected/contributed to your experiences getting mental healthcare, if at all?
5. How do you think being Autistic and LGBTQ+ affected/contributed to your experiences getting mental healthcare, if at all?

Part 3:

1. If you could tell doctors the best ways to help autistic LGBTQ+ people with their mental health, what would you tell them?
2. What advice would you give other LGBTQ+ autistic people about getting good mental health care?
3. What things help you with your mental health?
   1. Optional probe: What are some things that bring you joy?

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