A Grounded Theory Analysis of the Social and Friendship Experiences of Adolescent Girls with Developmental Disabilities

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Dedication

To my Dad: For teaching me the importance of showing up for people, and that the most powerful thing we can do at times is sit down and listen.

To my students: For trusting me with your stories. It is an honor and a privilege to be a small part of your lives.

To everyone fighting for a more inclusive world for all: Thank you for all that you do.

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Abstract of Dissertation

A Grounded Theory Analysis of the Social and Friendship Experiences of Adolescent Girls with Developmental Disabilities

This study utilized a qualitative constructivist grounded theory methodology to explore the social and friendship experiences of adolescent girls with developmental disabilities (DD). Participants included 12 adolescent girls with DD and 13 parents of adolescent girls with DD. In-depth interviews were conducted with each participant to better understand the social/friendship experiences of adolescent girls with DD from their own perspectives and the perspectives of their parents/caregivers.

Constant Comparative Analysis was used to analyze the data, and an emergent theory was created from these findings. Contrary to the persistent narrative of girls with DD as "anti-social" or disinterested in friendships, results displayed a strong interest in social opportunities and friendships. However, the social environments that girls with DD have been placed in are rarely tailored to their social strengths, support needs, and goals. Parents and caregivers are often expected to compensate for this lack of support by creating additional social opportunities for their child. This task is impossible given the many competing demands of life. As a result, participants reported a variety of social and friendship challenges, including limited social lives, bullying and rejection, and frequently comparing themselves to other teenage girls in their communities and on TV/movies/social media.

Recommendations for educators and school systems to improve social outcomes of girls with DD are discussed. Additionally, methodological advances for highlighting

the voices of individuals with cognitive/language support needs are reviewed, and recommendations for replicating these processes are provided.

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Chapter 1: Introduction

In many ways, social experiences are shaped by a person's unique identities. Race, ethnicity, gender identity, sexuality, and disability status (to name a few) can play a role in a person's interaction with the social world. A developmental disability (DD) brings with it a variety of social strengths, challenges, experiences and goals (Hoyle et al., 2020; Orsmond, Krauss & Seltzer, 2004; Orsmond et al., 2013; Mckenzie et al., 2017). Additionally, navigating a historically male-centric world as a young female draws additional complexities to surviving, let alone thriving, in a modern social world.

In current research on DD, it is rare for findings to be broken down based on biological sex and/or gender identity. In studies that do distinguish based on gender, most focus on males. Watkins (2014) analyzed 607 peer reviewed journal articles published on ASD between 2010 and 2012, and found that 81.82% of participants in those studies were male. Only 0.49% of articles focused exclusively on girls with ASD. This limited representation likely stems from a vicious cycle of gender-biased diagnostic tools, a lack of respect for self-diagnosis of autistic females, and limited awareness of the need to represent girls in ASD research (D'Mello et al., 2022). It is difficult to represent girls with DD in the research if they cannot get an accurate diagnosis. This lack of gender-sensitive diagnostic processes and support creates a cyclical dilemma of underrepresenting girls with developmental disabilities across census data, research, support programs, and advocacy platforms.

Girls with DD have a unique set of social experiences, strengths, challenges and goals, all of which may be quite different from their male counterparts (Stein, 2019; Kirkovski et al., 2013). However, few researchers and practitioners specifically address

the unique experiences of girls with developmental disabilities. In special education programs, female students are often far outnumbered by their male peers. Based on data from the National Center for Education Statistics from the 2017-2018 school year, the Pew Research Center projected that about two-thirds of students enrolled in special education in the US were males and only one-third females (Schaeffer, 2020). In special education programs that are often already limited by inadequate funding, staffing, and resources, female students are most likely placed in the same social groups as their male peers (if they receive support in this area at all) and it is unlikely that they have opportunities to explore their social experiences with other female peers (Morán et al, 2019). Existing social skills/social language programs focus mostly on the social support needs of males with DD (Lai et al., 2015). Given the discrepancy at hand, girls with DD likely have few opportunities to participate in programs created to address their specific social experiences, strengths, and support needs. Female students may rarely, if ever, be given opportunities to discuss and learn about their own unique social experiences, strengths, challenges, and goals with other female peers. It is, therefore, unsurprising that girls with developmental disabilities experience higher rates of mental health disorders, higher rates of exclusion from peer groups, and overall reduced acceptance by classmates in school than their non-disabled peers and male peers with developmental disabilities (Boström et. al, 2018; de Boer et. al, 2013). Programs that aim to support girls with developmental disabilities must consider the heterogeneous nature of their strengths and support needs and recognize that each individual has social/friendship needs that differ not only from their male counterparts, but also from one other (Cummins et al, 2018).

The problem at hand is twofold. Girls with DD are most likely required to participate in social skills/social language groups held outside of the general education classroom, composed of all or mostly male students. This limits their opportunities to connect with other female peers who may share similar experiences. In addition, the curricula and supports used within those groups are more likely to address the social support needs of their male classmates, leaving these individuals "doubly excluded" (Halsall et al., 2021). They are excluded from their female peers in the general education classroom based on disability, and excluded from their peers in the special education classroom based on gender. Furthermore, in social skills programs that focus heavily on neurotypical social standards, the potential negative impact on the social-emotional wellness of female (and male) students is even greater.

In the limited scope of research covering the social experiences of girls with DD, most work focuses almost exclusively on Autism Spectrum Disorder (ASD). This area of research is still emerging but has begun to uncover the gender biases that have influenced research, diagnosis, and treatment of ASD throughout history, many of which persist today (Loomes et al., 2017; Van Wijngaarden-Cremers et al., 2014, Lai et al., 2015). Existing research on girls with ASD highlights that many girls with ASD show a strong interest in friendships and may appear to have stronger social language skills than their male counterparts. However, the same girls have difficulty maintaining friendships, particularly as they move into adolescence (Cridland et al., 2013; Cook et al., 2018). Many adolescent girls with ASD report different strengths and challenges than their male counterparts, particularly as they navigate the female social world, one which typically involves significant skill in navigating conversation, sharing of emotions, and language-

based activities (Sedgewick et al., 2019). In research studies about girls with DD more broadly, young girls have been found to experience higher social exclusion, which may occur in part due to gendered social expectations and the unique social challenges faced by girls with and without disabilities (Morán et al., 2019). Although findings such as these are important in conceptualizing some of the experiences of girls with DD, this limited area of research needs to expand. Specifically, the social experiences of girls with DD, including intellectual disability (ID) and/or cognitive/language support needs, have yet to be comprehensively addressed. Though some research has been conducted to focus on the perspectives of girls with DD, these studies focus specifically on individuals without ID and/or cognitive/language support needs, most often individuals with ASD and average or above-average IQ. More information is needed about the variety of experiences of girls with DD, including girls with ID and/or cognitive/language support needs. Without including this population in quantitative and qualitative studies, research will continue to overlook the experiences of girls with DD, who may need more support or different methods to share their perspectives. This dissertation aims to build an understanding of the social experiences of girls with various cognitive profiles to provide a starting point for more inclusive research, stronger educational programs, and better social-emotional outcomes for this population.

This chapter introduces the work of this dissertation. It begins with reviewing the language used throughout and acknowledging the importance of inclusive language and practices. The researcher provides information on personal subjectivity in the qualitative research process, followed by a statement of the research problem. Research questions for this project and the significance of this area of study are reviewed. The conceptual

framework used for this dissertation and methodology is summarized, followed by delimitations, limitations, and key terminology.

Language

A variety of preferences exist for referring to disability, and the preferences of individuals should always be respected. Some prefer identity-first language (e.g., "autistic person"), while others prefer person-first language (e.g., "person with autism"). As this preference varies, so does the use of person first and identify first language throughout this dissertation. Due to the stated preferences of many individuals with intellectual disabilities, person-first language is used unless a preference for identity first language is known. If a preference is known for identity-first language (e.g., for autistic self-advocates mentioned throughout), identity-first language is used (National Center on Disability & Journalism, 2021).

Additionally, it is appreciated that the discussion of gender is not fully inclusive if considered binary. This dissertation focuses on cis-gender females, which is only one specific sector of the disabled population. All identities are valid, and the experiences of all female-identifying individuals are essential to discussing the female experience of disability. Other female-identifying individuals are not included in this discussion simply to ensure that assumptions are not made about their experiences based on the experiences of cis-gendered females.

Subjectivity

Qualitative research is naturally subjective, as the researcher serves as the major instrument of measurement (Merriam & Tisdell, 2015). Given this reality, the researcher

must acknowledge the subjective nature of their work and reflect on their own experiences, opinions, and thoughts that contribute to the overall research process.

My background is in Speech-Language Pathology, which I studied as an undergraduate student and as a master's student. As an undergraduate student, I also studied psychology, as I have always had a strong interest in mental health and the complexity of our human brains. In my career, I have worked at the same non-public special education school for 6 years, and have focused most of my work in the high school program with students with complex academic, social and adaptive support needs. In my work, I noticed how few girls were in our programs, and heard from my female students themselves that they felt isolated in their classes because there were no other girls. Even if they shared interests with their male classmates and enjoyed spending time with them, they still wanted to get to know other girls their age. Additionally, I noticed how different the strengths and support needs were for my female students, specifically related to pragmatic language and mental health. It occurred to me that we (and education systems more broadly) were providing the same social emotional and adaptive support to our male and female students. Given the differences at hand, this was likely inappropriate.

This led me to structure a weekly “girls group” for the female students in our high school program. We added a group for elementary/middle school girls through virtual instruction during COVID-19. These groups evolved and changed over time as I started to learn more about what these girls wanted out of a weekly group, what supports were still needed to form and maintain friendships with one another, and what other complexities came up as I spent more time getting to know them and their experiences.

Although my background is in Speech-Language Pathology more broadly, my biggest area of interest has always been pragmatic language (e.g., social communication, social relationships) and overall student social-emotional well-being. Additionally, I identify as a feminist, and it really struck my interest that these girls were essentially being thrown into social-emotional programming that was designed for white males with ASD. Considering the fact that a number of my girls were actually black girls with ID, I felt compelled to do something about this. In American society, treatment of adolescent girls can be extremely problematic for all girls, regardless of other identities. To further exacerbate this, many of the girls that I work with are women of color, which leads to even deeper intersectional discrimination. Finally, all of the girls that I work with have cognitive/language support needs, which intensifies the unfair reality that they are a group of people who are often judged but rarely listened to, and discriminated against based on gender identity, race and/or disability. These girls are thrown into existing programs that were not designed for them, simply because the time has not been taken to design something for them. It has been assumed that these girls can make things work wherever they are placed, rather than creating a place that works for them. It's frustrating for these girls, it's frustrating for their families, and it is frustrating for the educators who are trying to support young girls with DD in developing into strong, self-assured young women. It's time to do better, because these girls deserve so much better. My girls have brought so much joy into my life, and so much more knowledge about TikTok, boy bands and Disney channel movies. This dissertation is inspired by my love of working with the girls at my school, their willingness to be vulnerable and courageous, to share a piece of their lives with me, and to trust me with their stories.

Statement of Problem

Young girls are navigating a complex social world, including peer relationships, online socialization, gender and sexuality, and more. It is noted in research and practice that the social experiences of young females and males, including females and males with DD, are likely quite different (Mcgillivray et al., 2018; Morán et al., 2019; Oswald et al., 2016). However, special education programs have not consistently acknowledged this truth for their female students. Many girls continue to be placed in social programs with their male peers, which are likely designed to address the social experiences and needs of males with DD. It is clear from emerging research on the social experiences of girls with ASD that social experiences, strengths and support needs of girls with ASD are distinct from those of their male counterparts (Sedgewick et al., 2019; Oswald et al., 2016; Cook et al., 2018, Cridland et al., 2013). Additionally, it has been indicated through limited research on the social experiences of individuals with DD that ID and language/cognitive support needs may introduce an additional complicating factor for socialization in girls with DD (Griffin et al., 2019; Taheri et al., 2016; Morán et al., 2019). Of course, inclusive classrooms that welcome students of all gender identities are necessary, and this researcher does not intend to advocate for gender-segregated classrooms. However, the programs that are provided in special education classrooms as well as the social opportunities provided to students need to account for the unique social experiences, strengths, challenges, and goals of female students.

Although existing research is significant to the populations it studies, none specifically examines the experiences of individuals with DD who are female, and possess intellectual disabilities and/or language/cognitive support needs. To date, most

research provides information on the social experiences of males with DD. Existing literature on the social experiences of girls with DD focuses predominantly on girls with ASD and no language/cognitive support needs or ID diagnosis. Although these important research areas provide relevant information and a foundation for building a greater awareness of girls with DD and their unique social experiences, this population has yet to receive the attention and opportunities they need and deserve. While writing this dissertation, this researcher did not find any studies or educational programs that used the voices of adolescent girls with DD to inform research and practice. Most relied on educator and/or parent input, or did not address the perspectives of individuals/stakeholders at all. First-person information about the social experiences, strengths, challenges, and goals of girls with DD, including those with ID and/or cognitive/language support needs, is desperately needed in special education research and practice. Educators and stakeholders cannot create meaningful and beneficial social/language/educational programming for this population without this valuable information.

Purpose and Research Questions

The purpose of this study was to a) understand how adolescent girls with DD experience their social worlds and form/maintain friendships; b) understand how caregivers of adolescent girls with DD navigate the process of supporting their child socially; c) generate recommendations for the kinds of school based social/friendship support that would be beneficial and meaningful to adolescent girls with DD and their caregivers; and d) involve adolescent girls with DD and their caregivers as active members of the research team. The following research questions guide this dissertation:

1. What are the perceptions of adolescent girls with DD on their social/friendship experiences?

2. What are the perceptions of caregivers of adolescent girls with DD on their child's social/friendship experiences?

3. How do caregiver and adolescent girl perceptions converge and diverge?

Statement of Significance

In the limited scope of research that has studied girls with DD, young girls have been found to experience higher social exclusion, which may occur in part due to gendered social expectations and the unique social challenges faced by girls with and without disabilities (Morán et al., 2019). However, solutions to this problem, and more extensive research on the problems that girls with DD face are lacking. If research on girls with DD is lacking, their social-emotional programming is likely insufficient to meet their needs, insignificant or even harmful to them. This dissertation works to include girls with DD and their caregivers in the process of developing a framework for social/friendship-based programming for the school setting that is meaningful and informed by their own experiences, strengths, support needs, and stories. There is much for researchers and educators to learn about the social experiences of adolescent girls with DD. Based on what is known, current practice is likely falling short of supporting this population and their social-emotional development and wellness.

Conceptual Framework

In this study, Relational Cultural Theory (Miller & Stiver, 1997) and Critical Disability Theory as outlined by Meekosha & Shuttleworth (2009) were synthesized and used as a lens for reviewing the existing literature. The development of adolescent girls with DD was viewed as occurring within and through social relationships, meaning that social relationships (or the lack thereof) have the potential to significantly impact the growth and development of these young girls. Additionally, most existing research and practice in special education focuses on the white male experience of disability. Critical analysis of the literature informed this study to acknowledge the patriarchal norms that have left many girls with DD without resources and information that are specific to their unique experiences. Finally, a critical disability lens led the researcher to question existing research and programs that do not center on the voices and thoughts/opinions of actual disabled people.

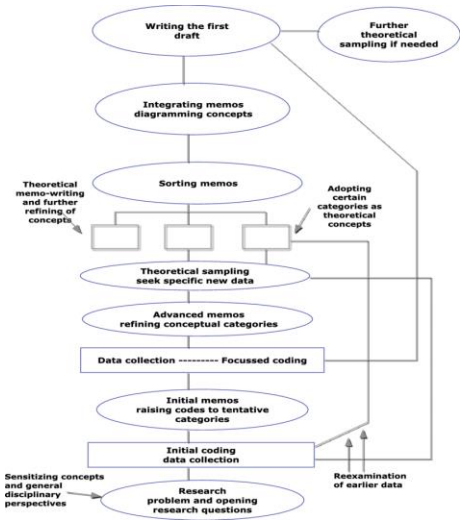
Summary of Methodology

In reviewing the literature on social experiences of individuals with DD, it becomes evident that most of the research and practice focuses on the male presentation of disability. Given this reality, research on the specific strengths, support needs, and goals of adolescent girls with DD is essentially non-existent, and curricula/programming for social-emotional learning of adolescent girls with DD is extremely limited. A framework for such programming is needed so educators and caregivers can provide evidence-based, individualized social-emotional support to adolescent girls with DD. In-depth, individual interviews with adolescent girls with DD and their caregivers were the primary source of qualitative data for this study. Interview methods were tailored to the

cognitive and language support needs of student participants. A constructivist grounded theory approach (as outlined in Figure 2) was used because it is flexible and acknowledges that there is no single truth, but rather many unique lived truths and experiences based on a variety of complex factors (e.g., gender, disability status, family support) (Charmaz, 2014).

Figure 2.

Constructivist Grounded Theory Process (Charmaz, 2006)



Delimitations

Delimitations of this study were largely based on the sample population. Participants were limited to adolescent girls who were currently enrolled in the same high school program, and their caregivers. Excluded were all male students, female students who were not currently enrolled in the school's high school program, female students who did not wish to participate in activities/discussion about female social development for any reason, and any students who may identify as female but did not do so openly with their teachers and classmates at school.

Limitations

Limitations for this study included geographic/school location, as all participants were recruited from the same school program. Additionally, some of the data used in this study was previously collected by this researcher (i.e. in the prior school year). Given the lag between data collection and data analysis, the exact process of Constructivist Grounded Theory data collection and analysis as described by Charmaz (2014) had to be adjusted. However, access to participants and the close relationship between researcher and participants with language support needs made this adjustment worthwhile for the sake of analyzing data that is often challenging to access. The data set offered the opportunity for extremely rich data, which outweighed the limitations (Charmaz, 2014).

Definition of Key Terms

Major terms used throughout this dissertation are provided below.

Autism Spectrum Disorder (ASD): A specific type of DD. The DSM-5 defines ASD as "persistent deficits in social communication and social interaction across multiple contexts" as well as "restricted, repetitive patterns of behavior, interests, or activities" (APA 2013). However, many autistic advocates and their allies reject this medical definition of ASD, and assert that these social "deficits" are in fact just differences from neurotypical social expectations (Brown, 2011).

Camouflaging: Attempting to hide difficulties/challenges, attempting to blend in with a peer group, often done by girls with DD.

Cis-gender: When a person's gender identity aligns with their biological sex at birth.

Critical Disability Theory (CDT): Highlights the intersectional experiences of disabled people as well as the racial, cultural, political, and social influences on those experiences.

It posits that Disability Studies work is rooted in social justice, and overlaps heavily with goals of queer and feminist theories (Hall, 2019).

Developmental Disability (DD): "a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the early childhood developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime" (CDC, 2022).

Doubly Excluded: Often experienced by girls with developmental disabilities, who are excluded from mainstream classrooms due to their need for special education services, but also excluded from their special education classroom due to being one of few or the only female students (Halsall et. al, 2021).

Intellectual Disability (ID): A specific type of DD, The CDC defines ID as "a term used when there are limits to a person's ability to learn at an expected level and function in everyday life (CDC 2022). ID may impact a child's pace of learning and development in areas of daily living (e.g., eating, dressing, hygiene) and academics.

Masking: Trying to hide one's ASD, typically by suppressing autistic behaviors (e.g., stimming) and adjusting one's social actions to match a neurotypical social presentation.

Medical Model of Disability: Disability is viewed as a pathological impairment in one's body or functioning that requires intervention to be "fixed" or "cured" (Olkin, 2022).

Neurodiversity: "The notion of disability as an interaction between social factors and personal deficits, the challenges of which do not necessarily make life less valid or worthwhile but an equally valid part of human diversity" (Kapp et al., 2013, p. 68).

Relational Cultural Theory (RCT): A theoretical approach created by Jean Baker Miller and colleagues (1993) that highlights social relationships as the context for growth

and development. RCT highlights the impact that societal expectations, culture, and traditional psychological theory have had on the development of girls and women.

Social Model of Disability Disability is viewed as a social construct, this perspective advocates for changes in society and a person's environment, rather than aiming to change the person themselves (Olkin, 2022).

Transition: The process by which adolescents with DD age out of special education services (i.e. by age 21) and move from school based programming to community based programming and work.

Individuals with Disabilities Education Act (IDEA): A U.S. federal law, requires that a free and appropriate public education be provided to all eligible students with disabilities, including special education and related services (Dept. of Ed., 2004).

Chapter 2: Literature Review

In discussing the social experiences of adolescent girls with developmental disabilities, numerous fields of work must be explored. Although research that addresses this specific population is limited, many other fields of work are significant to this discussion. This literature review begins with an overview of the conceptual framework used, including both Critical Disability Theory (CDT) and Relational Cultural Theory (RCT). Search criteria/procedures are briefly outlined, followed by an introduction to the first major pillar of this literature review, defining developmental disability. This section defines developmental disability as it is discussed in this dissertation to include a definition of ASD, ID, transition outcomes for this population, and caregiver experiences. Given the scarcity of research on adolescent girls with DD, this section includes information about caregiver experiences of adolescent girls with DD and caregiver experiences for those raising a child with DD more broadly. The second pillar of this review is introduced, describing friendship experiences for various populations. This section discusses literature on the friendships of adolescent girls, individuals with DD, adolescent girls with ASD, and adolescent girls with DD. Limitations of current literature and the need for more research on this population, particular research that includes adolescent girls with DD as key members of research teams, are discussed throughout.

Conceptual Framework

In reviewing the literature on this topic, a specific lens was used to search for and interpret existing research. Given the focus on girls with DD in this study and this researcher's value of social justice for disabled people, Critical Disability Theory (CDT) as described by Meekosha & Shuttleworth (2009) poses a significant influence on this

literature review. Additionally, as this work closely examines social relationships and evaluates their significance, Relational Cultural Theory (RCT) (Miller & Stiver, 1997) provides an additional theoretical perspective for this dissertation. These theories are synthesized to contribute to this researcher's lens. In this section, both CDT and RCT are described in greater detail. Following this description, the two theories are synthesized and represented visually.

Critical Disability Theory

There are numerous models of disability with varying levels of support from the disability community. The American Psychological Association describes the Moral Model, Medical Model, and Social Model as the three main models of disability studies. Using the Moral Model, a person's disability is thought to portray something about their moral character, often indicative of wrongdoing or evil. Conversely, some religious beliefs may consider disability a sign of proximity to God or strength. Although this model is less frequently discussed in research and practice, it is highly prevalent in current media and popular culture. Many members of the disability community are frustrated by what has been coined "inspiration porn", that is, videos and posts that describe people with disabilities as inspirational for simply existing or doing something that would be considered "normal" or "everyday" for able-bodied people. Saidee Wynn explains the harm in this line of thinking, sharing that

> "...perhaps the most harmful of all the effects of inspiration porn is the notion that our lives aren't worth living. When someone tells a disabled person 'you are so inspiring, I don't know how you do it, I couldn't live like that' what they are

> telling us is that they see our lives as miserable and unworthy. We are essentially being told we are inspiring for not killing ourselves" (The Mighty, 2017).

Although many may share these messages with the intention of celebrating disability and the accomplishments of people with disabilities, it is always critical to consider the thought and reasoning behind the post, video or article. Most importantly, that means stepping back and allowing people with disabilities to share their stories in the ways that they would like for them to be shared.

Historically, disability has been viewed, discussed, and supported using a predominantly Medical Model of disability. In the Medical Model, disability is viewed as a pathological impairment in one's body or functioning that requires intervention to be "fixed" or "cured". This model typically considers medical, psychology and education professionals as the "experts" in disability, rather than people with disabilities themselves (Olkin, 2022). Rather than assuming some responsibility of society to include individuals with disabilities, it is the assumption of the medical model that people with disabilities must change to assimilate to a society of able-bodied people. This model has been scrutinized by many, and Guevera (2021) summarizes some of the core issues poignantly, stating that

> "this model fixates the "problem" within the individual while simultaneously absolving society from any further consideration. It also ultimately perpetuates stereotypes, perceiving people with disabilities as incomplete or damaged and needing fixing to accomplish any task at hand" (p. 278).

Again, though the intentions may be positive of the many professionals who have supported disability for many years using a Medical Model, it is critical to consider the

social stigma and norms that this practice perpetuates, and how that practice negatively impacts the very people that professionals aim to support.

Often considered the contrast to the Medical Model, the Social Model of disability views disability as one aspect of a person's identity. The social model views impairments as socially constructed, identifying society as the problem, rather than the individual. The Social Model advocates for changes in society and a person's environment, rather than aiming to change the person themselves (Olkin, 2022). Ideally, using a Social Model to address disability would assuage the negative perception and self-perception of individuals with disabilities to create a more inclusive society, one in which people with disabilities are supported and included across contexts, without being forced to change or adapt to their environment. The Social Model is considered the dominant model in Neurodiversity and Disability studies, but it is far from being considered a "gold standard" of Disability studies. A major downfall of this model is that it has the potential to downplay or completely ignore some of the very real challenges that are a part of disabled life. In her striking work on a "Renewed Social Model", Liz Crow (1996) asks the question:

> "Why has impairment been so excluded from our analysis? Do we believe that admitting there could be a difficult side to impairment will undermine the strong, positive (SuperCrip?) images of our campaigns? Or that showing every single problem cannot be solved by social change will inhibit or excuse non-disabled people from tackling anything at all? Or that we may make the issues so complex that people feel constructive change is outside their grasp? Or even that admitting

it can sometimes be awful to have impairments may fuel the belief that our lives are not worth living?" (p. 3-4).

Though it is fairly agreeable for all to think that societal changes must occur to better support individuals with disabilities, the Social Model falls short if used alongside black and white thinking. As Crow suggests, perhaps there is room to renew the Social Model into a practice that acknowledges both the serious impact that disability can have on a person, as well as the immense role that societal oppression plays in the lives of disabled people.

Given the complexities of the models described above, it comes as no surprise that the field of Disability Studies serves as a meeting point for numerous theoretical and philosophical debates on the experience of disability. Aligning predominantly with the Social Model of Disability but also acknowledging the immense complexity of disability is Critical Disability Theory (CDT), one of two major theoretical underpinnings of this dissertation. CDT highlights the intersectional experiences of disabled people as well as the racial, cultural, political, and social influences on those experiences. It posits that Disability Studies work is rooted in social justice and overlaps heavily with goals of queer and feminist theories (Hall, 2019). Within this dissertation, the experience of being marginalized based on both disability and gender are explored. In using a critical lens to examine disability studies, particularly research and practice in ASD, it is evident that the dominant discourse favors the white, cis-male experience of disability (Gesi et al., 2021; McCrossin 2022; Dababnah et al., 2018). Discussion of the oppression of cis-gendered girls with disabilities has emerged as a current topic, particularly in the autistic community. However, this discussion is still rather limited in that it predominantly

focuses on the white, cis-gender female autistic population, particularly those with limited to no language/cognitive support needs. Though this is certainly better than no discussion of the female experience of disability at all, the conversation continues to miss the experiences of individuals with more significant language support needs, individuals of color, and individuals with diverse gender identities. Even within a field that is working toward justice for disabled people, the inclination to fall back on heteronormative, white, male-centric discourse is quietly, or at times not so quietly, omnipresent. In using CDT to examine disabled experiences, these ideologies are critically evaluated. Minich (2016) states that in this process, "this scrutiny of normative ideologies should occur not for its own sake but *with the goal of producing knowledge in support of justice* for people with stigmatized bodies and minds" (Minich, 2016, p. 3). This shift toward critically evaluating disability research and practice aims to support and highlight the voices of disabled people who bring with them a wide variety of intersectional experiences.

Meekosha & Shuttleworth (2009) describe four major components of CDT. First, they posit that CDT cannot be reduced to quantitative methods and that there are no "facts". Second, they theorize that "autonomy" is defined as separation from hierarchical social ideology, particularly ableist and/or neuronormative. The third component of CDT describes this work as a process situated within a specific context, with researchers aware of the historical and social factors that may influence that work. Finally, CDT involves open discussion amongst and within cultures, avoiding the fault of projecting thoughts or ideas onto another group or culture, and instead engaging in open dialogue.

Rosemarie Garland-Thomson (2005) poignantly outlines how Critical Disability Studies/Theory overlaps with Feminist Theory in works such as this dissertation that examine intersectional experiences, explaining that:

> [Feminist Disability Studies] is more than research and scholarship about women with disabilities, just as feminist scholarship extends beyond women to critically analyze the entire gender system. Like feminist studies itself, feminist disability studies is academic cultural work with a sharp political edge and a vigorous critical punch. Feminist disability studies wants to unsettle tired stereotypes about people with disabilities. It seeks to challenge our dominant assumptions about living with a disability. It situates the disability experience in the context of rights and exclusions. It aspires to retrieve dismissed voices and misrepresented experiences. It helps us understand the intricate relation between bodies and selves. It illuminates the social processes of identity formation…(p. 1).

Relational Cultural Theory

With CDT as a big picture overlay for this dissertation, Relational Cultural Theory (RCT) serves as a more focused theoretical underpinning for studying relationships and experiences of adolescent girls with developmental disabilities, similarly focused on feminist ideology. In the seminal work by Jean Baker Miller and colleagues (1993), RCT highlights the impact that societal expectations, culture, and traditional psychological theory have had on the development of girls and women. Jordan (2017) describes how RCT strays from traditional psychology. In dominant psychology discourse on development, development is individualistic and focused on the "separate self", which is seen as being "most developed (i.e. healthy and good) when it

demonstrates autonomy, independence, invulnerability and agency" (p. 228). This places personal success and achievements in a place of higher value than positive and nurturing relationships. Alongside construction of the separate self is the concept of "power over" relationships rather than "power through" relationships. In traditional psychology, individuals often seek out power over others by any means necessary and fail to see the power that may come through mutually beneficial, secure and equitable relationships. Rather than studying development in the context of individual change and growth, RCT examines development as a process that occurs within relationships, acknowledging that humans are hardwired for connection and that the need for connection is not a weakness or negative character trait. For various reasons, women often assume roles within relationships that aim to foster the growth of others (e.g., caregiving), putting them in a precarious position where they are more likely to experience one-sided relationships. This theory posits that mutually supportive relationships are a human necessity, and disconnect from mutual benefit and/or conflict within relationships leads to psychological distress. Miller (2008) indicates that perhaps dominant psychological theory has focused intently upon the individual development separate from others, when development of girls, and all people, is so tightly tied to functioning within social relationships. She explains that

> "...a relational context which does not allow the developing girl or adult woman to act within relationships to represent her experience toward building mutually empathic and mutually empowering relationships leads the girl or woman to construct restricted and distorted images of the possibilities of relationships between herself and others. These constructions further limit her ability to act

within connections, to know her own experience and to build a sense of worthiness" (p. 378).

Miller describes "The Five Good Things" that result from mutually beneficial relationships: Zest or Energy, Action, Clarity, Sense of worth, and desire for more connection (Jean Baker Miller Institute, 2003). When individuals experience more connection, they continue to benefit from more of each of these "Good Things". As individuals experience disconnection, they experience less of these "Good Things". They may feel less energy and action, confusion, lower sense of self, abandoning relationships, and/or negative conflict with others. RCT highlights "authenticity" and "movement toward mutuality" as key positive relationship indicators and developmental components. Authenticity in relationships involves showing up in the relationship as the truest self, which may be more or less available depending on the relationship's dynamic. "Movement toward mutuality" is described as "movement toward emotional and cognitive action that benefits both people in a relationship, which involves mutual empathy, authenticity, mutual empowerment, and mutual responsiveness (Jean Baker Miller Institute, 2003).

According to RCT, one cannot study the development of adolescent girls in isolation. Rather than being one aspect of overall development, relationships serve as the actual context for development, relationships are the "setting" of sorts, the place where development occurs. The absence of mutually beneficial relationships in adolescence can negatively impact self-efficacy and one's likelihood to pursue additional social relationships or the deepening of existing relationships. Smaller moments of disconnect within relationships may serve as opportunities for growth, but major disconnect are

more likely to lead to isolation and long-term distress. As will become apparent in reading the review of literature on friendships of girls with developmental disabilities, opportunities to form and grow in mutually beneficial relationships with others, particularly peers, are limited. Unfortunately, adolescent girls with developmental disabilities are often excluded from classes, extracurricular activities, and social events. Without these opportunities to form social relationships, they will have significantly fewer opportunities to develop a sense of mutual beneficence and individual self-worth. In focusing on increasing the availability and quality of social opportunities for adolescent girls with developmental disabilities, educators may reach far beyond simply providing extracurricular activities. This work has the potential to support personal and social growth/development for the young girls involved.

Synthesis of Theoretical Perspectives

Both CDT and RCT utilize critical analysis of societal norms and how they serve to oppress different populations. In the Figure 1, CDT and RCT are synthesized to provide an overview of the theoretical perspective of this dissertation. Elements of CDT are used to theorize initial factors that may lead to limited opportunities for girls with DD to engage in meaningful social relationships with their peers. When current practices in special education are critically analyzed, it becomes apparent that:

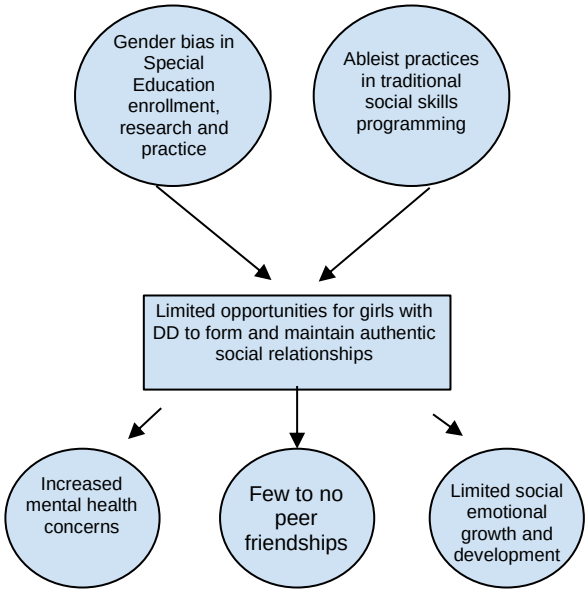
1) Many gender biases exist in special education research and practice

2) Many of the social skills programs and "friendship" supports that are provided in special education utilize ableist practices that may make it significantly more difficult for individuals with DD to form and maintain meaningful peer friendships.

These critical issues likely reduce the number of opportunities for meaningful peer relationships and interactions amongst adolescent girls with DD. RCT highlights social relationships as the context for girls to develop socially and to determine a sense of self. Viewing this lack of social opportunity through the lens of RCT leads to the hypothesis that girls with DD are more likely to experience mental health concerns, few to no peer friendships, and limited social-emotional growth and development. As RCT posits that strong relationships are the context for growth and development, this lack of opportunity likely leads to a similar lack of social progress and wellness.

Figure 1:

Synthesis of Relational Cultural Theory and Critical Disability Theory



Search Criteria and Procedures

For this review, an electronic search was completed using a university library database with access to EBSCO Host Academic Search Complete, ProQuest Central, PubMed Central, BioMed Central Journals Complete, SAGE Complete, Wiley Online

Library, Springer Link, Taylor & Francis Online, APA PsycNet, and Science Direct. The researcher prioritized articles published within the last 10 years. However, given the limited scope of research on this topic, older articles were also included if relevant to the review. Search terms included the following key terms: *social experiences, autism, developmental disability, intellectual disability, friendship, social relationships, peer relationships, girl, female, adolescent, transition, bullying, social skills, social-emotional, caregiver experiences, caregiver support, social goals, social strengths, social challenges.*

What is Developmental Disability?

Developmental disabilities are defined by the Centers for Disease Control and Prevention as "a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the early childhood developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime" (2022). Many developmental disabilities impact a child's language skills, academic progress, and social-emotional development. Though not an exhaustive list of conditions that fall under this category, some of the most commonly discussed developmental disabilities include autism spectrum disorder (ASD) and intellectual disability (ID). In the following section of this literature review, definitions of ASD and ID are considered. Current evidence on the transition process of youth with DD is reviewed, followed by experiences of caregivers of children and young adults with DD.

What is Autism Spectrum Disorder?

Likely the most heavily discussed developmental disability, ASD is a complex condition that has sparked numerous historical, medical, and educational discussions

throughout time. For the sake of defining ASD as it is frequently referred to in the medical and education worlds, complete definitions using the DSM-5 are provided in this section. However, it is important to note that the autistic community has advocated away from this Medical Model for discussing, diagnosing, and treating ASD. This section will end with a description of ASD as defined by the autistic community and advocates of the Neurodiversity movement.

The *Diagnostic and Statistical Manual of Mental Disorders-5th Edition* (*DSM-5*; American Psychiatric Association [APA], 2013) defines ASD as being characterized by "persistent deficits in social communication and social interaction across multiple contexts" as well as "restricted, repetitive patterns of behavior, interests, or activities" (APA 2013). As the *DSM-5* focuses on ASD as a spectrum, there is variability in the severity of symptoms for different individuals diagnosed with ASD. The *DSM-5* asserts that individuals with ASD have differences in social-emotional reciprocity that may lead to difficulty with reciprocal conversation, the sharing of emotions, and overall affect. Additionally, it outlines differences in understanding and use of non-verbal language as well as initiation and maintenance of peer relationships (APA 2013). This may translate to difficulty starting/maintaining conversation and understanding the viewpoints of others, making it particularly difficult to make and keep friends. In addition to social and communication differences, an individual must exhibit repetitive/restricted behaviors to receive a differential diagnosis of ASD (APA 2013). The *DSM-5* provides examples of these behaviors such as stereotyped/repetitive motor movements, use of objects, and/or speech. Individuals with ASD may also exhibit inflexible use of routines and/or ritualized patterns of verbal and non-verbal behavior (APA 2013). These differences may lead to

behaviors such as insistence on completing a task in the exact same way each time or taking the same route to school each day.

The *DSM-5* defines ASD as a spectrum disorder. This is a change from previous versions of the *DSM*. In the revision of the *Diagnostic and Statistical Manual of Mental Disorders-4th Edition* (DSM-IV-TR; APA 2000), four disorders that now fall under the umbrella of ASD were separated into distinct diagnostic categories: autistic disorder, Asperger's disorder, pervasive developmental disorder not otherwise specified (PDD-NOS) and childhood disintegrative disorder. Although Asperger's disorder, PDD-NOS and childhood disintegrative disorder are no longer diagnostic labels, it is critical to consider their previously separate diagnostic characteristics in discussion of current practices in diagnosis and treatment of ASD as a spectrum. Asperger's disorder was defined using the same criteria as autistic disorder, characterized by differences in social interaction and restricted, repetitive behaviors. However, Asperger's was unique from autistic disorder in that individuals diagnosed with Asperger's had no significant impairments in language, cognition, or adaptive functioning (APA 2000). Though the terminology of Asperger's may still be used informally today, it is no longer a formal diagnosis, and many autistic self-advocates prefer to not use the term given the anti-semitism that has recently been discovered of Hans Asperger's past (Autistic Self-Advocacy Network, 2018).

At this point in time, autism, Asperger's, PDD-NOS and childhood disintegrative disorder all fall under the umbrella of ASD. According to the Center for Disease Control's Early ASD and Developmental Disabilities Monitoring (ADDM) Network, 1 in 44 children (age 8) are diagnosed with ASD, with boys four times more likely to be

diagnosed than girls (Maenner et al., 2021). These numbers have raised extensive discussion, as they show a marked increase from past years. In 2000, prevalence was estimated at only 1 in 150 children (CDC 2000). Though this rise in prevalence is a topic of debate in the literature and even in the news, the evidence does not point to a simple cause of more children "developing" ASD. This has not been ruled out as a contributing factor, but the rise is more likely due to a combination of factors. Likely contributors include changes in ASD awareness among parents and professionals, increased access to diagnostic and support services, and changes in screening/evaluation measures (Blumberg et al., 2013). Additionally, discussions of racial, socioeconomic, and gender biases in the autism diagnostic process have increased in recent years. It is well documented that the diagnostic process is quite likely sensitive to the white male presentation of ASD, with little consideration for the presentation of ASD amongst other gender identities, and racial and ethnic groups (Loomes et al., 2017; Haney 2016; Kreiser & White, 2014; Tsirgiotis et al., 2021; Mandell et al., 2009; Durkin et al., 2017; Bilaver et al., 2020). The implications of this biased diagnostic approach are significant at micro and macro levels and have recently emerged as a discussion of not only individual development but also of social justice in our society.

In addition to advocating for these marginalized groups within the autistic community, many disability advocates have been vocal in their desire to steer the public away from viewing autism, and all developmental disabilities, through a Medical Model lens. Many autistic individuals have been active in the Neurodiversity movement and have advocated for a paradigm shift in social, research, and clinical practices. Neurodiversity refers to "the notion of disability as an interaction between social factors

and personal deficits, the challenges of which do not necessarily make life less valid or worthwhile but an equally valid part of human diversity" (Kapp et al., 2013, p. 68). Neurodiversity encourages the celebration of neurological differences as unique, not less, with the potential to make significant contributions through diverse processes of brain functioning. In this framework, it is not just ASD that falls on a spectrum, it is all human neurocognitive functioning. There is natural variance in how the human brain develops, and proponents of the Neurodiversity movement argue that this variation is not only natural, it is beneficial to our social worlds. Lydia X. Z. Brown, an autistic individual, has shared the social importance of using identity-first language to talk about autism, stating that:

> …when we say "Autistic person," we recognize, affirm, and validate an individual's identity as an Autistic person. We recognize the value and worth of that individual as an Autistic person — that being Autistic is not a condition absolutely irreconcilable with regarding people as inherently valuable and worth something. We affirm the individual's potential to grow and mature, to overcome challenges and disability, and to live a meaningful life *as an Autistic*. Ultimately, we are accepting that the individual is different from non-Autistic people–and that that's not a tragedy, and we are showing that we are not afraid or ashamed to recognize that difference" (Brown, 2011).

What is Intellectual Disability?

The CDC defines ID as "a term used when there are limits to a person's ability to learn at an expected level and function in everyday life" (CDC 2022). ID may impact a child's pace of learning and development in areas of daily living (e.g., eating, dressing,

hygiene) and academics. There are many possible causes of ID, including genetic conditions, problems during pregnancy/birth, and health problems. It is estimated that roughly 1% of children are diagnosed with ID (CDC 2017). Prior to publication of the DSM-5 in 2013, ID was clinically diagnosed as "mental retardation". The changes made in the DSM-5 adjusted not only the diagnostic label, but also the diagnostic process. Rather than diagnosing ID based on standardized intelligence tests alone, an individual's adaptive functioning must also be taken into consideration during the assessment process. Clinicians may diagnose ID based on difficulties across conceptual (e.g., language, reading, writing, math, memory), social (e.g., social judgment, interpersonal skills) and practical (e.g., personal care, maintaining employment) intelligence in addition to an IQ score of about 70 or below on standardized measures (APA 2013).

Contrary to many autistic advocates, many individuals with ID prefer person first language (i.e. "Person with ID" vs. "Intellectually disabled person"), as evidenced by advocacy groups like "People First", run by and for people with ID. As is the case with any language/diagnostic label, the decision of what language to use to refer to a person with a disability should be informed by the person. In a study by Monteleone & Forester-Jones (2013), individuals with ID were interviewed and asked to define their disability and describe their experiences as a person with ID. In this study, participants consistently described experiences of being "othered" and striving to be "normal", and strongly associated their identities with how their peers perceived them. In a society that emphasizes employment status, education and academic achievements, it is no surprise that individuals with ID feel devalued and overlooked. At the same time, adolescents with ID continue to share the same goals of independence, employment, and successful

adulthood with their non-disabled peers. Although they may have some worries about their ability to keep up with responsibilities, many adolescents with ID may feel quite optimistic about their futures (Salt et al., 2019). Given this intrinsic optimism, it is likely that individuals with ID are not to blame for continued negative outcomes in employment and transition or young adults with ID. Rather, the communities in which individuals with ID are living, learning and working are probably largely to blame for promoting societal attitudes that continue to exclude individuals with disabilities. In fact, in interviewing women with ID, Cytowska & Zierkiewicz (2020) found that participants did not feel that their gender or disability were inherently problematic, but that they faced external oppression in navigating life as a female with ID. This idea of societal oppression is significant because it is socially constructed and avoidable. If individuals with ID were given the support that they need to be successful across academic, social, vocational, and community settings, outcomes research may show a very different picture of intellectual disability.

Transition for Adolescents with Developmental Disabilities

Transitioning into adulthood is a complex psychosocial process for all adolescents, regardless of whether or not they have a disability. For adolescents with developmental disabilities, this process is further complicated by a drastic reduction or definitive end to services provided through special education and a variety of social, cognitive, and executive functioning differences. In a study by Hoyle et al. (2020), when compared to same-age peers without disabilities, young adults with DD were significantly more likely to report experiences of physical and sexual assault, criminal arrests, obesity, a sedentary lifestyle, smoking, diabetes, work disability, and failure to

graduate high school. Although special education programming has certainly improved over the last few decades, findings such as these indicate that programming continues to fall short of the needs of individuals with developmental disabilities and may be targeting more traditional academic subjects while missing critical opportunities to support social, emotional, and adaptive growth. Unsurprisingly, studies on the transition process for adolescents with ASD show low scores on assessments of quality of life across domains (Shipman, et al., 2011) and that many individuals experience social isolation with few peer relationships (Orsmond, et al.,, 2004; Orsmond et al., 2013). Additionally, families of adolescents with DD report significantly high levels of distress during the transition process, when supports that may have been provided through the individual's special education program are no longer available (Mckenzie et al., 2017). Individuals with ID are significantly less likely than their non-disabled peers to go to college and/or gain consistent employment, and this disparity is even stronger for girls with ID, individuals of color with ID, and individuals with ID who are in a low socioeconomic class (Xueqin et al., 2018). However, many interventions have proven effective in improving social outcomes of individuals with DD, particularly interventions that involve group interactions, personalized goal setting, the arts, and social communication targets (King et al., 2022). Educational researchers and practitioners may consider a shift from more traditional programming to focus on functional and meaningful social supports for individuals with DD.

Caregivers of Adolescents with Developmental Disabilities

Caregivers (e.g., parents, family members, guardians) of individuals with developmental disabilities each experience their child's transition into adulthood in

unique ways, though there are certainly themes across experiences. In a recent study by Kerr et al. (2022), parents of adolescents with ID reported difficulties related to societal views/expectations of people with disabilities, a lack of accessible and comprehensive services, and personal conflicting emotions and mental health concerns. Any one of these factors has the potential to impact a caregiver's well-being and quality of life significantly. The complexity of all factors occurring simultaneously and interacting with one another creates a particularly precarious position for caregivers of adolescents with DD. Unfortunately, many individuals with DD and their families continue to cite exclusion and discriminatory practices as commonplace in modern society, and, unsurprisingly, this stigma causes increased stress for caregivers of individuals with DD (Papadopoulos et al., 2018). It is not only the stressful process of caring for an individual with unique support needs that impacts caregivers, but also the normative structure of society at large that continues to exclude individuals with disabilities.

The process of caring for an adolescent with or without a disability can prove challenging, but caregivers of adolescents with DD also experience distinct challenges that are specific to their child's disability. Some caregivers may struggle as their child with DD transitions to adulthood, when behavioral and support strategies that were effective in past years may no longer be effective at this pivotal developmental period (Hamilton et al., 2015). Caregivers may rely heavily on school-based programming, making it exceptionally difficult when students graduate from special education and caregivers no longer have access to: a) structured/consistent programming for their child; and b) access to advice and consultation on strategies and supports to implement at home across different points of development. During the transition process, caregivers

frequently find themselves with limited social support networks. At the same time, they must navigate the changing structure of their own employment schedules and capabilities coupled with significantly reduced availability of formal support (Mckenzie et al., 2017). Of course, as shifts are made in their child's life, so too are they made in the caregiver's life. The need to be available to support their child with DD more regularly as they leave formal schooling has the potential to impact a caregiver's own career and daily life in significant ways. Employment support, access to social services, and safety/inclusion in the community are only a few of the issues that caregivers may be facing head on during this period of adolescence. The transition process of an adolescent with DD has the potential to make major shifts in the total family dynamic, which may place significant strain on caregivers.

Although the transition process appears rather bleak based on this literature, experiences vary across caregivers, families, and communities. Overall caregiver health is complex and depends on a combination of social/support factors, individual caregiver traits, characteristics of the individual with DD, and family dynamics (Marquis et al., 2019). Though limited, some literature exists that focuses specifically on the experience of caring for an adolescent girl with a developmental disability. In a study by Woodman & Hauser-Cram (2012), parents of male adolescents with DD reported increasing parenting efficacy as their child entered adolescence/adulthood, while parents of girl adolescents did not. This discrepancy may stem from various factors that are distinct to the experiences of gendered caregiving. One of the most striking causes for concern in the process of raising an adolescent girl with DD is the increased risk of sexual exploitation of girls with disabilities in general, but particularly those with ASD and/or

ID (Reid, 2018; Martin et al., 2016; Franchino-Olsen at al., 2020). It is logical to think that caregiver stress increases as the female child begins reaching a point in development when they are at greater risk for unsafe sexual experiences/sexual exploitation, often at the same time that they become increasingly interested in social independence. In addition to typical caregiver roles, many caregivers of adolescents with DD of all gender identities must take on an additional role of educating their child on sexual health and safety, as these topics are rarely taught comprehensively in special education classrooms (Stoffelin et al., 2017; Sinclair et al., 2015; Schmidt et al., 2020). For female adolescents with DD, sex-specific issues such as menstrual health, higher risk of sexual exploitation, and discussion of pregnancy/childbirth pose additional challenges, as caregivers must navigate these complex discussions in a manner that is accessible based on their child's cognitive and language support needs (Cummins et al., 2020).

In addition to concerns of sexual safety and wellness that may be either general or sex/gender identity-specific, caregivers of girls with DD often face barriers to accessing accurate diagnoses and support services. Caregivers of girls with ASD in particular, are at increased risk of difficulty accessing timely and accurate diagnoses and support services (Fowler & O'Connor, 2021; McDonnell et al., 2021). Additionally, caregivers of female students may struggle to form connections with other caregivers within special education programs. A great way to feel social support is to share experiences with other families and to gather advice from other caregivers who may be having similar experiences with raising their child. Although there are certainly many experiences that are shared by students of all gender identities in special education, there are many distinctly female experiences. Given that the Pew Research Center estimates that only 33% of students

receiving special education services under IDEA are female, caregivers of young girls may have a harder time connecting and forming a social network with other caregivers (Pew Research Center, 2020).

Although a review of current literature on the experiences of caregivers of individuals with DD as a whole includes a multitude of challenges, strong support systems show promise in negating any negative implications of those challenges. In a study on the coping strategies of parents of Black autistic children, Lewis et al. (2022) found that parents benefited from opportunities to share and discuss experiences with other parents of autistic children, both online and in person. The parents included in this study shared that they would like more opportunities for this kind of mutual social support. This finding is highly relevant to educational programs looking to increase family engagement and opportunities to support caregivers. Furthering the argument for strong social support, a study by Nolcheva et al. (2015) found that strong family support was a key factor in managing stress for caregivers of children with ASD/ID. Studies such as these highlight the importance of including caregiver support as a priority for supporting the social and friendship experiences of individuals with DD.

Friendships

Friendship is a critical aspect of overall well-being, and the presence or absence of high quality friendships can have a major impact on an adolescent's transition into new phases of life (Ng-Knight et al., 2019). This review begins with a discussion of friendship/social experiences of adolescent girls (i.e. with and without DD), followed by individuals with DD (i.e. all genders/identities). Given the relatively strong focus on girls with ASD in the literature on DD and gender, the next section provides a brief overview

of social/friendship strengths, challenges, and preferences of girls with ASD specifically, before ending with a broadened discussion of girls with DD and a variety of cognitive profiles. Through discussing each of these pieces of the identities of girls with DD, a clearer picture of the social complexity that they navigate emerges.

Friendships: Adolescent Girls

Although the topic of disability is central to this literature review, it is important to note that gender-based social differences are not unique to individuals with DD. The impact of gender roles, gender stereotypes, and unique biological/psychological/social experiences are felt by all adolescents, regardless of disability status.

In a youth-led research project by the Girls Leadership Foundation, a number of common themes related to being a young girl in today's world emerged through discussion with young girls themselves, and findings were supported by additional peer reviewed sources. First, many participants reported negative impact of gender stereotypes and gender discrimination, and that they had frequent experiences of peers and adults making assumptions about their abilities and interests based on their feminine identity (Carr 2021; Klaczynski et al., 2020). The second major finding was that young girls prioritize their social relationships and that families and friendships are important to their feelings of belonging, safety, and self-confidence (Carr 2021; Huntley & Owens, 2013). Finally, this research found that girls have strong opinions about advocacy and the importance of having strong female leaders in their communities. The perspectives of young girls in this study highlight specific challenges and priorities linked to their gendered experiences. Gender stereotypes persist in today's world, impacting how young girls navigate the social world. In fact, gender biases may be particularly strong in the

internal and environmental experiences of adolescence (Klaczynski et al., 2020, Basow et al., 2007), making this a particularly sensitive time for the social development of young girls.

Gilligan (2003) describes the female experience as one defined by connection with others, and that acceptance by other girls and women is often central to feminine identity. Indeed, strong female friendships are associated with fewer depressive symptoms (Rodrigues et al., 2020; Prinstein et al., 2005). Compared to their male peers, girls are more likely to share their feelings and personal problems with friends and are also more likely to respond with support during a friend's time of need (Rose et al., 2016). Despite the apparent importance and closeness of female friendships in these examples, much of the literature on adolescent female friendships focuses on bullying and relational aggression. Hadley (2003) explains relational aggression and its prevalence in writing and media. Peer-reviewed literature, fiction and non-fiction literature, and media, in general, are brimming with "mean girls" and clashes between adolescent girls occurring across school, social and online settings.

The theme of more recent writers, though played out in various ways by different authors, is that girls express their aggression in and through relationships in indirect, covert, and often hurtful ways. This aggression is frequently in the service of forming alliances that exclude some in order to affirm others. In detailing relational aggression in "the girl world", Hadley (2003) makes a unique point that perhaps girls possess a strong ability to navigate a multitude of social roles, and that they need guidance to use it constructively. Similarly, Gonick (2004) suggests that the "mean girl phenomenon" so widely seen in literature and media fails to account for the gendered and cultural

expectations of girls in society. Though adolescent girls are often viewed as "nasty, vicious, and backstabbing", there is little discussion of the societal norms and expectations that may lead them to relational aggression, nor is the same pathologizing quality applied in discussion of adolescent male socialization and conflict resolution. Additionally, given the covert nature of relational aggression coupled with societal expectations, the conflict that adolescent girls do experience may go unnoticed, or be normalized (Bouchard et al., 2018).

Although scholars have yet to reach a comprehensive understanding of relational aggression amongst adolescent girls, it exists just the same and can lead to various problems for young people (Basow et al., 2007). When dealing with relational aggression, girls seem to fare best when they have good problem-solving skills, strong emotional regulation, and adequate language skills (Huntley & Owens, 2012). Additionally, strong maternal and paternal relationships as well as larger friend groups are associated with a stronger ability to respond to relational aggression and peer group conflict (Huntley & Owens, 2012; Rodrigues et al., 2020).

In a study by Sedgewick et al. (2018), groups of girls with and without ASD were studied with boys with and without ASD. Although differences were found in the social experiences of participants based on disability status, there were also clear differences based on gender. Girls with and without ASD described the importance of having a smaller group of "best friends", the difficulties of arguments with friends, wanting to fit in, and the general importance of having friends for emotional support. Male participants with and without ASD reported very different social experiences, with a stronger focus on activity-based friendships and friends as "someone to do things with." Although

researchers found some differences in social experiences based on disability status, it is important to note that social norms, expectations and experiences differed for all adolescents based on gender. A conversation style involving frequent gossip is common in girl social groups, often considered a negative behavior in most schools and extracurricular settings. Although some gossip may be aggressive in nature, the amount of peer gossip that occurred in one study was positively correlated with friendship quality and social competence (McDonald et al., 2007). Some research has found that gossip in female social groups provides an opportunity for adolescent identity development and a developmentally appropriate space for adolescent girls to determine their viewpoints on various social issues (Guendouzi, 2020). Though behaviors like gossip are often considered maladaptive or negative, it is important to consider the wider contexts in which they occur. Given many adolescent girls' strengths in social communication and relationships, educators, families and stakeholders must use caution when labeling social behaviors as “good” or “bad”. Instead, contextual factors must be considered in order to generate solutions and programs that will truly support adolescent girls to enjoy positive social relationships and identity development.

Adolescents with and without developmental disabilities face a variety of social challenges. Some of those challenges are shared by all, while some may differ based on various complex and gender-driven factors. Regardless of disability status, there are certain aspects of being a girl in today’s world that are quite complex and unique to the female social experience.

Friendships: Individuals with DD

In addition to the influence of gender, social experiences are heavily shaped by disability status (Garolera 2021; Webster & Carter, 2007). Cognitive/language functioning, health status, and the many other facets of disability directly impact the context and content of adolescent social interactions. Research on the social and friendship experiences of adolescents with DD are limited. There is more extensive research on the social experiences of youth with ASD; however, the scope of this research is still limited. Few studies examine the social experiences of individuals with ASD and comorbid ID/cognitive and language support needs. Much of the existing research focuses on individuals with ASD with little to no cognitive/language support needs, and no comorbid diagnosis of ID. Additionally, most of the research on ASD focuses on the male presentation. Nonetheless, there are some pioneers in the field who are examining the social experiences of all individuals with DD.

Taheri et al. (2016) studied the social experiences of individuals with ASD and comorbid ID. This quantitative study used survey data to compare the social participation of children/adolescents with ID and/or ASD to their peers without ASD/ID. Students with ASD/ID were reported to participate in fewer social activities than their non-disabled peers. They were more likely to have fewer friends and a lower friendship quality. During a period of life heavily focused on social relationships and friend groups, these findings are particularly alarming when considering the social-emotional wellness of adolescents with DD. Without feelings of social inclusion and belonging, adolescents with DD are missing an important piece of social identity and wellness. A study by Biggs & Carter (2015) confirmed these findings. In a survey of the overall quality of life of transition-

aged youth with ASD/ID, their quality of life scores were significantly lower than norm-referenced peers. Of all domains, participants received the lowest scores in Social Support and Peers. The authors emphasize the need to understand that this significant aspect of overall quality of life is impacted not only by the individual and their social and behavioral functioning but also by the school environment and programming in which they participate. Rather than place the blame of this problem on the individual, it is time to consider the lack of social programming that exists. Additionally, it may be time to take a closer look at the existing programming to determine whether or not it is truly beneficial for individuals with ASD/ID, and whether or not they have had any say in the programs that they participate in (King et al., 2022).

In line with these findings, Merrells et al. (2019), found that young adults with ID experienced significant social exclusion. Despite having received comprehensive/community based social support services throughout their lives, participants reported being "segregated, excluded, and feeling like an outcast in the community" as well as having difficulties initiating and maintaining friendships with peers (p. 17). These voices highlight that it is not simply the presence or absence of support services that defines whether individuals with ID face social isolation. Perhaps it is the type of support that is being provided that needs to change to better support individuals with ID in feeling successful and fulfilled in their social worlds.

In contrast, targeted opportunities for social engagement and learning sensitive to the specific goals and desires of individuals with DD may have the power to counteract or at least reduce social isolation in a way that generalizes outside of the structured social groups. Wilson et. al (2017) studied a social group program that involved coordinator

support during activities like bowling and going to the movies, with a plan to slowly fade coordinator support until small groups of young adults/adults with DD initiated and maintained the outings on their own. These outings and the focus of each group were determined by the coordinators in partnership with the group members to ensure that all voices were heard, and that the focus of the groups was meaningful to all. At the end of the program, participants reported an increase in their social networks, reduced feelings of boredom, increased healthy activity, an increase in skills needed to successfully engage with a social group (e.g., travel skills, planning, budgeting), and a greater sense of social belonging. It is evident in this study that the right kind of support can transform social outcomes for individuals with DD. It is not the case that individuals with DD cannot maintain their own social circle, or that social groups can only be maintained with a non-disabled coordinator. Rather, the supports and programs that are put in place must be a) considerate of the voices, goals and preferences of participants; and b) systematically constructed to use evidence based practices for supporting individuals with DD.

Researchers purport that adolescents with developmental disabilities lack closeness in social circles. The cause of this lack of closeness could be a result of being left out or actively experiencing bullying. One study examined the impact of ID alone (i.e. no comorbid ASD diagnosis) on social experiences of young males and girls. This qualitative study by Griffin et al. (2019) consisted of semi-structured interviews with 18 adults with ID to discuss their social experiences across the lifespan, particularly as those experiences related to social exclusion/bullying. Through speaking with participants, researchers coded major themes of "bullying is hurtful", "why people bully", "bullying

can happen anywhere" and "bullying takes many forms". Unfortunately, this is just one of many studies that have shown bullying (including cyber-bullying) to be common among individuals with DD (Christensen et. al, 2012; Didden et. al, 2009). This research highlights the importance of providing individuals with ID/DD with support related to self-advocacy and social problem solving and the opportunity to share their experiences and stories with others. Just as research on girls more broadly indicates that girls with DD likely face unique challenges based on their gender alone, this research indicates that girls with DD may also face unique challenges based on their disability alone.

As it has been established that individuals with DD commonly experience bullying, it comes into question what exactly makes them "at risk" for this negative experience. Martinez-Cao et. al (2021) found a number of risk and protective factors through systematic review of 37 articles focused on bullying experiences of individuals with DD. Individuals in a public school setting, rather than a specific special education school, are more likely to experience bullying. However, individuals in special education schools are not free of risk, particularly when it comes to cyber-bullying (Didden et. al, 2009). Additionally, being girl was strongly associated with increased risk of being bullied. Protective factors included strong social skills and feeling safe in school, which may be emphasized as important areas of focus in special education programs and educational programs in general. In terms of long-term impact of bullying, adolescents in the study reported mental health concerns, reduced sense of belonging, reduced ability to resolve interpersonal conflict, reduced sense of safety at school, and poorer physical health. In considering bullying intervention and support, educators might inadvertently focus on bullying prevention in the absence of support for individuals already

experiencing the negative impact of past bullying experiences. Prevention is key, and it is of course ideal to take a proactive approach to these types of social issues. However, by the time they reach adolescence, individuals with DD (particularly girls with DD) likely have experienced more than one instance of bullying and/or negative social interaction. Social programming and support for individuals with DD must take this into consideration and move their aim deeper than surface level/neurotypical social skills. These experiences are in of themselves a mental health crisis, and educators/community support programs must consider the social-emotional needs of their participants if they are truly to change the negative social outcomes that are far too prevalent in this population.

Siperstein et al. (1997) examined the friendships and social interactions of children with and without learning disabilities to elicit interaction and friendship skills patterns. In pairs that included a child with a learning disability, interactions were determined to be "lacking in distinctive features of friendship" in that the pairs engaged in less verbal communication and less collaborative decision making, tended to work on separative activities vs. working together on one activity together, and engaged in limited laughter. This was interpreted to indicate an overall low level of active engagement with one another. Although the authors indicated that diverse social preferences and interests should be considered when interpreting these results, this article does little to explore what those diverse social preferences might be. Children and adolescents with developmental disabilities have experienced a long history of being labeled as "socially deficient", with little to no consideration for their unique social interests and preferences.

Perhaps they are not socially deficient or disinterested, but rather unique in their social interaction style and preferences.

Indeed, a closer look at the social perceptions and experiences of individuals with developmental disabilities themselves shows that friendship may look and feel different but that it is no less significant or fulfilling than "typical" friendships. Hurd et al. (2018) used qualitative interviews to gather the direct perspectives of adolescents with developmental disabilities on friendships and social relationships. Several themes emerged including that friendship is meaningful and differentially defined. To better understand and support the friendships of neurodiverse individuals, researchers and practitioners must expand their definition of what constitutes a meaningful friendship to acknowledge neurodiversity and its impact on social perceptions. In line with this notion, Rossetti (2014) discovered a variety of definitions of friendship through interviewing and observing adolescents with developmental disabilities. Additional themes included excitement and motivation to make friends, normalized support between friends, and mutual benefit. Similarly, Sigstad (2016) identified themes of mutual preference, mutual enjoyment, shared interaction, care, bonding, mutual trust and reciprocal nomination. These findings are significant when imagining the future of friendships and social support for individuals with DD. Educators, families and stakeholders must let go of their own biases in order to fully embrace and support a variety of social identities and preferences. Though some social interactions may be viewed as "non-interactive" by a neurotypical observer (e.g., two individuals sitting next to each other but engaging in two different activities), it may be considered highly supportive from a different perspective. Rather than noting the many ways that social preferences may differ amongst neurodiverse

groups, one can acknowledge that they may need to check their own biases and expectations before placing expectations on the social experiences of individuals with DD (Yu & Sterponi, 2023).

Friendships: Girls with ASD

In the scope of research that has been done on social experiences of girls with DD, the majority of studies have focused on girls with ASD. Although this research focuses on only one sector of the developmentally disabled population, it does provide a window into the intersectional experiences of girls with ASD that may be extrapolated to girls with DD more broadly as a starting point for exploration. Recent discussion in ASD research highlights the significant gender biases that exist throughout the history of the disorder, including research, diagnosis and treatment (Loomes et al., 2017; Van Wijngaarden-Cremers et al., 2014, Lai et al., 2015). When ASD research is traced back to its earliest published work, studies by Hans Asperger and Leo Kanner in the early 1940s focused on male research participants, and males have continued to be the focus of ASD research to this day (Wolff et al., 2004). The information through which diagnostic criteria, evaluation procedures and interventions are informed has been based almost entirely on the male representation of ASD. This realization has led to a focus on the need for a better understanding of the female experience of ASD. Subsequently, more stakeholders have narrowed in on the social experiences of girls with ASD than ever before.

Many autistic, female self-advocates have spoken about their experiences on social media and online platforms. Samantha Stein, an autistic YouTuber, has a variety of videos describing her experiences as an autistic woman who was diagnosed in adult life.

She describes experiences such as trying to imitate the behaviors of other girls to fit in, feeling anxious and isolated in social situations, attempting to hide stimming behaviors, and more (Stein, 2019). The literature supports these claims, with many researchers also focused on diagnostic issues, camouflaging/masking, and internalizing symptoms of girls with ASD.

Girls with ASD may show significantly fewer challenges when compared to their male counterparts at a young age, but greater social difficulty as they move into adolescence (Kirkovski et al., 2013). The demands of female friendships, which tend to be far more conversation based and involve more discussion of emotions, may become more complex as girls enter adolescence, placing girls with ASD in a particularly vulnerable social position as they attempt to form female friendships (Sedgewick et al., 2019). Given what is known about the different social activities of males and females, greater social/language skills may be required for girls to succeed socially, as well as a nuanced understanding of non-verbal social cues and unspoken social rules. This increased female social demand along with the social/emotional needs that are characteristic of ASD may unfortunately put girls with ASD in a position for increased social difficulty and internalizing symptoms.

Camouflaging or Masking/Internalizing Symptoms

Camouflaging (i.e. attempting to hide difficulties/challenges, attempting to blend in with a peer group) and masking (i.e. specifically trying to hide autism) are unfortunately common amongst girls with ASD, and may lead to a wide range of mental health concerns and internalizing symptoms. Halsall et. al (2021) completed interviews with adolescent girls with ASD, their caregivers, and their educators. Findings indicated

that camouflaging and masking were common amongst these girls, although often unsuccessful. Girls reported attempting to hide their social and learning difficulties across settings, with varying degrees of success. Girls reported feelings of immense exhaustion from attempting to camouflage and mask their autism across the school day. Of particular interest for the current study, girls in this sample were found to be "doubly excluded" in their social circles. They were often placed in resource classrooms with mostly boys, who had different support needs and were not well-matched social peers. Girls often found themselves excluded from their peer group in resource classrooms. At the same time, they were excluded from mainstream classes by being pulled into resource classrooms, so were also excluded from their mainstream peers. Finally, their attempts to camouflage had varying degrees of success in both settings, leading to exhaustion and additional social exclusion.

Given these findings, it is no surprise that researchers have consistently found increased levels of internalizing symptoms (e.g., anxiety, depression) in girls with ASD when compared to female peers who are neurotypical and male peers with ASD (Solomon et al., 2011; Oswald et al., 2015). It appears the combination of being a girl and having ASD may put individuals in a uniquely complex social position. In addition to facing gendered social challenges that are typical of all girls, girls with ASD are also facing social challenges related to their social language support needs and may have an even more difficult time navigating the nuances of female friendships. Difficulty socializing with neurotypical girls, girl-specific puberty issues and sexual vulnerability are a few of the concerns identified by researchers in interviews of adolescent girls with ASD (Cridland et al., 2014). Additionally, adolescent girls with ASD are more likely than

males with ASD to be anxious about general functioning within regular social domains (e.g., receiving/giving hugs, being touched, socializing with others) (McGillivray & Evert, 2014). Although girls with ASD may show fewer social difficulties than their male peers at a young age, their social environments and personal identities lead to a variety of complex challenges as they move into adolescence and adulthood.

Social and Friendship Preferences

Contrary to dominant discourse on individuals with ASD in the media, girls with ASD value friendships, and consider close friendships with peers to be of high importance. Ryan et al. (2021) found that adolescent girls with ASD value friendships with peers who share similar interests, and expect close friendships to transcend school-based interactions into hangouts outside of school/in the community. Contrary to boys with ASD in this study, female participants felt that the quality or strength of their friendship did depend on interacting outside of school. Girls cited a small group of friends (e.g., around 4 friends) as being ideal, and highlighted emotional connection and reciprocity as important components of friendship. Additionally, participants mentioned social media and phone communication as important aspects of friendship building and maintenance. Although this study focused specifically on girls with ASD, it would likely not be a far reach to assume that many of these preferences would suit girls with DD more broadly. Particularly in a world that relies heavily on technology, girls with DD need to navigate school interactions and maintain friendships outside of school and via technology. Although the social interest outlined in the studies above provides a positive indicator for social success, supporting girls with DD in navigating these diverse social

environments is highly complex. Perhaps this is part of the reason that so little information exists for supporting the social experiences of girls with ASD.

Friendships: Girls with DD

Until this point, this literature review has focused on research that relates to girls with DD but that does not specifically address this population as a whole. Though limited, some researchers have worked to study the social experiences of girls with DD, including those with cognitive/language support needs. In a study by Morán et al. (2019), the social experiences of males and females with ASD and comorbid ID were studied using the ASD-KidsLife Scale, completed for 420 participants between the ages of 4 and 21. Males obtained higher scores in social inclusion than their female counterparts, which the authors hypothesized may have resulted from different social expectations of males and females (e.g., the expectation that males tend to socialize through group activities like sports, while females were expected to socialize more through conversation based activities). The authors felt that these challenges could lead to exhaustion, discouragement, and social participation restriction for female participants. It seems that visibility of disability may play a role in the results and that girls (whose disability may be less apparent) may require greater social support. The authors conclude by stating that:

> It must be noted that social inclusion does not depend exclusively on the person with ASD, but also depends on the context, opportunities, and a gender perspective in the design, assessment, and implementation of individualized support, family strategies, professional practices, and organizational services aimed at enhancing social inclusion related personal outcomes (p. 2986).

This research emphasizes the need to acknowledge gender-based differences in not only the diagnostic process but also the education and support processes. Although this recommendation has started to emerge in the research, it may take time for it to transfer into practice.

Social exclusion is one of the many challenges that girls with DD face as they navigate their social worlds. Mental health concerns and negative social experiences may compound on social exclusion to make successful social interactions even more difficult. In a study by Boström et. al (2018), adolescents with ID/DD were significantly more likely to report mental health concerns and fewer positive social/familial experiences than adolescents without ID/DD. Additionally, all adolescent girls in the study (i.e. with and without ID/DD) were more likely to report mental health concerns and negative social experiences than were their male counterparts (i.e. with and without ID/DD). Unfortunately, this places girls with ID/DD in both groups, at risk based on their disability status and at risk based on their gender. Indeed, when broken down and grouped by disability status and gender, girls in this study reported more mental illness and poorer family, peer, and school relations than any other group. Additionally, girls with disabilities are less accepted by their same-sex peers when they have social issues in class (e.g., not getting along with a classmate, showing frustration) (de Boer et. al, 2013). This issue is distinct to girls, as boys with disabilities did not experience any changes in social acceptance by their same-sex peers following social difficulties in the classroom. Girls with disabilities may often find themselves at the mercy of the same-sex peers they are grouped with, and experience greater social exclusion. Girls in the study by Boström et. al (2018) who were rated as having more positive attitudes were also more likely to

show acceptance of their same sex peers with disabilities, while girls who were rated as having a more negative attitude were not. Although this finding may not be all that surprising, it shows that the social experiences of girls with disabilities vary at the individual level, making it more complicated to support across educational programs. A simple school wide initiative may not have the impact that is needed to alter individual interactions that girls with disabilities experience countless times throughout a single school day.

Similarly, through interviewing parents and teachers of girls with ASD and limited verbal speech, Cummins et. al (2018) found that the needs of girls, particularly as they navigate puberty, vary greatly. This population is not homogenous, and the support that is provided cannot be either if educators and caregivers are to truly make an impact on the strengths, challenges and goals of girls with DD. Of note, the researchers found that all participants were highly concerned about the social/sexual vulnerability of their child/student. Given the negative implications of this concern, along with the fact that it is shared by many caregivers and educators, it is critical that programming take this into consideration to protect the safety and well-being of girls with DD.

Limitations of current research

Young girls are navigating a complex social world including peer relationships, online socialization, gender and sexuality, and more. It is noted in research and practice that the social experiences of young people, including those with DD, are likely quite different based on gender (Mcgillivray et al., 2018; Morán et al., 2019; Oswald et al., 2016). However, special education programs have yet to consistently acknowledge this truth for their female students. Many girls continue to be placed in social programs with

their male peers, programs which are likely designed to address the social experiences and needs of males with DD. It is clear from emerging research on the social experiences of girls with ASD that social experiences, strengths, and support needs of girls with ASD are distinct from those of their male counterparts (Sedgewick et al., 2019; Oswald et al., 2016; Cook et al., 2018, Cridland et al., 2013). Additionally, it has been indicated through limited research on the social experiences of individuals with DD that ID and language/cognitive support needs may introduce an additional complicating factor for socialization in girls with DD (Griffin et al., 2019; Taheri et al., 2016; Morán et al., 2019). Of course, inclusive classrooms that welcome students of all gender identities are necessary, and this researcher does not intend to advocate for gender segregated classrooms. However, the programs that are provided in special education classrooms as well as the social opportunities provided to students need to account for the unique social experiences, strengths, challenges, and goals of female students.

Although existing research is significant to the populations which it studies, none specifically examines the experiences of individuals with DD who are a) girls; and b) possess intellectual disabilities and/or language/cognitive support needs. To date, the majority of research provides information on the social experiences of males with DD. Existing literature on the social experiences of girls with DD focuses predominantly on girls with ASD and no language/cognitive support needs or diagnosis of ID. Although these important research areas provide relevant information and a foundation for building a greater awareness of girls with DD and their unique social experiences, this population has yet to receive the attention and opportunities they need and deserve. Through completing this literature review, no studies to this researcher's knowledge used the

voices of adolescent girls with DD to inform research and practice. Most relied on educator and/or parent input, or did not address the perspectives of individuals/stakeholders at all. First person information about the social experiences, strengths, challenges and goals of girls with DD, including those with ID and/or cognitive/language support needs, is desperately needed in special education research and practice.

Chapter 3: Methods and Procedures

In this dissertation, Constructivist Grounded Theory methodology was utilized. In the following chapter, an introduction to qualitative research as a whole is provided. Grounded Theory is described, followed by a more focused description of Constructivist Grounded Theory. The sample population and sampling procedures for this dissertation are described. Data collection, management and analysis are detailed. This section ends with a description of the coding process and ethical considerations for this research.

Qualitative Research

While quantitative researchers are focused on numerical data and inferential statistics, "Qualitative researchers are interested in understanding how people interpret their experiences, how they construct their worlds, and what meaning they attribute to their experiences" (Merriam & Tisdell, 2015, p. 6). Quantitative researchers typically view the world in terms of statistical relationships between variables, while qualitative researchers tend to view the world in terms of people, situations, and events. The purpose of data collection is to gain a better understanding of how each of those constructs interact with one another (Maxwell, 2013). This dissertation utilized an constructivist approach to qualitative inquiry, and assumed that there is no absolute truth to be discovered. It followed the belief that reality is socially constructed, and multiple interpretations of the same event are possible, and even likely (Merriam & Tisdell, 2015). This dissertation aimed to use qualitative methods to highlight the voices, perspectives, and lived truths of adolescent girls with developmental disabilities and their caregivers.

Participatory Action Research

Participatory action research (PAR) is a dynamic, human centered approach to

research that emphasizes the importance of authentic human experiences. Rodriguez & Brown (2009) provide a succinct summary, stating that

> "PAR is an empirical methodological approach in which people directly affected by a problem under investigation engage as co researchers in the research process, which includes action, or intervention, into the problem" (p. 23).

Baum et al. (2006) describe three distinct features of PAR which separate it from other traditional approaches to research. First, its goal is to support action, which occurs through a reflective cycle. Participants and researchers become one, and action is driven by first-hand experiences, voices and opinions. Secondly, power relationships are closely examined between the "researcher and the researched". In traditional methodologies, participants are not highly involved in the research process. In PAR, participants and researchers generate findings together, action is formed based on group decision-making, and reflection takes part together, not separately. Finally, PAR posits that research should not be removed from the contexts in which it is significant, making it particularly important that the people and places being researched are informing the research process and the action that results from that process.

Critical to applying the principles of PAR to this research is removing barriers to research participation for individuals who might otherwise be blocked from sharing their authentic voices and experiences (Baum, 2006). Individuals with developmental disabilities may find themselves studied but not listened to, asked questions but not given the power to ask questions, or left out of the research entirely. PAR provides a means of challenging this unjust research practice so that individuals with disabilities are given the rightful opportunity to drive the research that will inform future programming in special

education settings. Without their input, support, and authentic approach to the research, researchers run the risk of conducting research that is inaccurate, insensitive, or that lacks meaning for those with real lived experiences.

In this study, numerous modifications were made to typical research procedures to ensure that participants were given the space to actively share their perspectives. First, the two interviewers were familiar/trusted adults and speech-language pathologists familiar with each student and their language support needs. Visual supports, simplified language, and answer choices were provided to support student language when needed. Clarification of questions, repetition of questions, and modification of language style were used flexibly throughout interviews to ensure full participation and understanding. Rather than attempting to follow a prescriptive interview procedure, interviews were completed dynamically to center the voices of adolescents with a variety of cognitive and language support needs.

Grounded Theory

Grounded Theory research is one of many approaches to qualitative inquiry. This methodology moves beyond simply describing or categorizing to actually generate a novel theory or explanation (Corbin & Strauss, 2007). Creswell (2013) explains grounded theory as "a qualitative research design in which the inquirer generates a general explanation (a theory) of a process, an action or an interaction shaped by the views of a large number of participants" (p. 83). According to (Creswell, 2013), grounded theory work should be "grounded in data from the field" and incorporate the following characteristics:

1) The researcher focuses on a distinct/specific process or action

2) The researcher seeks to develop a new theory
3) Memoing occurs throughout the research to support theory development
4) Primary data collection typically occurs through interviewing
5) Data analysis can be structured to use open coding, axial coding, and selective coding

Constructivist Grounded Theory

This dissertation used constructivist grounded theory as outlined by Charmaz (2014) to ensure that a flexible approach to inquiry was prioritized, allowing the researcher to consistently center the perspectives of adolescents and their caregivers, rather than focusing on a prescriptive methodology. In grounded theory work, a researcher follows their data as it unfolds, but Charmaz explains how constructivist grounded theory takes the researcher a step further:

> "...you try to make everyone's vantage points and their implications explicit- yours as well as those of your various participants. Not only does a constructivist approach help you to remain clear about the antecedents of your constructed theory, this approach helps researchers and policy makers to establish the boundaries of the usefulness of your grounded theory and, possibly, to ascertain how and where to modify it" (Charmaz, 2014, p. 339).

With a goal of completing applied research that improves the lives of adolescent girls with developmental disabilities, it was particularly important that my research was clear to other researchers, policymakers, and educational stakeholders in general. Additionally, Charmaz (2014) explains that constructivist grounded theory serves as a complement to other approaches, including the critical inquiry that is centered in this dissertation.

Much of the current literature in special education focuses on quantitative research. Many curricula and programs are designed and created without the input of students and their families. Without including those who the researcher aims to support in the research process, there is significant risk that the outcomes, programs and curricula that are created will not be meaningful and/or relevant to the real-life experiences of participants. A constructivist grounded theory approach acknowledges the complexity of disability, social-emotional wellness, adolescence, caregiving, and the interaction amongst each of those experiences. It respects the fact that there is no single truth or answer to the research questions at hand, but rather many different answers based on the complex interaction of social, biological and cultural factors.

Sample Description

The 12 adolescent participants in this sample were all students from a non-public special education day school in the Washington, District of Columbia Metropolitan area. Each participant was enrolled in the high school program on either a certificate of completion or high school diploma track at the time of interviews. All participants were assigned female sex at birth, and were ages 14-18 at the time of interviews. To the knowledge of school staff, all participants identified with female gender (though this was not explicitly discussed and thus cannot be assumed with certainty). All adolescent participants received speech and language services through their Individualized Education Plans, required highly structured academic/social support in a small group setting, and had diagnosed language, attention and cognitive support needs. Seven participants had primary diagnoses of ASD and seven participants had primary diagnoses of Other Health Impairment (i.e. including seizure disorder, microcephaly, intellectual

disability, visual impairment, specific learning disorder, receptive/expressive language disorder, Down Syndrome, and attention deficit/hyperactivity disorder). Seven students identified as Black or African American, five students identified as White, one student identified as Hispanic, and one student identified as Multiple Races.

Caregiver participants in this sample were 12 female mothers and one male father of the adolescent participants. Each caregiver participant was matched to an adolescent participant. All caregiver participants were legal guardians/biological parents of their adolescent participants. Seven caregiver participants identified as Black or African American, six caregiver participants identified as White, one caregiver participant identified as Hispanic, and one caregiver participant identified as Multiple Races. All caregivers lived in the same home as the adolescent participant and were involved in the adolescent participant's life as a caregiver since birth. For the sake of brevity and given the school setting of this research paired with the fact that all caregiver participants were parents, participants will be referred to as "Parent Participants" and "Student Participants" throughout the rest of this dissertation.

Sampling Procedure

The researcher was a related service provider at the school where participants were recruited. This project involved analysis of data collected across two school years, and every interview from the data set was included in analysis. Given the proximity of the researcher to students/families and the goal of conducting applied research with this group of participants, purposeful sampling was used as an initial sampling method to recruit participants from a pre-existing weekly social language group (Maxwell, 2013). Focusing specifically on this group of students and their parents opened the door for in-

depth understanding of information-rich cases (Merriam & Tisdell, 2015). The grounded theory strategy of theoretical sampling was used following the first nine parent interview sessions and first nine student interview sessions to refine and elaborate on emerging themes, categories and theory (Charmaz, 2014). The remaining three parents and three students were then recruited to participate in the study.

Informed consent was sent to the caregivers of all 12 students who were participating in "girls group" social language groups in school. Additionally, assent forms were provided for all 12 students. Each student/parent pair returned completed forms, leading to a 100% participation rate for participants that were initially contacted. This method of purposeful sampling was appropriate for the research questions and goals of this dissertation in that it allowed the participants to be actively involved in the generation of knowledge and truth to shape their own programming. It highlighted the elements of participatory action research that are included in this dissertation by allowing the students who were already participating in social groups to inform the generation of theory that will serve their own future social emotional programming.

Sample Size

Charmaz (2014) advocates for a focus on theoretical saturation rather than a specific number of participants or interviews. That is, data collection and participant recruitment ends when gathering additional data no longer sparks any new theory or insight (Charmaz, 2014). In this study, 12 student participants and 13 parent participants were interviewed (i.e. one student/parent pair included two parents) to reach saturation. An initial sample of 10 parents and nine students were recruited. Following initial data

analysis, an additional three parents and three students were recruited to participate in the study.

Negative Case Selection

A traditional, between participants "negative case" was not found in this study, as many participants shared unique yet similar experiences. Negative case analysis is a critical component of strengthening grounded theory (Charmaz, 2014). However, given the specific population included in the study and limited access to participant recruitment outside of this particular school, the researcher was unable to recruit a negative case for examination of the theory. Additionally, the researcher questioned whether or not recruiting and interviewing a negative case participant that was not an adolescent female with DD stayed true to the nature of PAR in this work. However, negative cases between questions were noted throughout this study, and will be reviewed in greater detail in chapter 5.

Data Collection Process

Semi-structured interviews were the primary method of data collection for the caregiver participant groups in this study. For student participants, a semi-structured interview format was also used, though additional structure was added based on the participants' cognitive and language support needs. This method of data collection was chosen to align with grounded theory methodology, as it "focuses the topic while providing the interactive space and time to enable the research participant's views and insights to emerge" (Charmaz, 2014, p. 85). Interviewing allowed for open communication and gave participants the space to share their experiences in ways that

other research methodologies could not accommodate. Additionally, the process of collecting interview data fit into the process of building grounded theory nicely. The use of interviewing methods allowed the researcher to constantly compare the data gathered from participants with emerging theory, gathering additional data as the theory developed (Creswell, 2013).

Two related service providers (i.e. this researcher and one colleague) collected all interview and focus group data. One provider was present for each individual interview, and both providers were present for a focus group to share findings and gather feedback from parent participants. Both providers met consistently prior to data collection and throughout the data collection process to ensure consistency of interview methods and to make adjustments to the interview process as needed.

Parent interviews occurred virtually via Microsoft Teams and lasted for 30-60 minutes. Each parent participated in an interview session, for a total of 12 parent interviews (for one student participant, both her mother and father joined the same interview session). Given that the interviewers were both related service providers in the school, parent participants were familiar with the researchers, and many had already formed relationships and rapport with them. In line with the preferences of Charmaz (2014), this familiarity allowed for a conversational style of interview and participants may have been more open with the researchers than they might otherwise have been. A semi-structured protocol was used, though the focus on different questions in that protocol varied based on the participants' responses and the natural flow of the conversation between researcher and participant. A virtual focus group was held to follow-up on initial findings and discuss interview questions as a group. All 10 original

parent participants were invited to participate in the focus group virtually via Microsoft Teams, though only four parents joined the 45-minute session. All participants provided consent for recording of interview sessions and focus groups to support in future coding and review of data.

Each student participant participated in a 30-minute interview during their school day. During this time, each participant was pulled from their classroom to participate in a 1:1 interview session with the provider/researcher in her office. Given that the interviewers were both related service providers in the school, participants were familiar with the researchers and had already formed relationships and rapport with them. Given that student participants had a variety of language, attention and cognitive support needs, researchers used a visual interview template to support active participation in the interview process. For each question, the interviewer first read the question out loud using a reduced rate, pauses, and checks for comprehension. The interviewer rephrased or repeated the question as needed. If the student was unable to answer the question, the researcher provided a written fill-in-the-blank to support receptive and expressive language. If the participant continued to require additional support, the interviewer provided a visual of up to 7 answer choices with pictures and written captions. Finally, if the visual answer choices were not helpful, the researcher presented each visual answer choices one at a time and asked a yes/no question. During student interviews, the researchers made modifications and adjustments (e.g., providing a few answer choices at a time, circling answers as students provided them, repetition of questions and answer choices, increased wait time) to support participants in accessing the interview process as

successfully and independently as possible. All modifications and support provided during student interviews are noted in the transcripts.

Interviewing Practices for Participants with Cognitive/Language Support Needs

Although research has been done to support individuals with cognitive/language support needs, few studies actively include this population in the co-construction of knowledge. The research process is often conducted with individuals with disabilities as "subjects" rather than active participants. In this study, specific methodological strategies were used to ensure access to the interview process and sharing of knowledge for participants with a variety of language/cognitive support needs.

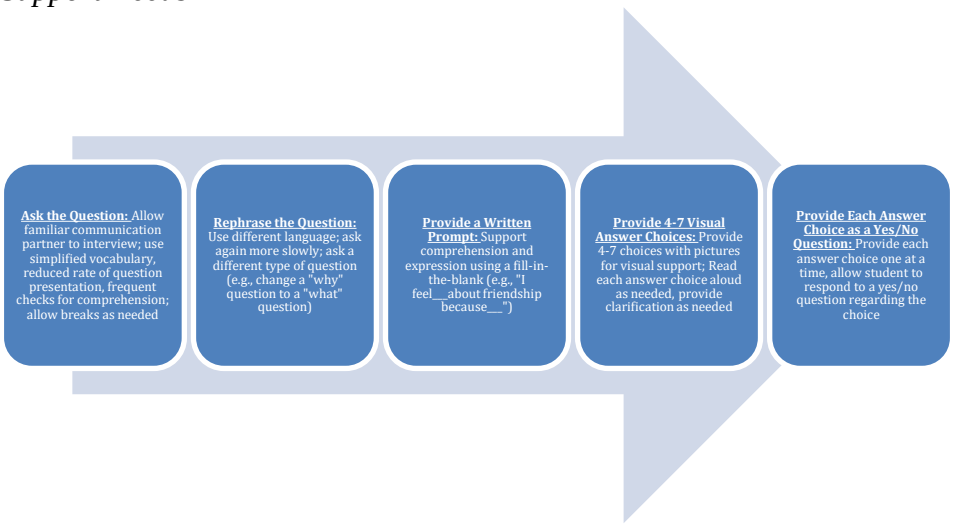
One of the major components of this project that supported participation was familiarity of the interviewers/researchers. The interviewers were both licensed speech-language pathologists who worked with the group of students being interviewed on a weekly basis. Both interviewers were familiar with effective language strategies for supporting individuals with cognitive/language support needs, while also possessing a strong understanding of each individual participant's cognitive/language profile, history, and social communication preferences. This familiarity provided a deeper understanding by the interviewer, and likely increased comfort by both parties throughout the interview process. Participants were likely more available to share personal stories and insights given the existing relationship with both interviewers as trusted adults/staff members.

Additionally, interviewers were trained in strategies for supporting interactions with individuals with cognitive/language support needs. Although this background training certainly supported the interview process, researchers do not need to be Speech-Language Pathologists to successfully involve individuals with cognitive/language

support needs as active voices and participants in their research. An overview of strategies implemented in this study are reviewed in Figure 3 below.

Figure 1.

Supports Used to Ensure Access to Interviews for Participants with Cognitive/Language Support Needs



General Interviewing Practices

As already mentioned, I had a pre-existing relationship with caregiver and adolescent participants in this study. Although some researchers may view this as a threat to the validity of my research, I actually believe it to be one of the greatest strengths of my study. I feel that this pre-established trust allowed for more open communication during interviews with participants. I also believe that it set the stage for student participants to participate in the interview process in ways that may not have been possible with interviewers who were not familiar with the student's communication style and cognitive/language support needs. In line with this viewpoint, Charmaz (2014) emphasizes the constructivist interview as "emergent interactions in which social bonds may develop…hence this approach attends to mutuality during the course of the interview and ways to build that mutuality" (p. 91). Far removed from the idea that data

collection must be fully standardized, this process allows for human interaction and experience to be centered in the interview process. In order to answer my research questions, I needed to gain access to stories and personal, lived experiences. It would be somewhat negligent of human emotion and dignity to think that participants should openly share that information without established trust with the interviewer and research process.

One of the biggest practices that I worked to adhere to in this study was "asking good questions", using language that made sense to my interviewees and that would lead to sharing of experiences, feelings, and events (Merriam & Tisdell, 2015). This was particularly important for my student participants, who many would deem "unable" to participate in interviews due to their language and cognitive support needs. It is a major goal of this dissertation to assert that it is improper data collection methods, not individuals with DD, that are flawed. With the correct methods and support in place, individuals with developmental disabilities can and should be active participants in research regarding their education and development.

A final interviewing practice that was used frequently in this study was probing, or asking follow-up questions during interviews. These questions were not planned in advance, as they unfolded during the interview process and depended on the flow of the conversation (Merriam & Tisdell, 2015). These "probes" provided the opportunity for participants to reflect on responses, often leading to even richer data (Charmaz, 2014). This practice was important because it not only led to richer data, but it also served as a check on the interviewer. It ensured that the interviewer was not making inferences based on participant responses, but rather clarifying and gathering more information to ensure

that they were representing the participants' actual message, not what they thought the message might be.

Memo-writing

Creswell (2013) describes memo writing as one of the core components of grounded theory work. This process allows the researcher to take notes throughout their study and track the development of theory. Given that this project occurred over the span of two different school years, memo-writing was critical to ensure that information was not forgotten as time progressed. Following each adolescent interview, a brief "impressions" memo was written and dated to represent the researcher's impressions of the adolescent's "performance" per se during the interview session. The researcher provided impressions on whether or not the interview seemed like an accurate representation of the adolescent's thoughts/feelings/experiences, as well as overall thoughts and ideas about the discussion that took place. Additionally, memo-writing was used during each data analysis session to both "capture" and "facilitate" analytic thinking about the data (Maxwell, 2013). Ideas for themes and critical areas of development were noted throughout the process.

Data Management

Each caregiver interview/focus group was recorded using Microsoft Teams and saved to a password protected and encrypted digital drive. Interviews were transcribed by hand and saved to the same protected drive. Each adolescent interview was audio recorded and saved to the encrypted/password protected drive. Following download, each recording was deleted from the recording device. Interviews were transcribed by hand and saved to the same protected drive. All names and identifying information (e.g., name,

school name, name of hometown) were removed during the transcription process. Transcripts will be saved on the school's password protected/encrypted drive to support future research and programming. This was agreed upon in the informed consent that participants signed prior to participating in the study.

Data Analysis

The researchers transcribed all interviews by hand. Though labor intensive, this allowed for familiarity with the data (Maxwell, 2013). Following transcription of the first 9 parent interviews and 9 adolescent interviews, an informal list of themes was generated and checked with a fellow researcher and a small focus group of parents. Once this process concluded, 3 more parents and 3 more adolescents were interviewed to continue building theory. Following transcription of all 24 interviews, data analysis followed the system outlined by Charmaz (2014), starting with initial/open coding, moving into focused coding/categorizing, and ending with theoretical coding. Initial analysis of the data occurred simultaneously as data collection progressed, and memo-writing was heavily utilized. Focused coding and theoretical coding were more heavily utilized following completion of all interviews, though elements of both coding processes were present throughout the interview processes.

Constant Comparative Methods

Constant comparison is an active process that allows the researcher to compare different interviews, to compare data within interviews, and to compare data collected sequentially over time (Charmaz, 2014). This allows the researcher to "saturate" the categories and codes until the data that they are collecting no longer leads to any new insight or contribution to their emerging theory (Creswell, 2013). This led to particularly

interesting findings in this study, given that each adolescent participant was matched to a caregiver participant or participants. Comparison was made not only between different caregiver interviews and different adolescent interviews, but also between each caregiver/adolescent pair. Gaining information from each caregiver/adolescent pair allowed for deeper understanding of the emerging themes, and the social dynamics that contributed to those themes.

Initial Coding

In the initial coding process, transcripts were de-identified and uploaded to Dedoose Software. Line by line reading/coding was the first step in the process, as it "helps you to see the familiar in a new light" (Charmaz, 2014 p. 133). This careful consideration of each transcript allowed the researcher to go deeper in the interview to ensure that specific detail was not lost in the bigger picture of the interview. Although close reading and consideration of each line was a part of this process, many of the initial codes contained a few lines of text. This ensured that each excerpt provided the context needed to support the code. A priori codes were not determined for this study, rather, the researcher used a variety of code types (e.g., in vivo, process) as the need to do so emerged in the analytic process. This allowed for flexible analysis that followed the data rather than a predetermined, prescriptive methodology (Creswell, 2013). Each initial code was listed in Dedoose for further organization and analysis. At this point, the researcher aimed to formulate categories through constant comparison. It was noted, for example, that multiple adolescent and caregiver participants discussed past experiences of the adolescent being bullied in previous school placements. This initial coding process

allowed the researcher to start forming connections within and between participants, setting up for the next step of focused coding.

Focused Coding

Creswell (2013) uses an accessible metaphor to describe this step in the coding process, when the researcher attempts to build common ideas based on frequent or repeated codes. He describes this as "a family of themes with children, or subthemes, and even grandchildren represented by segments of data" (p. 186). This metaphor hints at the complexity of this process, and the fact that each focused code or category could continue to grow in many directions. Focused coding aims to organize that family tree to focus on the most significant aspects of the data, highlighting the pieces that are most important to your emerging theme. These focused codes move you closer to the theoretical side of analysis vs. simply labeling and organizing (Charmaz, 2014). Through moving and grouping codes in Dedoose, an organization emerged that grouped initial codes into focused codes. Any additional initial codes that did not fit with the focused codes were left on the list in Dedoose, but deemed less important to emerging theory.

Theoretical Coding

Charmaz (2014) cites Glaser (1978), explaining theoretical coding as a way to conceptualize "how the substantive codes may relate to each other as hypotheses to be integrated into a theory" (p. 150). This level of coding takes the focused codes and moves them a step further into the formation of theory, and the generation of new knowledge/ideas. Charmaz (2014) cites Glaser (1978) once again when discussing theoretical coding, explaining that theoretical codes "weave the fractured story back together" (p. 150). The purpose of this step in the coding process is to make the analysis

more cohesive, and in my case, more usable in future educational research and practice. In this step of the analytic process, I moved 22 focused codes onto Google Jamboard for visualization. I looked for patterns and categories that could be used to provide a stronger picture of the social/friendship experiences of adolescent girls with DD by comparing codes to one other and to my initial conceptual framework. In this step of the coding process, I was also looking for specific patterns and categories that could inform educational and social emotional programming for girls with DD. Given my frame of mind as an educator, specific practice recommendations/areas of need emerged, and I compiled those into a separate list. Discussion of this list with my advisor led to the realization that the boundary needed to be pushed further from practical findings to theoretical findings (Charmaz, 2014). Instead of stopping at these practical recommendations, a further explanation of the "why?" behind those recommendations was investigated through continued reading of the codes and integration of my conceptual framework and personal subjectivity.

As I returned to Google Jamboard, the challenges of girls with DD were highlighted across focused codes, which began the process of expanding and searching for an explanation of why those challenges occur. I began working backwards from challenges to consider why those challenges were present, and what information was shared within interviews to explain that experience. From the perspective of parents, I noted consistent messages of limited capacity and a general sense of being overwhelmed. From the perspectives of the girls, I noted a number of environmental barriers to their own social fulfillment, either through their specific responses or through inferencing based on information provided. All of this was particularly problematic because it was at

odds with the consistent report that social opportunities and friendships were important to both the student and parent participants. I visualized different interactions of these variables, considering whether there was a linear relationship, whether one factor built on another, or if all factors co-existed in the same space. Using this visual tool, I was able to move components of the theory around until I landed on a conceptualization that seemed to accurately reflect the interconnectedness of each of these theoretical codes. At the same time, I was considering the "so what?" of this work, which further guided formulation of theory that was both situated and useful (Charmaz, 2014). This step in the coding process allowed me to integrate my conceptual framework, focused codes and personal subjectivity into a theory situated in the shared experiences of girls with DD and their parents.

Essential Considerations

In conducting any qualitative research study, there are a number of essential questions that must be asked to ensure not only the quality of the research, but also the respect of participants and their stories. Essential considerations for this study are described in this section.

Trustworthiness

Maxwell (2013) asserts that it is impossible to prove validity or a single reality. Rather than focus on "validity", qualitative researchers are better served focusing on the "credibility" or "trustworthiness" of their work (Merriam & Tisdell, 2015). Within their work, Merriam & Tisdell (2015) outline four major processes for ensuring trustworthiness of qualitative research, all of which were utilized in this study:

Triangulation, Member Checks, Adequate Engagement in Data Collection and Reflexivity.

Triangulation

Triangulation of the data refers to the use of multiple methods to collect and compare data, ensuring that a single biased source is not used to draw inaccurate conclusions. Triangulation was used throughout this study. Interviews with adolescents were compared to interviews with caregivers, a second round of interviews was conducted with an additional set of adolescents and caregivers, memos and informal observations contributed to findings, and follow-up questions were used after interviews as needed.

Member Checks

Additionally, member checks were completed for each participant. The researcher shared an electronic copy of the drafted framework with each caregiver participant, and invited each participant to a focus group for discussion and review of findings. Additionally, the researchers reviewed the framework and discussion points with adolescent participants during their regularly scheduled social language group at school to gather further input and preferences. These additional checks provided participants the opportunity to give feedback, and served as a critical moment for researchers to ensure that they were interpreting the data accurately, rather than being clouded by their own biases and perceptions (Merriam & Tisdell, 2015). Additionally, the caregiver focus groups gave caregivers the opportunity to bring up topics in conversation with one another that were missed by the interview protocol and/or did not naturally emerge in the interview.

Adequate Engagement in Data Collection

In order to seek out any potential alternative explanations in the data, the researchers conducted a second round of interviews with three new caregivers and three new adolescents during the following school year (i.e. the next school year after initial interviews were completed). This supported findings by "testing the data" so to speak to see if emerging categories and theory held up following additional interviews.

Reflexivity

In the context of conducting such highly personal research, researcher reflexivity is critical. Merriam & Tisdell (2015) describe the importance of this process as a means for readers to understand how a specific researcher may have navigated the research process and drawn certain conclusions. This process of reflexivity provides a context in which the research occurred and the data was analyzed. Qualitative research can be a highly subjective process, and humans cannot separate themselves from their own experiences, beliefs, and biases. Instead, it is important to be aware of these constructs and how they might influence the research process, reflecting on possible influences throughout the entirety of the study.

Given the proximity of this researcher to participants and this study, reflexivity is paramount. It is essential that I consider the impact my identity, career, and position in this world may have on my research. I have worked as a related service provider at the recruitment school for six years, and have worked closely with each adolescent participant and their families throughout the IEP process during the participants' high school careers. This research relationship is very different from a situation in which a researcher comes in from outside to complete interviews. I am a trusted adult and a

trusted educator from within this circle of students, parents and educators, which is not a position to take lightly or to take advantage of. I consistently worked throughout this project to ensure that my students and their access to the highest quality of services and programs came above all other research goals and questions. However, I also believe that my proximity to my participants provided an opportunity for deeper understanding and awareness of their experiences, as well as greater potential to implement change that is meaningful to the students and families that I work with.

In addition to being a special educator, I am an able-bodied, neurotypical, heterosexual, cis-gender, white female with two bachelor's degrees and a master's degree. Although my greatest joy lies in working with and learning from people of all backgrounds, it is critical to consider the position of significant privilege that I approach that work from. I will never understand the experiences of many of my participants, as I have not lived out those experiences. However, I can dedicate myself to listening, exploring, and highlighting their voices, which are far too often silenced or overlooked. I am not completing this dissertation in the hopes of being considered an expert of the experiences of girls with developmental disabilities or their caregivers. That role is reserved for my participants, my students, and their families. I will always refer to my participants as the experts of their own lived experiences. I am simply here to learn more, to stand firm as an ally, and to highlight the voices of disabled individuals whenever and wherever possible.

Finally, in supporting adolescent female participants, it is critical to highlight that there are many different expressions of feminine identity, and that many expressions do not align with heterosexual and cis-gendered norms. Without careful consideration of the

complexities of gender and sexuality, my efforts to support adolescent girls with developmental disabilities could quickly turn into yet another form of othering for these young people. It is important not only for my research, but also for my personal values as a human that I work to address any assumptions or biases that might exist in my work so that I can be cognizant and supportive of individuals not only with diverse gender identities, but of all people with a range of diverse identities (e.g., race, sexuality, disability status).

Human Participants and Ethical Considerations

Given that this research involved human participants, including minors, detailed safeguards were in place throughout the process. Initial data collection was completed by this researcher and one other colleague, who obtained Institutional Review Board (IRB) exemption through their school's Human Subjects Research Chair under the category of 45 CFR 46.101, "Research in established or commonly accepted educational settings, involving normal educational practices, such as a) research on regular and special education instructional strategies; or b) research on the effectiveness of or the comparison among instruction techniques, curricula, or classroom management methods." All caregiver participants signed informed consent for their own participation as well as their child's participation. Each adolescent participant signed an informed assent, and the research project was explained in detail to all participants prior to signing.

In order to formally analyze this data and collect follow-up data for the purpose of this dissertation, IRB approval was obtained from the George Washington University IRB. All transcripts were de-identified to protect anonymity of participants.

Summary

The methodology of this dissertation was outlined in this chapter. This study uses a constructivist grounded theory approach to qualitative inquiry. Semi-structured interviews, focus group feedback, and informal observations were analyzed using constant comparison analytic strategies. Interview data was coded using initial, focused, and theoretical coding. Information on trustworthiness of the study and researcher reflexivity were described in detail.

Chapter 4: Results

The purpose of this qualitative study was to:

1) Understand how adolescent girls with DD experience their social worlds and form/maintain friendships

2) Understand how caregivers of adolescent girls with DD navigate the process of supporting their child socially

3) Generate recommendations for the kinds of school based social/friendship support that would be beneficial and meaningful to adolescent girls with DD and their caregivers

4) Involve adolescent girls with DD and their caregivers as active members of the research team, a role that they are too often excluded from

The following research questions guide this dissertation:

1. What are the perceptions of adolescent girls with DD on their social/friendship experiences?

2. What are the perceptions of caregivers of adolescent girls with DD on their child's social/friendship experiences?

3. How do caregiver and adolescent girl perceptions converge and diverge?

This chapter will begin by providing demographic and background information on the 12 students and 13 parents who participated in the study. Next, grounded theory will be briefly introduced based on the first hand perspectives of adolescent girls and their parents. An in-depth description of participant experiences and responses will be provided, including direct quotations, to provide a context for the social experiences of adolescent girls with DD and the grounded theory that was constructed. Tables will be

utilized to provide participant responses that are relevant to the generated theory. Following each table, in depth description of the findings with additional review of participant quotes is provided.

Participants

The 12 student participants in this sample were all students from a non-public special education day school in the Washington, District of Columbia Metropolitan area. Each participant was enrolled in the high school program on either a certificate of completion or high school diploma track at the time of interviews. Seven students were pursuing a high school certificate of completion, and five students were pursuing a high school diploma. All participants were assigned female sex at birth, and were ages 14-18 at the time of interviews. To the knowledge of school staff, all participants identified with female gender (though this was not explicitly discussed and thus cannot be assumed with certainty). All student participants received speech and language services through their Individualized Education Plans, required highly structured academic/social support in a small group setting, and had diagnosed language, attention and cognitive support needs. Six student participants had primary diagnoses of ASD and six participants had primary diagnoses of Other Health Impairment (i.e. including seizure disorder, microcephaly, intellectual disability, visual impairment, specific learning disorder, receptive/expressive language disorder, Down Syndrome, and attention deficit/hyperactivity disorder). Six students identified as Black or African American, four students identified as White, one student identified as Hispanic, and one student identified as Multiple Races.

Parent participants in this sample were 12 female mothers and one male father of the adolescent participants. Each parent participant was matched to a student participant.

All parent participants were legal guardians/biological parents of their student participants. Seven parent participants were identified in educational records as Black or African American, five parent participants were identified as White, and one parent participant was identified as Hispanic. All parents lived in the same home as the adolescent participant at least part time and were involved in the student participant's life as a caregiver since birth.

Table 1.

Background Information/Demographics – Education Records

Participant	**Age**	**Race/ Ethnicity**	**Primary Diagnoses**
Student 1	16	White	Down Syndrome
Student 2	18	White	Autism, Selective Mutism, Seizure Disorder
Student 3	17	Hispanic	Autism
Student 4	16	Black	Intellectual Disability, Speech-Language Impairment
Student 5	18	White	Autism
Student 6	17	Black	Intellectual Disability, visual impairment, hearing loss
Student 7	18	Caucasian	Intellectual Disability
Student 8	15	Black	Autism
Student 9	16	Black	Intellectual Disability
Student 10	14	Black	Autism
Student 11	16	Black	ADHD, Microcephaly, Epilepsy
Student 12	15	Multiple Races	Autism

Sampling Procedure

The researcher is a related service provider at the school where participants were recruited. Given the proximity of the researcher to students/families and the goal of conducting applied research with this group of participants, purposeful sampling was

used as an initial sampling method to recruit participants from a pre-existing weekly social language group (Maxwell, 2013). Focusing specifically on this group of students and their caregivers opened the door for in-depth understanding of information-rich cases (Merriam & Tisdell, 2015). The grounded theory strategy of theoretical sampling was used after the first nine parent interviews and first nine student interviews had been completed to refine and elaborate on emerging themes, categories and theory (Charmaz, 2014). Three additional student/parent duos were included in this process. Although all caregivers were invited to participate in the study, the resulting participants were all parents of the students.

Informed consent was sent to the caregivers of all 12 students who were participating in girl social language groups in school. Additionally, assent forms were provided for all 12 students. Each student/parent pair returned completed forms, leading to a 100% participation rate for participants that were initially contacted. This method of purposeful sampling was appropriate for the research questions and goals of this dissertation in that it allowed the participants to be actively involved in the generation of knowledge and truth to shape their own programming. It highlighted the elements of participatory action research that are included in this dissertation by allowing the students who were already participating in social groups to inform the generation of theory that will serve their own future social emotional programming.

Sample Size

Charmaz (2014) advocates for a focus on theoretical saturation rather than a specific number of participants or interviews. That is, data collection and participant recruitment ends when gathering additional data no longer sparks any new theory or insight (Charmaz, 2014). In this study, 12 student participants and 13 parent participants

were interviewed in total to reach saturation. An initial sample of 10 parents and nine students were recruited. Following initial data analysis, an additional three parents and three students were recruited to participate in the study. Additional detail on data collection and interview practices can be found in Appendix A.

Data Analysis

Data was analyzed using constant comparative methods. Below, the coding process is reviewed, followed by a description of how coding was integrated into grounded theory.

Constant Comparative Methods

Constant comparison is an active process that allows the researcher to compare different interviews, to compare data within interviews, and to compare data collected sequentially over time (Charmaz, 2014). This allows the researcher to "saturate" the categories and codes until the data that they are collecting no longer leads to any new insight or contribution to their emerging theory (Creswell, 2013). This led to particularly interesting findings in this study, given that each student participant was matched to a parent participant or participants. Comparison was made not only between different parent interviews and different student interviews, but also between each student/parent pair. Gaining information from each student/parent pair allowed for deeper understanding of the emerging themes, and the social dynamics that contributed to those themes.

Initial Coding

In the initial coding process, transcripts were de-identified and uploaded to Dedoose software. Open coding was used to identify important lines and sections of the text. A close, line by line reading allowed strong familiarization with the text as it "helps you to see the familiar in a new light" (Charmaz, 2014 p. 133). This careful consideration

of each transcript allowed the researcher to go deeper in the interview to ensure that specific detail was not lost in the bigger picture of the interview. At the same time, most codes were initially generated using larger chunks of text (i.e. multiple lines) and then reduced to shorter sections as needed. A priori codes were not determined for this study, rather, the researcher used a variety of code types (e.g., in vivo, process) as the need to do so emerged in the analytic process. This allowed for flexible analysis that followed the data rather than a predetermined, prescriptive methodology (Creswell, 2013). Each initial code was organized in a running list on Dedoose. Once all interviews went through initial/open coding, the researcher aimed to formulate categories through constant comparison. It was noted, for example, that multiple adolescent and caregiver participants discussed past experiences of the adolescent being bullied in previous school placements. This initial coding process allowed the researcher to start forming connections within and between participants, setting up for the next step of focused coding.

Focused Coding

Creswell (2013) uses an accessible metaphor to describe this step in the coding process, when the researcher attempts to build common ideas based on frequent or repeated codes. He describes this as "a family of themes with children, or subthemes, and even grandchildren represented by segments of data" (p. 186). This metaphor hints at the complexity of this process, and the fact that each focused code or category could continue to grow in many directions. Focused coding aims to organize that family tree to focus on the most significant aspects of the data, highlighting the pieces that are most important to your emerging theme. These focused codes move you closer to the theoretical side of analysis vs. simply labeling and organizing (Charmaz, 2014). Given the longer list of

open codes, I worked to organize the codes into categories and families that allowed some codes to be grouped together under larger themes and categories. Some initial codes became focused codes, so initial codes were grouped with other focused codes. The process of organizing codes at this step was aimed at analyzing relationships between codes. Any additional initial codes that did not fit with the focused codes were left on the list of codes, but deemed less important to emerging theory at that time.

Theoretical Coding

Charmaz (2014) cites Glaser (1978), explaining theoretical coding as a way to conceptualize "how the substantive codes may relate to each other as hypotheses to be integrated into a theory" (p. 150). This level of coding takes the focused codes and moves them a step further into the formation of theory. Charmaz (2014) cites Glaser (1978) once again when discussing theoretical coding, explaining that theoretical codes "weave the fractured story back together" (p. 150). The purpose of this step in the coding process is to make the analysis more cohesive, and in my case, more usable in future educational research and practice. In this step of the analytic process, I was looking for patterns and categories that could be used to produce grounded theory and create a framework for future curricula and programming. I was also looking to theorize about why adolescent girls with DD face such significant social challenges. I pulled out some of the most salient themes and began moving them around on a virtual sticky note board using Google Jamboard to look for relationships and deeper meaning. I generated 4 theoretical elements, with 4-6 thematic codes attached to each. These theoretical elements appeared to have a semi-linear relationship, where different factors were combined and built upon to lead to the social challenges discovered throughout interviewing and coding.

Constructing a Theory of Friendship Experiences of Adolescent Girls with DD

Many studies that aim to understand the experiences of adolescents with DD focus specifically on males, with very few researchers focusing specifically on girls, and even fewer incorporating first person perspectives (Watkins 2014; D'Mello et al., 2022). This research study aimed to transcend current research and practice to highlight the voices of adolescent girls with DD, as well as the parents/caregivers who support them. The following research questions guide this dissertation:

1. What are the perceptions of adolescent girls with DD on their social/friendship experiences?
2. What are the perceptions of caregivers of adolescent girls with DD on their child's social/friendship experiences?
3. How do caregiver and adolescent girl perceptions converge and diverge?

This section begins with a brief review of analysis of data. Next, the constructed theory will be introduced. Finally, each component of the constructed theory will be discussed in detail, and interview data will be presented to support each theoretical component. For each component of the theory, tables are provided to provide an overview of the many unique responses across participants. Following the tables, each component is described in greater detail, and connections are drawn between participant responses to describe larger themes that contributed to the theory.

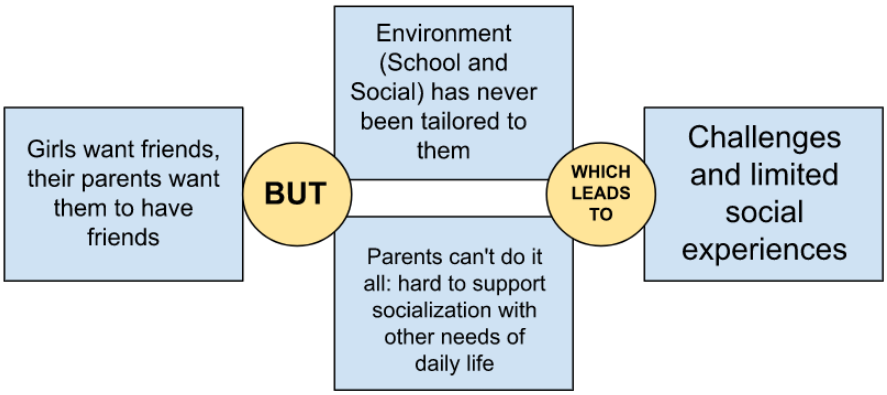
Review of Analysis of Data

After initial and focused coding, 22 codes were moved from Dedoose software onto Google Jamboard to allow for visualization of code groups and emerging theory. The codes were organized into four separate groups, each group containing four to seven

codes. These four groups emerged as the four major components of theory, “Environment has never been tailored to them”, “Girls want to have friends, their parents want them to have friends”, “Parents can’t do it all: It’s hard to support socialization with other needs of daily life” and “Challenges”. Relationships between components were considered, resulting in the final constructed theory. This theory offers a view of the social and friendship experiences of girls with DD that a) contradicts the longstanding view of people with developmental disabilities (particularly ASD) as disinterested in social relationships; b) acknowledges the significant and unique challenges that girls with DD face in forming meaningful relationships despite this interest; and c) potential explanation for why these challenges persist.

Figure 2.

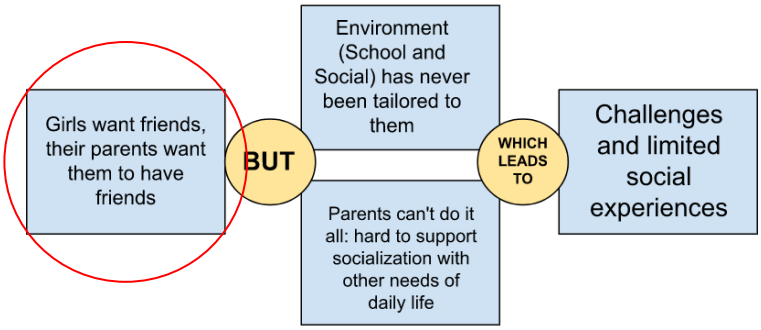
Grounded Theory: Social and Friendship Experiences of Adolescent Girls with DD



Components of Constructed Theory

Each component of Figure 4 is described in greater detail below, moving through the figure from left to right.

Girls Want Friends, Their Parents Want Them to Have Friends



It became clear early in the interview process that friendships and social relationships were very important to both the adolescent girls and their parents. Girls frequently shared about their goals to make new friendships, strengthen existing friendships, and grow friendships into something that remains with them as they transition to adulthood. They shared a variety of reasons why friendships are important to them. Parent participants frequently shared their desire for their child to have connection with peers and to feel like they have good friends that they can turn to, as teenagers and in the future. Additionally, parents frequently mentioned that their child wants to be accepted by others, though often is not.

Table 2.

Student Perceptions of Friendships

Participant	**Response to the Question "Do you want to make more friends?"**	**Response to the Question "How Important are Friendships to You?"**
Student 1	"Yea"	"Really important"
Student 2	"Yes"	"Very important"
Student 3	"I do but I don't, it's a maybe"	"Yea. Important"

Student 4	“Yes”	“Very”
Student 5	“Yes”	“Very important”
Student 6	“I want to make more friends”	“Important”
Student 7	“Yes I do”	“Very important”
Student 8	“Not really, because I have too much friends.”	“Important”
Student 9	“Yea”	“Very important”
Student 10	“I’m fine with the friends I have”	“...I guess they’re important”
Student 11	“I do”	“Very important, because they mean the world to me”
Student 12	“Yes. I would like to travel with friends”	“Important”

Table 3.

Parent Perceptions of Friendship.

Participant	**Parent Response that Highlights Desire for Their Child to Make Friends**
Parent 1	“So I would definitely like her to be able to negotiate those without me…like initiating ideas of things to do with friends, coming up with ideas, initiating them, making a plan.”
Parent 2	“Probably the same as what we mentioned, you know, just having some nice friends, getting to do things socially, she loves birthday parties, she loves outings…”
Parent 3	“...and in that sense it would be great if these friendships you know blossom into something that they want to share a house, they know each other, they don’t have to do everything the same but at least to have a companion you know in the other room, that would be amazing.”
Parent 4	“She wants to make friends.”
Parent 5	“Yes, to create an environment where she has independence but has the community that is part of her life.”

Parent 6	“I really want all of that for her. I don’t want her to not be able to make friends because she’s different. That’s something that I don’t want. She’s a very friendly person and people have no problem sitting here speaking to her, but I've noticed she is in general, when they can’t understand her, they find a way to turn away from her. Because they look at her as being different. So I want her to be able to do all of that without there being any issue to, like you said, keep friends.”
Parent 7	“Just to have a little group of friends, just to have some friends and eventually you know when kids are comfortable…even having like a facetime social group on friday night, doesn’t have to be friday night but you know just relaxing with these girls I just want her to have a niche of friends. I had it in high school, I had it in college, I just want her to have a group of friends that she trusts and can just communicate well with. That’s all I want.”
Parent 8	“I would like for her to have at least one, I would like more but at least one friendship where you know they can carry on a conversation, someone where they have common interests, I want to see her have the kinds of relationships that she sees kids having on tv and online because I can tell that’s what she wants.”
Parent 9	“I think she just wants to be accepted honestly, now what does that look like for I don’t know you would have to ask her, but just maybe you know looking at the bigger picture I think she definitely wants to be accepted and wants that group of girlfriends, and like I said that hanging out, her and her friends shared like the dream home that they all want to live in together.”
Parent 10	“But making friends and keeping friends most definitely because she has two friends.”
Parent 11	“It’s not that she needs to have a lot of friends, she just needs like one good friend. I wish, but it’s hard but even though she does have one good friend, if we aren’t there to make it happen, get them together, I don’t know how she would do that later in life, you know, we just don’t know. I just want her to have a friend, just someone she can talk to hang out with, you know, just like every other person.”
Parent 12	“...definitely develop sincere friendships that are maybe not just based on you know the parents get along so you two are automatically friends, but being able to find people that share her interests and that she’s comfortable around and happy around. So I think a lot of that will come down to communication.”

Interest in Friendships

Both student and parent participants consistently noted a desire for the student participant to make and keep new friends. Many also indicated a desire to maintain and strengthen existing friendships. Though many prevailing stereotypes of developmental disabilities like ASD may claim a lack of interest in social relationships, this was undoubtedly not the perspective shared in interviews.

Student 11 shared her desire to make and keep friends, explaining that:

> "[Friendships are] very important. Because they mean the world to me…they're like my entire heart."

When asked why she answered this way, student 11 said:

> "[I want friends] so I don't have to be so alone."

Parent 11 shared a similar desire for strong and lasting friendships, along with concerns about the

feasibility of friendship maintenance for her child:

> "It's not that she needs to have a lot of friends, she just needs like one good friend. I wish, but it's hard but even though she does have one good friend, if we aren't there to make it happen, get them together, I don't know how she would do that later in life, you know, we just don't know. I just want her to have a friend, just someone she can talk to hang out with, you know, just like every other person."

Student 5 shared a deep desire to maintain friendships, sharing that:

> "They're building blocks in life and you learn valuable skills from them."

Student 6 described a similar desire for friends, explaining:

> "I like to hang out with them at school. And I like to meet some more people."

Parent 8 described her child as someone who is interested in forming close female friendships,

recounting an experience with her child:

> "I'm laughing because we went out for my mom's birthday a few months ago, and she was so excited because we let her get a shirley temple, and she kept saying we're having girls night, we're having cocktails, and she's raising her drink to toast, and she's like cocktails ladies, and I just had to laugh because it's something she's seen in a movie, but she was so happy so I think it's something she would like to, you know she aspires to do things like that with her friends…she won't be having real cocktails but (laughs)"

Parent 3 described her child's desire for positive social relationships that are similar to

"what all

people want":

> "What she enjoys typically, she desperately wants friends, and she enjoys friends, wants to share things with them, wants to play games, wants to go out, wants to go to the movies, wants to paint their nails, wants to go to shopping areas, go eating…you know like anybody does."

Parent 1 described some of her child's positive friendship qualities and desire for

friendship:

> "I mean I think she generally likes to be around her friends, she likes to compliment her friends, and so I think she generally makes them feel positive. I think she is open to trying the things that they like to do even though it's not really her thing she will at least give it a try. I think she can be empathetic towards them. And she will remember things that they've said or they've done and bring that up, so that makes them feel like ok she has a sincere interest in me."

Parent 8 discussed her goals for her child's friendships, explaining:

> "Um, I would like her to learn how to share her feelings with friends, how to share good news, especially when you're excited about something to share with friends, to learn how to confide in someone, how to trust someone, I think overall having a good time, feeling connected-to have a sense of connection."

Student 6 stated her desire for friendships:

> "I want teachers to help me get new friends, get a new friend in school."

Desire for Friendships to Move With Them in Transition to Adulthood

In addition to interest in friendships during the adolescent's K-12 experience, many participants shared an interest in maintaining friendships into the adult years to support an overall positive transition process. Girls and their parents recognized the importance of social relationships post-graduation and frequently noted their desire to support maintenance of friendships.

Parent 3 shared:

> "...it would be great if these friendships you know blossom into something that they want to share a house, they know each other they don't have to do everything the same but at least to have a companion you know in the other room, that would be amazing. And I think that's what she would love, you know."

Similarly, student 3 explained the importance of maintaining friendships over time:

> "When I get out of school, they'll still have my email, my personal email address."

Parent 7 described a desire for a close knit social group for her child to connect with:

> "Just to have a little group of friends, just to have some friends…I just want her to have a niche of friends. I had it in high school, I had it in college, I just want her to have a group of friends that she trusts and can just communicate well with. That's all I want."

Desire for Acceptance

Parent and adolescent participants frequently discussed a desire for acceptance and connection with others. This desire for acceptance may stem from a number of past experiences including bullying and exclusion in previous school placements, as well as the desire for social acceptance that all humans feel. Many parents and adolescents reported difficulty with gaining acceptance, perhaps due to adolescents seeking acceptance in maladaptive ways (e.g., online with strangers, via repeated messages to

peers) or due to a limited number of peers who understand the adolescent and their unique communication/social profile.

Parent 9 shared:

> "I think she just wants to be accepted honestly, now what does that look like for I don't know you would have to ask her, but just maybe you know looking at the bigger picture I think she definitely wants to be accepted and wants that group of girlfriends, and like I said that hanging out, her and her friends shared like the dream home that they all want to live in together."

Parent 12 explained the joy that her child feels when she receives replies to social messages and feels accepted and valued socially:

> "I know she wants she likes to be around people. She likes the attention and just being surrounded by people so I can only imagine that she wants to develop more of those bonds with people. But I don't know if that's a goal in her mind, but I would have to guess it is because of the way she is reaching out by text and email. She wants to make those connections and she gets really excited when she gets a text or email message or when someone likes a photo, she gets a kick out of that."

Unfortunately, some participants reported a desire for acceptance that has not often been met. Parent 3 shared:

> "And I am going to be honest, she wants to be invited to people's houses. That's something that's never happened in 17 years. Well, 3 occasions probably."

Parent 11 shared similar thoughts:

> "I don't think it matters if it's a girl or a boy, she just wants to be friends with them, yea. It's just, she wants to be liked."

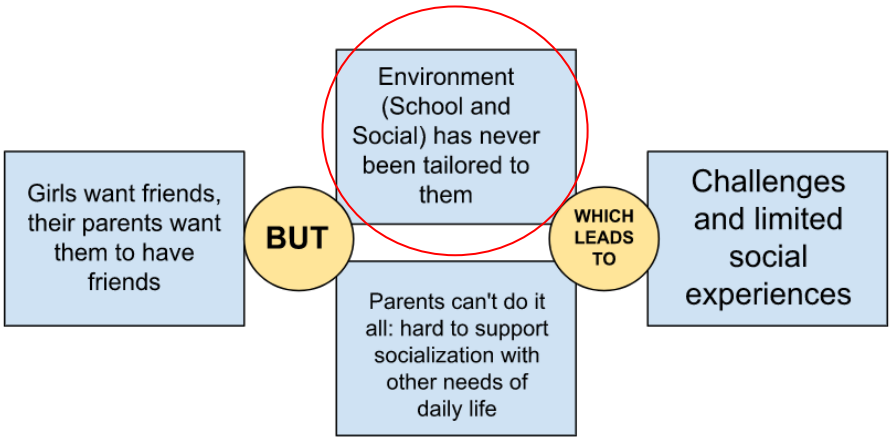
Parent 8 shared her daughter's desire to do the things that "everyone else is doing", explaining:

> "I think she would love to be able to do, and again I'm going back to what is portrayed in movies, things girls are seen doing like going to the mall together, going to the movies, out shopping, activities you know bowling things like that."

Summary

It became clear throughout interviews that the student participants desired friendships with their peers. In general, most girls reported a desire for a small group of close friends rather than a large group or one best friend. Girls frequently shared that friendships were of high importance to them. Likewise, parents consistently reported a desire for their child to make meaningful friendships with peers, and in many cases, concern that their friendships were not strong enough to be considered meaningful relationships. Girls and their parents hoped for friendships that would transition with them into their adult years, and raised concerns related to the feasibility of doing so without continued adult support. Additionally, girls and their parents consistently reported that the girls have a strong desire for acceptance. Many girls reported past experiences with bullying and exclusion, which may pair with current challenges in acceptance to create an overall challenging situation for girls in terms of mental health and social success.

Environment Has Never Been Tailored to Them



Themes emerged throughout interviews that highlighted difficulties related to both gender and disability. Many parents and girls reported experiences of being outnumbered by boys in special education, but excluded by female peers without disabilities. Additionally, many students and parents reported social challenges related to disability, and environments/social settings that are not created to accommodate a variety of social preferences and sensory, language and cognitive support needs. Many of the students have special interests, which social communication partners may not always understand or accept. In the tables below, quotes are included to highlight these perspectives. Many student participants focused on the fact that others don't share their specific interests, while a few focused on sensory needs or experiences of bullying/rejection. Many parent participants focused on their child's exclusion from neurotypical peers and the complexity of attempting to socialize in environments that are not built with sensory needs, executive functioning supports or preferred interests in mind.

Table 4.

Student Perspectives: Social Environment Not Tailored to Them

Participant	**Quotes: Difficulty Fitting into the Environment**
Student 1	"I don't actually have anyone who has the same interests that I have."
Student 2	"Sometimes I feel nervous or stressed"
Student 3	"If they act like in a loud volume [it is hard]"
Student 4	"They like to do different things."
Student 5	"Um, because, some people don't like horses like I do, but, and have other interests."
Student 6	"When I get older, I can go to their house, but now when I'm a

	student, I don't."
Student 7	"I'm more interested in video games and making my own youtube channel when I'm getting older and mostly hanging out with people and getting to know them, because I'm not that girl like I said who's going to want to go shopping for clothes or makeup and all that stuff or fashion, I feel like that stuff to me is kind of boring."
Student 8	Points to "we have different feelings" and "we like to talk about different things"
Student 9	"I need help with being a good friend…they sometimes don't like me"
Student 10	"Because like I'm a bit anti-social and so are some of the other people in here…I mean a lot of them are like, I never know what's going on with most of the other girls."
Student 11	"Because some people just love when they reject me."
Student 12	"Sometimes I have different feelings, different emotions. Sometimes different experiences…We have different interests."

Table 5.

Parent Perspectives: Social Environment Not Tailored to Their Child

Participant	**Quote Highlighting Parent View That Social Environment Isn't Tailored to Their Child**
Parent 1	"She was in a girls group in elementary school for similar reasons, even though she wasn't in a specialized school you know boys just outnumbered girls for some reason again."
Parent 2	"We live in a neighborhood that when she was very little, it was very easy to go out the door, and there's all your friends. But you know, they kind of took off in a way, and she kinda stayed in one place, in the area that you know." "Yeah so funny story, first probably couple months she's at (school), she's one of the very few girls in that age group, when they were in the middle school."
Parent 3	"[People need to be] talkative [but] not too much fun, nice, fun [but] not too exciting, because she gets excited and it ends not good so she knows her limitations sometimes."

	"She's really eager to engage in activities that she likes, in subjects that she likes, and sometimes she goes into her own world you know, and she has many ideas in her head and sometimes she isn't able to express it and the group gets lost and the interest goes away, you know."
Parent 4	"As she got older…I think the type of [different] school environment…She realizes that she's different."
Parent 5	"[she is] interesting in that she's very typical autism in the sense of "in her own world."...She would be completely content just being at home, and doing her own thing, and be completely fine."
Parent 6	"She's a very friendly person and people have no problem sitting here speaking to her, but I've noticed she is in general, when they can't understand her, they find a way to turn away from her. Because they look at her as being different."
Parent 7	"So she had a really tough time, obviously with her maturity level she's had a tough time making friends. When girls were into iphones and youtube, which is ironic that she is so into that now, but at the time, she has always been a late bloomer, at the time she was more into cartoons and spongebob where these girls were into netflix and way above what she was into, so she had a hard time making friends."
Parent 8	"She had a little experience when she went to middle school, in 6th grade, this little girl was not nice, and was making fun of her, saying she talked like a bear. And [she] does not like to be teased, she will shut down, and I noticed that she was becoming very withdrawn. And then [the other student] was saying things on social media, [participant's child] sent her a friend request and she said 'stay off my page'."
Parent 9	"it was a great idea for you guys to do that because it's funny, before [she] came to [current school] I think she was always since she's been in special education she's always been in class with boys, and she hated it'
Parent 10	"You know, even when I watch her with her typically developing peers, she'll just kinda be off on her own and you know the girls are talking about whatever it is that the girls talk about and she'll just kinda still be off on her own in a corner. Whereas if you were to come to her and say, "Hey, you know, there's this new anime movie that I heard about," you see a light

	go on in her eyes and she wants to know all about that and talk all about that."
Parent 11	"We play tennis, she likes playing tennis. She used to take lessons but being coached is really hard for her to learn the rules and um learn exactly what she needs to do to participate in everything."
Parent 12	"Last year she was harping on that because she was the only girl in the classroom and I don't know if it was because it was pointed out to her you know you're the only girl or if she just latched onto that…Yea well for sure I can say the typical gaming stuff that like a lot of the boys and maybe some of the girls too are interested in, she's not interested in at all, she doesn't really use media the same way a lot of other kids will do."
	"So it's just trying to find those activities that are going to be fun but not uncomfortable that will sustain her interest and will put her in the best position to be able to socialize so that she's not fixated on bugs or heat or feeling uncomfortable or too much noise."

Preferred Interests

Parent 10 explained the social engagement that her child displays when discussing her preferred interest, and how different it looks from social settings that do not involve her interest:

> "You know, even when I watch her with her typically developing peers, she'll just kinda be off on her own and you know the girls are talking about whatever it is that the girls talk about and she'll just kinda still be off on her own in a corner. Whereas if you were to come to her and say, "Hey, you know, there's this new anime movie that I heard about," you see a light go on in her eyes and she wants to know all about that and talk all about that."

Student 7 explained how she felt her preferred interests stray outside of the norm for teenage girls, sharing:

> "I'm more interested in video games and making my own youtube channel when I'm getting older and mostly hanging out with people and getting to know them, because I'm not that girl like I said who's going to want to go shopping for clothes or makeup and all that stuff or fashion, I feel like that stuff to me is kind of boring"

Student 1 felt it was difficult to find other people who share her special interests:

> "I don't actually have anyone who has the same interests that I have."

Parent 12 felt that her daughter struggled with not sharing the same interest in technology that most teenagers share:

> "Yea well for sure I can say the typical gaming stuff that like a lot of the boys and maybe some of the girls too are interested in, she's not interested in at all, she doesn't really use media the same way a lot of other kids will do."

Uncomfortable or Unsupportive Social Expectations

Student 12 explained the difficulties that she faces in many social environments:

> "Yea sometimes it can be very overwhelming with too many people talking at once…So I may need to ask for breaks or step away."

While Student 7 explained texting and phone communication as a means of social communication that she felt she was supposed to engage in but did not like:

> "The reason I'm not a person who's like I'm going to go text someone or facetime them is because I don't know how to carry on a conversation in a text…and then I'm awkward because I don't even know what to say next, I don't know how to carry on the conversation, so I'm not a person who likes to do that."

While Parent 7 described her daughter's interest in using technology to engage in her preferred interest:

> "I think in her ideal world she would have the other girl on an ipad and they would be playing a video game to be totally honest…So honestly to answer that question I think she would like to have a friend to sit with and play video games rather than actually having a conversation or you know watch a movie…"

Parent 12 described the difficulties of expectations in typical teenage social settings that

interfere with her child's sensory support needs:

> "...or say we do go to an amusement park and she gets tired or she gets too hot or she's not into it anymore and those can kind of interfere with like the social part of it because she's just not able to deal with whatever the sensory part of it or she's tired or hot and that interferes with the social part of it."

Parent 8 shared her impression of her daughter hiding parts of herself throughout the

school day,

and "letting it out" once she gets home to a safe space.

> "...it is definitely not something that she does during the school day, when she was in middle school and my mom would pick her up my mother said as soon as she got in the car it was like letting air out of a tire, she would kind of unleash, and as soon as she got to the house she would run upstairs…I definitely think she holds it in…"

Student 8 shared her difficulty with many social interactions, explaining that:

> "[it is hard to understand their] language"

Parent 7 explained her daughter's exclusion from typical teenage social events, and

disinterest in

the kinds of events that were happening at her school:

> "When girls were having sleepovers [she] was never invited, you know prom or dances or any of that, that was never. I don't want to say it was out of her league, but you know it never seemed to bother her."

Parent 6 described difficulties faced due to her child's disability, and the feeling of her

child being discriminated against due to her disability:

> "One of the main things for her socially, I just want her to interact with everyone else without being looked at differently. And being able to be understood."

Outnumbered by Boys

Many girls reported being outnumbered by boys at school and in disability support groups. Parent 12 shared:

> "Last year she was harping on that because she was the only girl in the classroom…But I think she was complaining a lot last year about how she's the only girl, she wants to be with more girls, and I think that's something she talks about. So whether that's really the case or whether she knows that girls hang out with girls…"

Parent 9 also shared her child's experience being the only girl:

> "always since she's been in special education she's always been in class with boys, and she hated it, I believe maybe like her 7th grade year there was finally like one girl in the class, and then she came here and she loved it"

Parent 2 shared similar experiences:

> "Yeah so funny story, the first probably couple months she's at [the new school], she's one of the very few girls in that age group, when they were in the middle school."

Student 3 shared discomfort in being surrounded by only boys, and explained:

> "I feel more comfortable when there are more girls close to the same age as me."

Parent 4 described difficulties that her child faced in the past when she was outnumbered by boys at school and faced bullying:

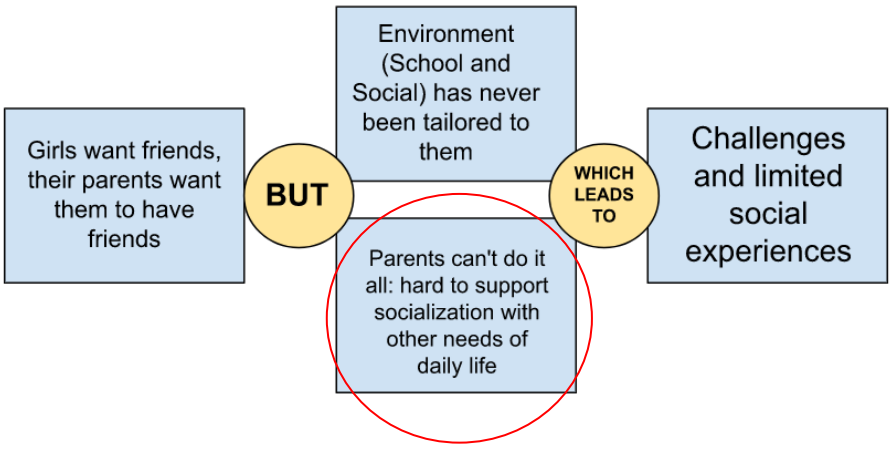
> "But it was kind of difficult when she was in elementary school, and some kids were mean. She had a friend or maybe no friends…And the boys sometimes had really strong behavior problems. She's never ever been in an environment when she's been really socially forward and you know really strong advocate for herself."

Summary

While girls and families consistently reported a desire to form meaningful friendships, they went on to explain a number of barriers that made it difficult to do so.

Many of these barriers were related specifically to their disability. It was frequently reported that adolescent girls felt excited when given the opportunity to share a preferred interest with others, but that opportunities to do so were often quite limited. Additionally, many of the typical social expectations of teenage girls are not supportive of participants' diverse sensory needs, social interests, or cognitive/language support needs. They reported being left out of typical social events like prom and sleepovers, and a need to act differently or hide parts of themselves to be successful in their social environment. Finally, many participants reported being outnumbered by boys throughout the K-12 experience in special education, which is unsurprising considering the many missed and misdiagnoses of girls with DD (Loomes et al., 2017; Van Wijngaarden-Cremers et al., 2014, Lai et al., 2015). Together, these factors leave many adolescent girls unable to reach their fullest potential in forming meaningful relationships with others.

Parents/Caregivers Can Only Do So Much



Parents are responsible for meeting the multitude of needs in their families, and the presence of a disability in their family brings with it some additional challenges. Parents are often strained in their attempts to balance the many demands of working,

parenting, and taking care of the additional social needs of their child with DD. The table below provides an introduction to the variety of challenges that parents face in "getting it all done", with further description and discussion of common themes to follow.

Table 6.

Parent Perspectives: "We can only do so much"

Participant	Parent Response that Highlights Their Own Limitations for Supporting Child' Social Life
Parent 1	"So that's one thing and then it's just bandwidth, it's just me um and you know, yea bandwidth."
Parent 2	"You know, it's hard to say because when you have a disability in your family, some of your life is just day-to-day. You take one day at a time. So, that far down the road, even though it's not that far down the road, seems you know like you want to cross that bridge when you come to it. You know, you just hope for the best always."
	"I would say the biggest thing, is as her father, there are certain things that I can't help her with that her mother has to, and that in turn means that mom gets to carry a heavier weight. So the more independent she can become in those areas, the better, but you know, for the most part, it really kind of falls on mom to do that."
Parent 3	"And it's tough, even when you…I don't care you know, I really want my child to socialize, I bring people to my house, I do everything, I take them or whatever, it's my initiation you know, it's my initiative always."
Parent 4	"Respecting each other's space and privacy…sometimes I feel like she doesn't allow me to have privacy."
Parent 5	"...she needs to have more social interactions to continue to grow her independence. But, you know two parents that are constantly working and three kids and two of them are active, and sports and all of these other things. And so is [student], she does horseback riding every Sunday and so it's like we're just constant on the go, so I think the challenge is giving more time to it."
Parent 6	"I feel as though I'm only one person and there's only so much I can do, if I can get other hands to be able to help me, I'm for it."
	"Anything that she wants to do, I'm going to support it unless it's just like interfering with daily schedules or stuff like that. Like school,

	she wants to participate in a lot of things that you guys be having on Saturdays, and you know, after school. But we can't. For the simple fact, we live 45 minutes away, so that's traffic…So I have to wait for her, on top of [that] I have to pick her sister up so when it comes down to things like that, that's pretty much the only thing as far as time and location. That's our big issue. Other than that, I'd take her to anything that she wants to go to, it's just that certain things and certain days I can't support her in those things because the time is not on our side."
Parent 7	"I can't even get her to send a text message to my sister or nephew to say happy birthday, no mom you do it no mom you do it, honey it's not my phone."
Parent 8	"I feel like I have to kind of separate her from the virtual world. That has been her retreat in the absence of people. She spends a lot of time online, I monitor her content, I've had to enforce breaks, I call them disconnect breaks, try to get her to read a book or I'll say why don't you call someone. She gets an attitude when I do it. I feel like in order for her to really engage more with people, I have to do better with disconnecting her from the virtual space."
Parent 9	"Like if I go out and say hey I'm going out to dinner, she may call. I don't answer, I may text and say hey I can't talk it's loud in here, it's going to be continuous calling until I pick up." "I'm probably missing it all because I'm learning how to deal with all of this, they have a lot, they have a pandemic, they have virtual learning some days they have, it's just a lot, bullying, I know we did have a little bullying thing going on too, so yea I'm open to any resources, anything that would be helpful at all."
Parent 10	"You know, I know that it's out there but I have to remember like you said, that road to independence, not a straight path so I gotta kinda remember you know where do I put that? Where do I insert those types of conversations? So I think that's a challenge."
Parent 11	"...it's just hard to support her, it doesn't have anything to do with her sex, it's just new for me, I'm learning as I go along, no one in my family has a special needs child, it's hard to support her with a lot of things day to day, we cope with it as we go along the best we can."
Parent 12	"...But you know it requires me to get involved and it doesn't always work out because of scheduling, it takes coordination."

Reduced Parent Bandwidth: "I am Only One Person"

Parent participants in this study consistently shared that their child's social opportunities are often limited by their own parental and personal bandwidth. Many parents reported busy family life, work, doctor and therapy appointments and the effort needed to support their child in more pressing tasks of daily living as responsibilities that may overshadow a focus on social opportunities. Additionally, parents reported that they need to assume a significant role in the planning and implementation of social events outside of school for their child, which they often may not have the time, energy or information that they need to do successfully. Finally, many parents reported that their child may share an interest in socialization, but refuse to participate once it comes time to carry out the social plan.

Parent 1 inspired the wording used in this theme, sharing:

> "So that's one thing and then it's just bandwidth it's uh I'm a, it's just me um and you know, yea bandwidth."

Parent 6 shared similar feelings, explaining:

> "I feel as though I'm only one person and there's only so much I can do, if I can get other hands to be able to help me, I'm for it. If it's something that I don't agree with, I have no problem voicing my opinion when it comes down to that."

Similarly, Parent 5 shared:

> "Uh, challenges, there are a couple different things because I think we need, she needs to have more social interactions to continue to grow her independence. But, you know two parents that are constantly working and three kids and two of them are active, and sports and all of these other things. And so is [child], she does horseback riding every Sunday and so it's like we're just constantly on the go, so I think the challenge is giving more time to it."

Parent 6 also explained logistical barriers that can get in the way of supporting social interactions:

> "Anything that she wants to do, I'm going to support it unless it's just like interfering with daily schedules or stuff like that. Like school, she wants to participate in a lot of things that you guys be having on Saturdays, and you know, after school. But we can't. For the simple fact, we live 45 minutes away, so that's traffic…[she] doesn't get home until after 4 o'clock. So I have to wait for her, on top of I have to pick her sister up so when it comes down to things like that, that's pretty much the only thing as far as time and location. That's our big issue. Other than that, I'd take her to anything that she wants to go to, it's just that certain things and certain days I can't support her in those things because the time is not on our side."

Parent 3 shared that even when she does initiate and plan social activities for her child, the parents/caregivers of her child's peers may not have the ability to support on the other end. She explained:

> "And it's tough, even when you…I don't care you know, I really want my child to socialize, I bring people to my house, I do everything, I take them or whatever, it's my initiation you know, it's my initiative always. And then you feel like is the other person invested in friendship? You start to wonder, why push something if they're not invested in it."

Parent 11 described the importance of taking things day by day, sharing:

> "...it's just hard to support her, it doesn't have anything to do with her sex, it's just new for me, I'm learning as I go along, no one in my family has a special needs child, it's hard to support her with a lot of things day to day, we cope with it as we go along the best we can"

Parent 2 shared a similar viewpoint, explaining:

> "...when you have a disability in your family, some of your life is just day-to-day. You take one day at a time. So, that far down the road, even though it's not that far down the road, seems you know like you want to cross that bridge when you come to it. You know, you just hope for the best always. You hope for good things, improvements in her areas across the board. And that will lead to, um, maintaining social interactions and making new friends, and maintaining old ones."

Many parents shared the exhaustion that came from feeling like they had to repeat the same things over and over, or try to support their child in doing something socially that they didn't want to do. Parent 7 explained:

> "Yes, if someone texts you, and its vice versa, she doesn't have to text you all the time, she doesn't seem to understand that, why don't you start the conversation, why don't you text her and say what's going on, she will not do that, she will not engage. And I know she can, I know she can. She's also very strong-willed and stubborn."

Similarly, parent 3 explained:

> "...so this week I said do you want to invite her to make valentines cards and give it to somebody or the nursing homes, why don't you do that, invite your friend or invite your peer from best buddies, two hours, you'll come here, I'll get all of the supplies, she hasn't done it."

Parent 8 agreed, saying:

> "A lot of the time she makes comments about wanting to go to the mall and hang out with her friends, and I say you tell me who you want to invite and I'll call the parents, I'll pick everyone up, feed them, you know I'll let you guys go off on your own while I hover back and watch from a distance. When it comes time to invite someone she says never mind."

Parent 4 explained the energy that it took to consistently initiate the idea to her child, sharing:

> "When she get together with her friends at home, it's always my idea. She never asks, 'Can (classmate) come over?'"

Many parents mentioned the difficulties that arise when their child's disability intersects with the teenage desire for independence, sharing:

> "but it's uh, it's more challenging now that she is a teenager, suggestions from me she will just be like ugh you just want it your way, so that, sometimes (gestures butting heads sign, puts hands over eyes) it's so funny because every Friday and Tuesday or Monday and Friday I get reported to [child's mental health provider] she keeps track of my behaviors, but it's ok (laughs) I think back I say I never did that to my parents, this generation is different"

Difficult to Prioritize Social Opportunities with Competing Demands

In addition to the demands of other aspects of their life, parents reported that it can be challenging to prioritize social opportunities when there are concerns about their child's health and safety that may need to come first. In addition, so many aspects of

being a teenager in the modern social world come with challenges that parents must support their child in navigating. Parent 8 described significant challenges in supporting her daughter with social media and safety, explaining:

> "I closed her social media. We allowed her to have a Facebook and only connect with family. I checked it one day and she had 1300 friends, and out of the 1300, 20 were family and friends, everyone else was men from other countries. So I was horrified, we shut it down immediately and had a conversation because she had put her phone number and birth date on her profile. She's very smart when it comes to computers, navigating registrations and things like that and one of the things that she and I have butt heads about is her saying I'm not a child don't treat me like a baby, nothing is going to happen to me nobody is gonna kidnap me. I'm from New York City so my kids are always telling me we're in Maryland now, stop acting like we are in New York, and I'm like ok things can happen anywhere. She and I clash about that a lot. When I went through her friend list and I said look at these men, some of these men are old enough to be her father. And that's when we had to have a serious conversation about sex and trafficking, I said why do you think somebody old enough to be her grandfather would want to be friends with you? And she really didn't get it, she says she gets it but I now monitor everything she does on social media."

Parent 6 had significant concerns about her child's physical safety, explaining that:

> "It's kinda hard when it comes down to the family because, when it comes down to the family, everybody has to look after her because they don't want her to fall, they don't want her to trip… Compared to wanting her to jump in full feet, you can't jump in full feet with everybody else because you can't swim. So, we can't do that, so I just don't like the limitations that I have to put on her."

She also shared difficulties with being the only caregiver that truly understands her child's strengths and needs, saying:

> "Not saying that I don't trust people, but me personally, and it's nothing against her father or her grandparents, nobody is going to look after her the way that I look after her. That's been my job for sixteen, almost seventeen years. Even when she goes with her dad, I try not to sit here and say, "Hey, hey, hey, make sure you watch this, make sure you watch that." I have to let him be a dad. But I know when she's with me, I know her…That's what I'm used to, these are the things that I'm trying to teach her."

Many parents shared their focus on their child's transition into adulthood and long-term planning, which can easily consume any energy that might otherwise focus on socialization. Parent 5 described this, saying:

> "you can't protect her from everything, so you kind of give her the tools to be able to protect herself and so how do you, that's the one piece right now. And I think it's just growing and top of mind for me since we're on the verge of getting to a place where we need her to start figuring out what her independence looks like, if she's going to be able to have it. It may be that she needs a structured, supportive setting post high school and for future, which is fine too. It's just a matter of figuring all that out. Those things are just things that of course any parent worries about just in general, but even more so with a child that has an intellectual challenge."

Parent 5 also shared medical and self-care needs that she was reckoning with at the time:

> "...we talk about contraception, and we talk about all these things, not because of a relationship they're in but because one, unfortunately, they can be easy targets. The other piece is that it can help with hygiene and managing a lot of different things, so those type of challenges I think are just becoming known, we're starting to be more aware of them now that we're having to take steps to address some of that."

Similarly, Parent 4 shared a focus on increasing her child's advocacy and community navigation, describing:

> "I've been trying to support her and I'm hoping that that matures her a little more. You know, having her navigate stuff by herself…she's not always going to have me to be there…So we were in Target one day and I said to her, she couldn't find something, and I said, "Did you ask one of the Target team members?" She was like "no." I said, you need to go back over there and they have the badge on, look for the badge, and ask them where is such-and-such. And she did it, and she came back and she was all excited…so I want to set her up for a successful environment… help build confidence."

Parents also shared about the extensive energy that it took to be an advocate for their child throughout the years, and the difficulties that arose in the process. Parent 8 shared:

> "Yea. She had a little experience when she went to middle school, in 6th grade, this little girl was not nice, and was making fun of her…So I had to have a meeting with the teacher, the principal, um and then had a meeting with the little

> girl and her parents because I was like you are not bullying my child, absolutely not. I know I'm calm and reserved now, but I can be a little bit of a firecracker when it comes to my kids. That's how we got her into (current school), I'm not just going to stand by and let things happen."

Parent 10 explained the challenge of finding time for all of the important conversations that she wanted to have with her child, related to being a woman and being a good person in general:

> "These are things that are specific to women. People seeing you as not as strong or you know maybe not as smart or not as worthy of a certain position. Um and in the workforce, like I have to learn when and where I'm going to explain those things to her and integrate those things into life because that kinda goes with that whole, you know you have to, you gotta fail to succeed and kinda understand you gotta work twice as hard when you're a woman to make guys respect you. You know, I know that it's out there but I have to remember like you said, that road to independence, not a straight path so I gotta kinda remember you know where do I put that? Where do I insert those types of conversations? So I think that's a challenge."

Parents Want Support and Information from School

During interviews, parent participants were asked about their preferences for topics that are discussed or not discussed in school. The majority of participants reported that they were open to all discussions in school, including social topics like sexuality and romantic relationships. Even the few parents who had reservations about school based teaching of specific topics were very interested in gathering information from the school about their child's social interests/preferences, and peers that match with their child's social preferences and interests. Parents also reported a desire for information and guidance on how to have conversations with their child in ways that their child would understand.

Parent 12 explained that:

> "You know like I don't think any topic is really inappropriate to talk about at school, I mean you know taking your lead too in talking about what school is doing is helpful because as a parent it's not always easy to know how to approach it in a way that they can understand."

Parent 1 explained the need for support and guidance on social opportunities, explaining:

> "I feel like there's opportunities there I just don't know how to use them."

Many parents reported a desire to connect with other parents from school and get to know the other families to better support socialization. Parent 1 said:

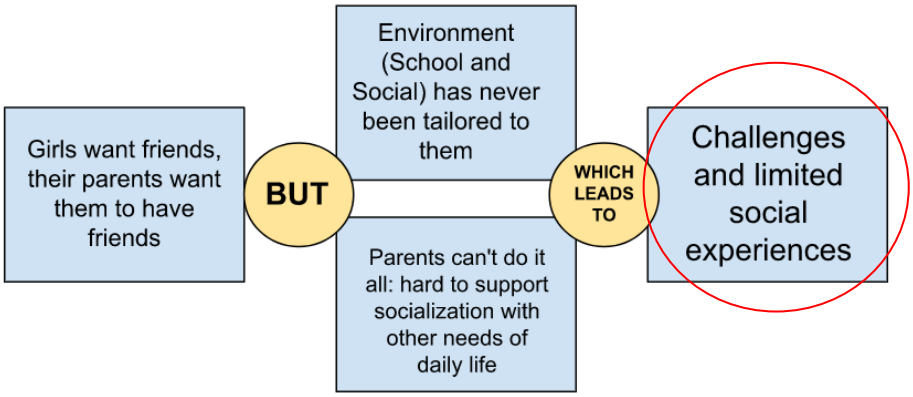
> "And it would be nice to have, I don't know maybe there's an equivalent parents group to their girls group, some way to you know reach out…and I've gone to PTA meetings but that's a big group, not necessarily kids around her age."

Summary

Many parent participants reported the difficulty they have faced supporting their child's social success when other needs require so much of their energy. Parents reported family and work demands as well as the time and energy that it already takes to support their child in other areas (e.g., safety, self-care, daily living) as barriers to supporting their child socially. When there are multiple areas in need of support, parents have to prioritize the most pressing ones, which often end up being safety related. Many parents dedicated significant time and energy to supporting their child's more basic needs, like safety and access to an appropriate education. Finally, parents consistently reported a desire to partner with school staff and receive additional support and guidance. Many of the girls interviewed struggle to share about themselves without language supports, which means it is difficult for them to go home and share about their experiences with family at the end of a school day. This means that parents are often unsure of which peers their child is spending time with and what they like to do with them. Parents reported a need for information from school about strategies for supporting their child socially, peers who

may be a good match for their child, and social opportunities in the community. Rather than seeing school involvement as an intrusion on the family's parenting process, parents reported this as a welcomed support to their already overbooked lives.

Girls with DD Face A Number of Social Challenges



Girls and their parents desire meaningful friendships and social experiences, but given the barriers described, a number of challenges have presented themselves in the process. Due to their disability, many girls do have gaps in skills needed for social success. However, one might also argue that the social environments that these girls are in are not supportive of their social strengths and support needs. Many girls have unfortunately experienced bullying and rejection throughout their K-12 experiences. For a wide variety of reasons, their social worlds were reported to be fairly limited, and in this absence of a strong social support system, many girls may turn to social media, tv and movies to gather their own information on social expectations. In the tables below, challenges are highlighted across participants, and broken down in greater detail thereafter. Student participants tended to focus on challenges of solving problems with

peers and initiating social interactions with new people. Parent participants also noted challenges with initiating social interactions and navigating a variety of social problems.

Table 7.

Student Perspectives: Social Challenges

Participant	Student Response That Highlights Challenges Faced in Forming Friendships
Student 1	"Well I have none [no friends] in school but I have a past friend from a past school."
Student 2	"Sometimes I feel nervous or stressed"
Student 3	"[I need help with]...Oh, how to have conversation…[also points to written answer choice "how to solve problems"]"
Student 4	"It's harder for me to ask what your name is."
Student 5	"It's hard to find a time to hang out, especially during Covid."
	"Uh, some friends might manipulate you and talk behind your back."
Student 6	[Circles 'how to solve problems']
Student 7	"Hard to get along with them or once you get along with them maybe you don't know if they're going to want to be your friend or not, once you get to know them more."
Student 8	"Having different interests and don't know what to say"
Student 9	"Me and (classmate) get frustrated sometimes…If they say I'm best friends with my best friend"
Student 10	"Like [with] a bunch of new people….[I am] a little hesitant at first"
Student 11	"A lot of things have been difficult in my life…I used to get bullied at my old school"
Student 12	"[it is hard] Maybe if I met them for the first time."

Table 8.

Parent Perspectives: Social Challenges

Participant	Parent Response that Highlights Challenges Their Child Has Faced Forming Friendships
Parent 1	"So I think there's this big gap for her where I'm at school and I know I'll be a grown up one day, but how she's gonna get there she hasn't spent a lot of time thinking about"
Parent 2	"So you say, maybe you could be the one to reach out. Like the other day I asked her, 'Have you heard from so-and-so?' and she said 'No.' So I said, 'Why don't you text her and see how she's doing? You can check in with her. It doesn't always have to be someone reaching out to you.' So taking the lead on just, you know, saying, 'Hi, how are you, haven't talked to you in a while.' Or 'Hey, you know, maybe we could go to the park one day or go to a movie.'"
Parent 3	"Phases of interaction, positive interaction, just to be positive when she talks, be um, you know compromises, not to be negative, if you don't like something that I like it's not because you don't like me. And um develop maturity because all those things with maturity come up, I understand we're not the same, you like something, I can do this, I can receive your suggestion but I don't have to follow it, but accept it with calmness and maturity."
Parent 4	"It's just that I feel like I have to prod her a lot, 'What do you think about this?' and 'Would you like to go here?' and 'I read about this place in Utah where you can do hiking…' But she doesn't initiate, it's mainly me initiating about social environments and things to do." "It's hard for her to make friends outside of her comfortable shell…And for her age, she won't, she might say hi but I have to prod her to say hi. And I'd like to see her initiate more, especially with people she don't know, if they're her age."
Parent 5	"I think maybe interacting more. So [she's] interesting in that she's very typical autism in the sense of 'in her own world'...If someone doesn't proactively reach out and engage, she rarely will lean in."
Parent 6	"She's a very friendly person and people have no problem sitting here speaking to her, but I've noticed she is in general, when they can't understand her, they find a way to turn away from her. Because they look at her as being different."

Parent 7	"Yes, if someone texts you, and its vice versa, she doesn't have to text you all the time, she doesn't seem to understand that, why don't you start the conversation, why don't you text her and say what's going on, she will not do that, she will not engage. And I know she can, I know she can. She's also very strong willed and stubborn."
Parent 8	"A lot of the time she makes comments about wanting to go to the mall and hang out with her friends, and I say you tell me who you want to invite and I'll call the parents, I'll pick everyone up, feed them, you know I'll let you guys go off on your own while I hover back and watch from a distance. When it comes time to invite someone she says never mind."
Parent 9	"I know one of the challenges is her ability to have meaningful conversations. Because as you know she loves to talk, she loves to converse, she's super energetic, friendly, but sometimes the conversations aren't meaningful. When I say that I mean they aren't on track or appropriate. Lets just say we are heading out to dinner, she may bring up something really random that happened two years…you know what I'm saying? It's like the conversation isn't on track. And that's even in a one on one setting with a peer, I've noticed that it may not be a challenge for her, but I notice like the non-verbal cues from the peer that's kind of like you know well wait where did this come from, or we could be talking about one subject and its abruptly changed because of a thought she had. So that's one of the biggest challenges." "And I would also just say social media, and that's probably a challenge for children across the board right now. And that's just like navigating it appropriately, safely. We struggle with the ability to discern you know who is your friend. Like you see these people on social media and you exchange numbers and now they're your "friend" (Uses air quotes). So now you're having these conversations that are very friend-like, but it's with a complete stranger. So that's my biggest challenge right now."
Parent 11	"No, she's very persistent until the point when the other person, the other child might become really annoyed and angry and then it becomes kind of a bad situation…she always wanted to be friends with (classmate) and it wasn't going that way and it went on for a while."
Parent 12	"I feel like we are still kind of in that place where she does need to practice the basics. A lot of time at least when she's talking to people she can talk but not really read the cues that the other person is not understanding or following her, or she might say something out of the blue and not lead into the topic properly so there's

miscommunications”

A Gap in Skills and Practice Opportunities

Throughout interviews, it became clear that many adolescent girls had specific gaps in their social emotional skills, some of which simply may not have developed without the right opportunities for practice. Parent 1 shared about her child’s difficulty with long term planning and goal setting, impacting her ability to set social and friendship goals that extend beyond her current life, explaining:

> “So I think there’s this big gap for her where I’m at school and I know I’ll be a grown up one day, but how she’s gonna get there she hasn’t spent a lot of time thinking about.”

Many student participants reported difficulty with understanding the social rules of conversation, how to generate questions/comments, and feelings that they “aren’t good at conversation”. This lead to many reports of feeling nervous or uncomfortable when attempting to initiate or maintain social interactions with others.

Student 7 described this experience, explaining:

> “Sometimes I’m like ok I don’t know what to say. And then sometimes I feel like they might have different interests in other things”

She also shared about difficulties with knowing what to say in conversations with romantic interests, describing:

> “...say there’s a boy you’re talking to and you like that boy… it’s hard to carry on a conversation or you don’t know them well that’s hard to have a conversation. I remember I had a high school crush…when I tried to talk to him it was hard because I was nervous and I was mostly shy at the time because I didn’t know how to carry on a conversation since I liked him so much…”

Student 8 shared a similar difficulty with knowing how to navigate conversation, and explained that she would like more support with:

> " …like what to do with friends. And how to be polite with friends…like anytime someone asks me something like what I like to do, I like really have no idea what to do say. And like if a friend wants me to do something that I really don't want to do."

Student 5 agreed, saying:

> "Sometimes I'm just blank and don't know what to say."

Multiple parents reported that their child had difficulty understanding types of social relationships, and how their actions might affect their ability to form deeper and more meaningful relationships. Parent 3 described difficulty with helping her child understand the different social circles and relationships, saying:

> "Another goal that we have hopefully you will take into consideration is develop an
> understanding of phases of a relationship, that is very important, and develop maturity to manage phases of a relationship. Because it's always, it's challenging. That is basically
> what I want as the first goal on this."

Parent 11 described her child's limited understanding of the impact of her own actions on her relationships, stating:

> "she kind of makes the person feel bad you know I don't know if she realizes that their feelings, you have to be careful with what you say and how you behave because you could hurt someone but I don't think she's aware that she's hurting someone or making them feel bad."

Difficulty with the skills needed to navigate social media and phone communication were mentioned frequently. Parent 9 described her child's strong desire to interact with others electronically, but limited knowledge of rules for doing so and limited skills for initiating and maintaining those interactions successfully, she explained:

> "I would say the next challenge in our day to day, our next biggest challenge is kind of along the lines with the social media thing, but with the phone-appropriate texting, that can be like just because you are up at 5 in the morning because you randomly got up to use the bathroom, doesn't mean you can call someone at 5 o'clock. I know we had a challenge with her in the beginning of her years at (school) I guess that was two years ago with the calling, like if someone says hey I'm going to eat I'll call you back she'll immediately call, she might wait 5 minutes or so, to her you should be done eating so I'm gonna call you, but you didn't answer so I'm gonna keep calling you excessively, and I had to tell her that's pretty much harassment at this point you know."

Parent 9 also described her child's difficulty with discerning who is safe vs. unsafe online, which is further complicated by her desire to be accepted and liked by others. She shared that:

> "We struggle with the ability to discern you know who is your friend. Like you see these people on social media and you exchange numbers and now they're your "friend" (Uses air quotes). So now you're having these conversations that are very friend like, but it's with a complete stranger. So that's my biggest challenge right now."

Rejection and Bullying

Unfortunately, experiences of bullying and rejection were frequently described by the girls and their parents. Of note, parents and girls consistently reported that they had not experienced this in their current non-public school setting, but rather in prior placements. Student 11 described this experience, saying:

> "A lot of things have been difficult in my life…I used to get bullied at my old school. [It made me feel] sad."

She went on to explain her typical response to rejection:

> "Because some people just love when they reject me. And I just reject them back."

Parent 3 also explained an example of rejection that her child faced:

> "Just going back to the challenges I think is she had a couple of cases of rejection, or her voice was too high, or because she didn't like each other, and that gets in the back of her mind forever so that is a challenge with some relationships…In a

> couple of occasions we saw people in the community and she was so happy to see them, so she (puts hand up in air) hi!!! And totally ignored. It's not reciprocal, you know"

Student 9 described the difficulty of best friendships, and conflict over prioritizing friendships:

> "Me and (classmate) get frustrated sometimes…If they say [they are] best friends with my best friend"

Student 3 shared her experience with being excluded from peer groups, stating:

> "Other girls are not being giving attention to me" as well as "When they [are] actually kicking me out, and [I'm] not feeling good."

Student 9 shared a similar message:

> "They sometimes don't like me."

Parents also reported their child's difficulty in this area, along with their perspective on the situation and how their child typically responds. Parent 11 shared:

> "If you're not her friend she gets really upset about it, if the person doesn't want to interact with her, she's still kind of like that but she doesn't get upset as much as she used to, now she just complains about it, why won't she be my friend, why won't she be nice, in that way, and I have to explain to her well not everyone wants to be friends you know"

Parent 7 shared her child's difficulty with fitting in with peers and making friends successfully:

> "So she had a really tough time, obviously with her maturity level she's had a tough time making friends. When girls were into iphones and youtube, which is ironic that she is so into that now, but at the time, she has always been a late bloomer, at the time she was more into cartoons and spongebob where these girls were into netflix and way above what she was into, so she had a hard time making friends."

While Parent 6 attributed some difficulties directly to others perceptions of her child as being different due to her disability:

> "Yeah, all of them. I really want all of that for her. I don't want her to not be able to make friends because she's different. That's something that I don't want. She's a very friendly person and people have no problem sitting here speaking to her, but I've noticed she is in general, when they can't understand her, they find a way to turn away from her. Because they look at her as being different."

Limited Social Life

Given the challenges that girls with DD face in forming relationships, many reported a fairly limited social life. Many reported limited opportunities to participate in social hangouts outside of school for a wide variety of reasons. While some girls may not have seemed terribly bothered by a limited social life, they did still report a desire to increase the number of social opportunities outside of school that they participate in, and some parents reported that their child engages in a variety of different behaviors in the absence of social hangouts with peers.

Parent 1 shared consistent concern with her child's limited social circle, explaining:

> "That's actually something I am pretty concerned about, that she doesn't really have a social life at all."

Parent 8 reported her child's unique experiences in the absence of social activities with peers, explaining:

> "So when she is alone in her room, she has conversations that sound like a party is going on. A lot of times when I listen it sounds like she is reenacting her day, but in the absence of real people. You know she has imaginary friends, and I was really concerned, I am still concerned to be honest, but this has been going on for some time now. When she was younger the doctors said well she has a developmental delay, when she gets older she'll grow out of it. This has been happening since maybe third grade, in my opinion it's getting worse because I feel that she's sort of insulating herself. I've noticed that she's less social. When she was younger she was a sort of social butterfly, now she is more reserved or shy and sometimes she will open up, but when she's with her entourage as I like to call them, there are full-fledged conversations going on. Asking a question in one voice and then responding in another…but I really feel like she's doing this in the absence of having real people to talk to."

Parent 11 reported that while her child does have a friend or some friends that may reach out to engage, social opportunities do not happen if not initiated by others:

> "So [she's] interesting in that she's very typical autism in the sense of "in her own world." In her mind, she knows she has friends, she has tons of friends, but it's not like she engages with them. Like she'll engage like [with her Classmate], but it would be like [her classmate] proactively reaching out. If someone doesn't proactively reach out and engage, she rarely will lean in."

Perhaps explaining why that is, student 2 shared that while initiating social interactions:

> "Sometimes I feel nervous or stressed"

Reasonably, Parent 1 cited logistical barriers as a partial explanation for her child's limited social life, explaining:

> "I would say the biggest challenge is just access to other humans (laughs) right so some of it was a matter of bad timing, you know she came to [her current school] just before the pandemic and making friends when classmates are all so scattered is a real challenge and at the same time we moved about 6 months ago and she had a couple of friends on the block and you know that's also very location based so yea, she um…you know even moving from elementary to middle school kids changed schools."

Parent 2 described similar logistical barriers along with the fact that their child developed differently from other children who live nearby, sharing:

> "We live in a neighborhood that when she was very little, it was very easy to go out the door, and there's all your friends. But you know, they kind of took off in a way, and she kinda stayed in one place, in the area that you know."

Comparing Self to Others and Media

In the absence of consistent opportunities to socialize with peers in a variety of settings outside of school, many parents theorized that their child may be getting information about social norms, expectations and experiences from platforms like tv, movies and social media. Additionally, many girls shared information that highlighted

their natural process of comparing themselves to other teens, or to people they have seen in media.

Parent 12 shared speculation of the expectations that her child places on herself, explaining:

> "I mean I guess I wonder how much of that is just seeing what other girls their age or siblings are doing and wanting to emulate that but not knowing how to get there, you know. Versus maybe there being some kind of internal desire to be that way, or natural desire to be that way, or if it's just because that's what you see, teenage girls hanging out and being friends and doing things together. I'm curious about that"

Parent 8 shared similar thoughts, explaining:

> "No I think that covers it, I can't say she's experiencing anything else specific to being a girl other than, well, you know the regular peer pressure that she may see in videos and movies and on tv. She doesn't watch tv at all, she watches streamed shows and a lot of Disney shows. So when she's watching shows and there's the mean girls, I don't think she's experiencing that at (school), I think she definitely would have said something, but I think she just kind of internalizes that. She's definitely an empath and when she sees things in the arts she absorbs it. So I think that might be a challenge for her, I don't know if sometimes she's anticipating that she might experience something like that one day but I think that might be a challenge, she's thinking maybe that's just what girls are like."

Interestingly, some girls did share experiences with topics often seen in media, but their parents reported that they were not experiencing those challenges, indicating that they were perhaps "absorbing" information about how girls typically act through tv, movies and media. Student 5 shared:

> "Like [it can be] difficult to find friends that send a positive example and don't do drugs and bad stuff. And find the perfect friends. Or like friends that you can trust and that won't lead you to dangerous situations…some people can be mean and like some girls if they're popular they care about like if you're like skinny or yeah…some friends might manipulate you and talk behind your back."

While she reported multiple specific issues related to friendship building, these difficulties were not reported by her parent, indicating that perhaps these were themes of

girlhood that she was taking in through media. Many girls also compared themselves to other teens, often considering themselves "different" or outside of typical social expectations for teenage girls. Student 10 shared:

> "I'm a bit anti-social and so are some of the other people in here…like introverted. I never know what's going on with most of the other girls."

Summary

Girls and their parents desire meaningful friendships and social experiences, but frequently struggle to make it happen. A lack of skills and support needed to navigate social interactions successfully can cause a major barrier to social success. Experiences of bullying and rejection are painful and lasting, impacting girls' self-perception and feelings toward social interactions throughout their lives. For a wide variety of reasons, their social worlds were reported to be fairly limited, and in this absence of a strong social support system, many girls may turn to social media, tv and movies to gather their own information on social expectations.

An Overview of the Theory

Findings from this study support a theory for explaining the social and friendship experiences of adolescent girls with DD. Girls desire friendships, and their parents want them to have meaningful friendships as well. However, girls have rarely been placed in social environments that are tailored to and supportive of their unique social strengths, support needs and preferences. Additionally, parents and caregivers have limited capacity to support social relationships and create supportive social environments for their child given the numerous demands placed on them daily. Unfortunately, adolescent girls with

DD therefore face a number of challenges in their social worlds. The next chapter will discuss this theory in greater detail.

Chapter 5: Discussion

Current research on the social experiences of adolescents with DD is limited, and focuses primarily on the male presentation of DD. Additionally, existing research rarely includes adolescents with DD in the research process, running the risk of conducting research and generating findings that are not meaningful to the population that it aims to support. This qualitative study utilized a constructivist grounded theory approach to generate knowledge and understanding of the lived social and friendship experiences of adolescent girls with DD, using information gathered directly from adolescent girls with DD and their parents. Results from this study highlight the authentic voices of adolescent girls with DD and their parents from a first person perspective. Interviews were conducted with 11 student/parent pairs and one student/parent trio (i.e. both parents opted to participate in the interview session). Participants shared their experiences, goals, opinions and recommendations for educators. The goal of this work was to develop a working theory on the social/friendship experiences of adolescent girls with DD to support educators in better tailoring social and friendship supports to this population in a way that is meaningful and effective. This chapter includes: a) an overview of the participants and findings from interview data; b) an interpretation of data and resulting theory; c) a review of conceptual frameworks that were used to guide this research; d) an explanation of how the existing frameworks fit into the resulting grounded theory; and e) implications of findings and recommendations for future research and practice.

Overview of Participants and Findings

The 12 student participants in this sample all attended a non-public special education day school in the Washington, District of Columbia Metropolitan area. Each

student participant was enrolled in the high school program on either a certificate of completion or high school diploma track at the time of interviews. All student participants were assigned female sex at birth, and were ages 14-18 at the time of interviews. To the knowledge of school staff, all participants identified with female gender (though this was not explicitly discussed and thus cannot be assumed with certainty). All student participants received speech and language services through their Individualized Education Plans, required highly structured academic/social support in a small group setting, and had diagnosed language, attention and cognitive support needs. Seven participants had primary diagnoses of ASD and seven participants had primary diagnoses of Other Health Impairment (i.e. including seizure disorder, microcephaly, intellectual disability, visual impairment, specific learning disorder, receptive/expressive language disorder, Down Syndrome, and attention deficit/hyperactivity disorder). Parent participants in this sample were 12 female mothers and one male father of the student participants. Each parent participant was matched to a student participant. All parent participants were legal guardians/biological parents of their student participants.

Through discussion with each participant, rich interview data was collected. Constant comparative analysis led to construction of theory based on four major findings of this research, co-constructed by student participants, parent participants, and the researcher, shown in Figure 4:

1) Girls with DD want to have friends, and their parents want them to have friends

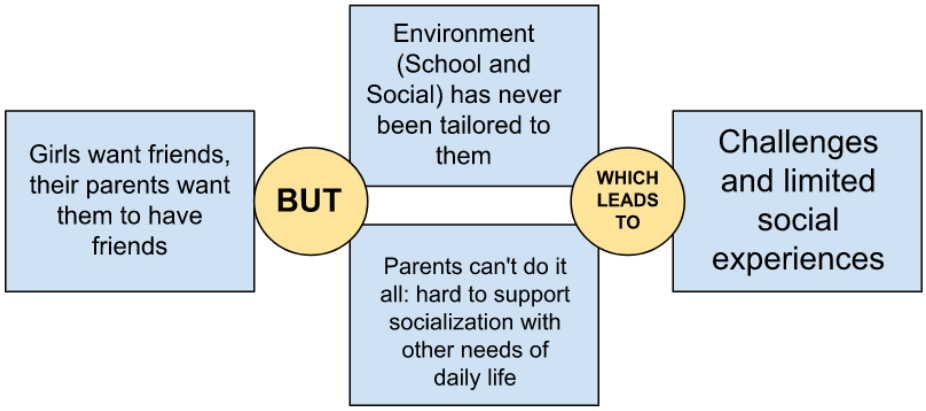
2) School and social environments have never been tailored to girls with DD

3) Parents cannot do it all, there are limitations to how they can support their child's social life

4) Given the limitations and barriers present, girls with DD face several social and friendship based challenges.

Figure 4.

Grounded Theory: Social and Friendship Experiences of Adolescent Girls with DD



Negative Case Selection

A traditional, between participants "negative case" was not found in this study, as many participants shared unique yet similar experiences. Negative case analysis is a critical component of strengthening grounded theory (Charmaz, 2014). However, given the specific population included in the study and limited access to participant recruitment outside of this particular school, the researcher was unable to recruit a negative case for examination of the theory. Additionally, the researcher questioned whether or not recruiting and interviewing a negative case participant that was not an adolescent female with DD stayed true to the nature of PAR in this work. However, negative cases between questions were noted throughout this study. The negative cases between participants at the level of individual questions highlighted the importance of individualizing support for

adolescent girls with DD, as there was no specific answer that was consistent across all participants. Although there were themes and commonalities, each participant brought a unique perspective to their interview, and their responses varied. In reviewing interview responses void of background information on the participants, it may appear that Participant 10 emerged as a negative case, given her responses that appeared to differ from her peers on multiple questions. For example, when asked how important friendships were to them, most student participants responded that friendships were "important" or "very important" to them. Participant 10 stated "...I guess they're important". When asked if they were interested in making new friends, most participants agreed that they were interested in either making new friends, or strengthening their relationships with existing friends. Participant 10 strayed from this response, and shared "I'm fine with the friends I have". While Participant 10 emerged as the most likely negative case from this group, background knowledge on this participant paired with later responses in the study created questions as to how this participant's responses may have been impacted by a guarding of herself, and awareness that she was different from others. Later in the interview, she went on to explain "…I'm a bit anti-social and so are some of the other people in here…I mean a lot of them are like, I never know what's going on with most of the other girls." Given background knowledge of this student as someone who reports enjoying social interactions that involve her preferred peers, activities and conversation topics, this participant may serve better as a reminder of the variety of social preferences that exist, rather than a true "negative case".

Limitations

First, all participants were enrolled or parents of a student enrolled in the same non-public school, in the same geographical area. Additionally, the support needs of students at this school are highly specific. Given this fact, generalization of findings is cautioned. Additionally, given the presence of cognitive/language support needs, interviews with student participants required support from the interviewer. While findings are still considered to be an accurate representation of student participant voices, there is always the possibility that responses were impacted by the support being provided by the interviewer. Additionally, given the close relationship between researcher and participant, there is a risk of participants, particularly student participants, aiming to please the researcher in their responses (i.e. saying what they think the researcher wants to hear). Given the researcher's continued involvement in the student participants' daily education, both student and parent responses may have withheld information or adjusted their response according to the educator role of the researcher.

Through this work, it was highlighted that a variety of social relationship/friendship preferences exist. Although this finding is far from erasing the important tenets of RCT, it is important to critically consider the definitions of friendship and relationship that exist within this theory. Given the variety of social preferences that were described in this study, the basis of RCT, and its conceptualization of friendship/social relationships should be contemplated. Although neurotypical social standards (including those highlighted by RCT) indicate a close female friendship as one that involves sharing of feelings, consistent conversation, and frequent in-person interaction, this is only one view of friendship. For many females with DD, friendships that are based online, involve

reduced conversation, or are based around activities may provide the needed social fulfillment and joy. In conceptualizing the importance of social relationships outlined by RCT, one must consider the variety of relationship preferences that exist. Using a strict definition of social relationship/friendship would limit the inclusivity of this study.

Conceptual Frameworks and Relationship to Grounded Theory

Although the lack of previous research and theoretical background was a driving force of this research, existing theory did contribute to the overall lens used by the researcher. In reviewing the literature on this topic, a specific lens was used to search for and interpret existing research. Given the focus on girls with DD in this study and this researcher's value of social justice for disabled people as a whole, Critical Disability Theory (CDT) as described by Meekosha & Shuttleworth (2009) posed significant influence on this study. Additionally, as this work closely examines the female experience of social relationships, Relational Cultural Theory (RCT) (Miller & Stiver, 1997) provided additional theoretical perspective for this dissertation. These theories were synthesized to contribute to this researcher's lens. As the study progressed, the researcher's own grounded theory emerged. Despite this theory being novel and constructed throughout the study, the influence of CDT and RCT are still prominent. Figure 1 shows the synthesis of CDT and RCT that was introduced in Chapter 2, and used as a lens for this study. Figure 4 outlines the constructed theory of this study, with components of CDT and RCT that contribute to this theory highlighted.

Figure 1.

Synthesis of Relational Cultural Theory and Critical Disability Theory

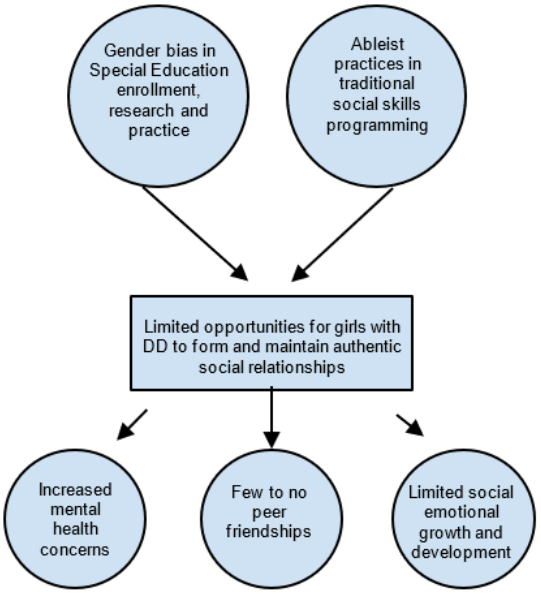
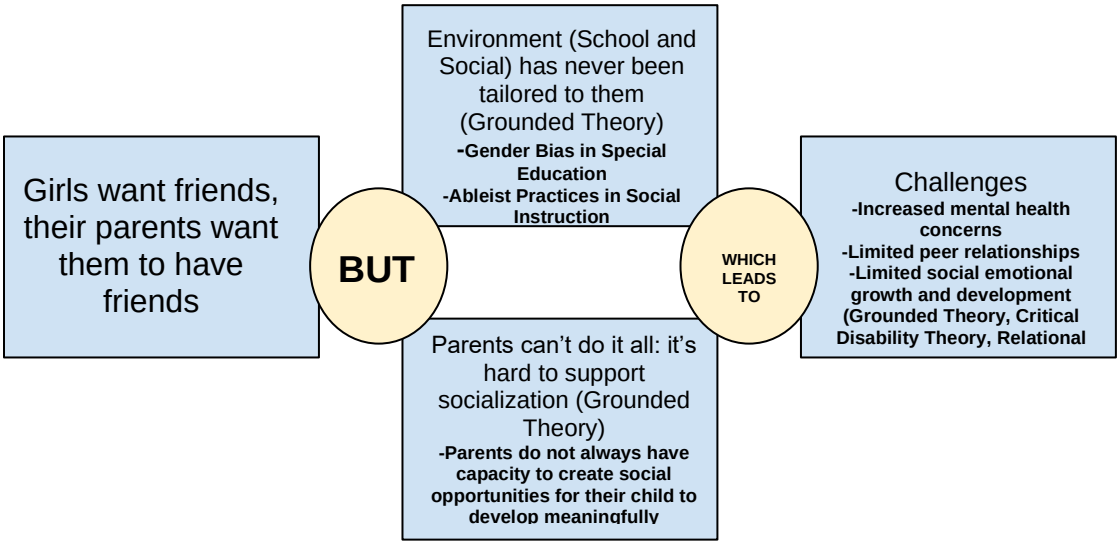


Figure 3.

Synthesis of Grounded/Constructed Theory, Critical Disability Theory and Relational Cultural Theory



The grounded theory overlap with CDT and RCT are particularly clear in the components of the grounded theory that discuss the child's environment. It became apparent throughout interviews that adolescent girls with DD exist in social and educational environments that are not tailored to their specific strengths and needs, disability, gender, social and sensory preferences. This idea that the environment has never been tailored to adolescent girls with DD, though constructed throughout this study, came to fruition through the questioning of current practice that is characteristic of CDT. In using a critical lens to examine disability studies, particularly research and practice in ASD, it is evident that dominant discourse continues to favor the white, cis-male experience of disability (Gesi et al., 2021; McCrossin 2022; Dababnah et al., 2018). In addition to critically questioning the impact of gender and intersectionality, CDT encouraged the consideration of disability more generally. The Medical Model that remains dominant in medicine and education proposes that people with disabilities must change to assimilate to a society of able-bodied people. This model has been scrutinized by many, and Guevera (2021) summarizes some of the core issues poignantly, stating that "this model fixates the "problem" within the individual while simultaneously absolving society from any further consideration. It also ultimately perpetuates stereotypes, perceiving people with disabilities as incomplete or damaged and needing fixing to accomplish any task at hand" (p. 278). In this study, CDT contributed to questioning of the adolescent girl with DD's social and educational environments based on: a) gender; b) disability; and c) the intersection of gender and disability.

In addition to the significant contributions of CDT, RCT also provided an important influence on this study. Miller (2008) indicates that perhaps dominant

psychological theory has focused intently upon the individual development separate from others, when development of girls, and all people, is so tightly tied to functioning within social relationships. She explains that

> "...a relational context which does not allow the developing girl or adult woman to act within relationships to represent her experience toward building mutually empathic and mutually empowering relationships leads the girl or woman to construct restricted and distorted images of the possibilities of relationships between herself and others. These constructions further limit her ability to act within connections, to know her own experience and to build a sense of worthiness" (p. 378).

Considering the many limitations placed on young girls with DD when it comes to social opportunities, they may be experiencing a sort of snowball effect, and their limited social opportunities at a young age compound over time and contribute to reduced mental health and reduced opportunity to develop and grow within social relationships. It is often the expectation that parents and caregivers will create opportunities for their child with DD to learn and grow within social contexts, but that is not always feasible or accessible. This lack of opportunity for social relationships raises questions about the challenges that girls with DD face, and whether those challenges are "skill deficits" as they are so often labeled, or rather opportunity deficits. However, given the variety of social preferences that were described in this study, the basis of RCT and its conceptualization of friendship/social relationships should be contemplated. This is not to say that findings from this study refute RCT; in fact, findings supported the notion that adolescent girls need opportunities for social interaction and connection. Rather, findings from this study

and from discussion of Neurodiversity more broadly indicate that it is important to consider the many different definitions of friendship and social relationships that exist across neurodiverse social preferences. Although neurotypical standards indicate a close female friendship as one that involves sharing of feelings, consistent conversation, and frequent in-person interaction, this is only one view of friendship. For many people, friendships that are based online, involve reduced conversation, or are based around activities may provide the same amount of social fulfillment and joy. In conceptualizing the importance of social relationships outlined by RCT, one must consider the variety of relationship preferences that exist.

In essence, the grounded theory and findings from this work highlight a need for stronger collaboration between the fields of Special Education and Disability Studies. Findings emphasize the importance of bringing Disability Studies into educational settings and supporting students to become strong self-advocates. This aligns with concepts already coined by other special educator/disability scholars, such as the members of the Disability Studies in Education sector of the American Educational Research Association (AERA). Members of this group have outlined the critical components of synthesis of these two disciplines in educational settings, including the following:

> "contextualize disability within political and social spheres; privilege the interest, agendas, and voices of people labeled with disability/disabled people; promote social justice, equitable and inclusive educational opportunities, and full and meaningful access to all aspects of society for people labeled with disability/disabled people; assume competence and reject deficit models of disability." (Connor, 2019, p. 11; AERA, 2023).

Special Educators and Disability Scholars must work together, not against each other, to support students with DD in reaching their fullest and most authentic potential. A place to start in bringing both parties together would be revisiting Liz Crowe's (1996) Renewed Social Model, and acknowledging the experience of disability as multifaceted. On the side of Disability Studies Scholars, the medical model is critiqued as being too deficit-based, and failing to make space for individual variation amongst humans. On the side of special education, the social model is critiqued as ignorant to some of the very real challenges that are a part of disabled life.

As Crow suggests, and as this study supported, there is room to renew the Social Model into a practice that acknowledges both the serious impact that disability can have on a person, as well as the immense role that societal oppression plays in the lives of disabled people. This study is proof that these two disciplines can come together in ways that increase the benefit to students in significant and meaningful ways, enabling disabled youth to have an active voice in their education.

Interpretation of Data

Findings from this study are synthesized, implications are discussed and recommendations for change are provided. First, areas of impact that society, educators and researchers seem to be getting wrong are discussed. Next, a synthesis of existing theory and the formulated theory is reintroduced to provide a context for the resulting recommendations. Finally, recommendations for addressing each area of impact are presented, and the importance of initiating change in the environments of girls with DD is emphasized.

What Are We Getting Wrong?

Despite the efforts of well-meaning educators, researchers and stakeholders, there are a number of things about girls with DD that we seem to be getting wrong. In failing to include the voices of girls with DD in research and program planning, it is likely that major areas of meaningful change have been missed or ignored, and many areas that have been chosen as a focus for girls with DD have been less than meaningful to them. The following section describes major areas of impact. The fact that girls with DD want social relationships is reviewed, followed by the important realization that caregivers cannot do it all, no matter how committed and supportive they might be. Finally, a shift in perspective is encouraged from viewing the challenges faced by girls with DD as primarily skills deficits to primarily opportunity deficits. Table 9 highlights components of the generated theory and their relationship to targeted areas for change.

Table 9.

Connection of existing theory, generated theory and identified areas for change

Existing Theoretical Component	**Generated Theoretical Component**	**How Does This Highlight the Things We Have Gotten Wrong?**
Girls develop in the context of social relationships (RCT)	Girls want friends, their parents want them to have friends	The prevailing idea that girls with DD are not interested in social relationships does not appear to be based in reality, they actually seek out relationships as a natural part of their social emotional development.
Girls with DD are doubly excluded, meaning that they are excluded from their female peers due to their disability, and their	The environment has never been tailored to them	Current practice in special education encourages the same social-emotional programming for all genders. However, given that the experiences of girls with DD are likely quite different

disabled peers due to their gender (CDT)		from their male peers and peers of diverse gender identities, current practice is likely insufficient to meet their needs and provide meaningful support.
Girls with DD need numerous positive relationships to serve as opportunities for social emotional growth (RCT)	Parents can't (and won't) do it all	Given the existing literature on caregiver stress as well as the responses from parents in this interview, it is unfair to assume that parents/caregivers can create the social opportunities necessary for their child to find and maintain these kinds of positive relationships all on their own. That burden cannot be placed entirely on parents/caregivers, and progress is unlikely if educators continue to do so.
There are challenges that exist when social relationships and intersectionality are not considered (RCT, CDT)	Girls with DD face a significant number of social and friendship challenges	Rather than viewing challenges primarily as skills deficits, they should be viewed as primarily opportunity deficits given the limited exposure girls with DD have had to close peer relationships (as they define them) outside of school.

Girls with DD Want Social Relationships

Many researchers and educators continue to operate under the assumption that individuals with DD, particularly autistic individuals, are not interested in forming social relationships, and lack social motivation. Taheri et al. (2016) studied the social experiences of individuals with ASD/ID, and students with ASD/ID were reported to participate in fewer social activities than their non-disabled peers. They were more likely to have fewer friends and a lower quality of friendship. It appears many see results such

as this and jump to the conclusion that low social participation occurs due to limited interest in social interactions. However, that conclusion cannot be made without talking to individuals with DD and asking about their social goals and experiences. Without giving individuals with DD the opportunity to share their perspectives, researchers and educators may jump to conclusions that are inaccurate or even harmful. Similar to the findings of this study, Ryan et al. (2021) found that adolescent girls with ASD value friendships with peers who share similar interests, and expect close friendships to transcend school based interactions into hangouts outside of school/in the community. Additionally, Wilson et. al (2017) studied a social group program that involved coordinator support during activities like bowling and going to the movies, with a plan to slowly fade coordinator support over time until small groups of young adults/adults with DD initiated and maintained the outings on their own. These outings and the focus of each group were determined by the coordinators in partnership with the group members to ensure that all voices were heard, and that the focus of the groups was meaningful to all. At the end of the program, participants reported an increase in their social networks, reduced feelings of boredom/increased healthy activity, an increase in skills needed to successfully engage with a social group (e.g., travel skills, planning, budgeting), and a greater sense of social belonging. Taken together, findings such as these indicate that:

1) The prevailing assumption that individuals with DD are not socially motivated is not supported.

2) While individuals with DD participate in fewer social activities than non-disabled peers, they experience success when social opportunities are tailored to their specific social strengths, support needs, interests and preferences.

Girls with DD participate in fewer social activities and friendships than their non-disabled peers. However, it is likely not their desire or motivation for friendships that causes this. Rather, the fact that their social environments have never been tailored to them is likely to blame for much of the social difficulty that they have experienced. When the social environment does not fit the child, much of the responsibility to "make it work" falls on the parents and caregivers of that child. However, no parent or caregiver can turn every environment into a supportive and inclusive one, nor should they have to. Ideally, the social environments that children and adolescents participate in would accommodate a wide range of diverse social interests and preferences, creating a safe and supportive space for positive social interactions. Rather than continue to place the blame for limited social success on adolescent girls with DD, it is time to take a hard look at the environments that these girls are placed in, and how they can be altered to make adolescent girls with DD more comfortable, happy and successful in their social lives. Adolescent girls with DD deserve social opportunities that are affirming to their gender and disability, amongst other aspects of their identities. It is time to begin looking at the problems within environments rather than problems within individuals.

Caregivers Can't (And Won't) Do it All

Currently, much of the responsibility of structuring social opportunities and ensuring social success for adolescent girls with DD falls on their parents/caregivers. During the transition process, caregivers frequently find themselves with limited social support. They must navigate the changing structure of their own life as a parent of an adolescent with DD coupled with significantly reduced availability of formal support through programs that their child may have participated in throughout their development

(Mckenzie et al., 2017). While their child may have been involved in multiple programs as a younger child, the availability of social and extracurricular activities for adolescent girls with DD becomes increasingly limited as students get older. Given this fact, much of the responsibility falls on parents and caregivers to create social opportunities for their child. However, given the many demands of daily life and the added challenge of supporting other factors of their child's disability (e.g., health needs), many parents and caregivers will fail to support their child in pursuing social opportunities that are consistent and fulfilling. This failure is not a reflection of their care or motivation to support their child, but rather a limit on their overall capacity as a human being. If environments are not adjusted to support the participation and success of girls with DD, parents and caregivers are set up for failure; they cannot do all of the work that is needed to make up for this lack of supportive environment. Different families will experience different degrees of success and failure in this process, though parents in this study tended to agree that there are significant limitations on what they can and cannot support their child with socially, and most indicated that they wished they could do more. This may cause significant stress for many caregivers, making it even more difficult to find success in the process. Caregiver stress for families of a child with DD is well documented, and this is particularly problematic as their child transitions into adolescence and adulthood (Hamilton et al., 2015). Overall caregiver health is complex and depends on a combination of social/support factors, individual caregiver traits, characteristics of the individual with DD, and family dynamics (Marquis et al., 2019). However, one can assume that trying to fix a broken system (i.e. the environments that are not tailored to their child) only further contributes to negative caregiver health

outcomes. Stakeholders cannot assume that parents and caregivers will single-handedly support the social participation of adolescent girls with DD. If they do, they will continue to find challenges and negative experiences that caregivers cannot change alone.

Challenges as an Opportunity Deficit

In the traditional practice of special education, challenges that students face are often attributed to "skill deficits" and targeted as areas for improvement. This is no different for girls with DD. As they face challenges in forming social relationships and participating in social activities, stakeholders in their lives may be looking for behaviors to adjust and "skill deficits" to target through special education services. Indeed, numerous challenges were brought up throughout this project in support of targeted special education services. For example, many parent and student participants mentioned difficulty with language and communication and actively requested services that supported the student's growth and development in those areas to support increased social success. However, many challenges faced by adolescent girls with DD emerged in a such a way that the researcher began to question not the girls themselves, but the systems that they are attempting to succeed in.

For the many reasons outlined in this dissertation, adolescent girls with DD have limited opportunities to participate in successful social activities and events with their peers. Adolescent girls experience significant growth and development in the context of social relationships. However, in the absence of these relationships, girls with DD may be missing critical opportunities for social development, which may compound on itself over time. According to Relational Cultural Theory, these relationships are one of the most important, if not the most important context for girls to develop their sense of self and

connection to their communities. Miller (2008) explains:

> "...a relational context which does not allow the developing girl or adult woman to act within relationships to represent her experience toward building mutually empathic and mutually empowering relationships leads the girl or woman to construct restricted and distorted images of the possibilities of relationships between herself and others. These constructions further limit her ability to act within connections, to know her own experience and to build a sense of worthiness" (p. 378).

This line of thought begs the question: what would the social functioning of adolescent girls with DD look like if support was provided early to ensure positive social relationships and opportunities? Where would these girls be if their environments and opportunities were adjusted at a young age to ensure that they feel socially successful? Would the challenges that they face in adolescence still exist, or would they have had significantly greater opportunity to develop within social relationships such that the supposed "deficits" that we see in adolescence would never come to be, or would emerge to a lesser degree? Most importantly, would internalizing symptoms and mental health concerns still be as prevalent in this population?

During informal observations of the student participants in their classrooms, many of the adolescent girls with DD in this study demonstrated a number of social challenges prior to participation in a weekly girls' social group. Many struggled to initiate and maintain conversation with peers, had difficulty maintaining a single topic, or appeared completely disinterested in socializing with their peers. However, given an opportunity to interact with peers who shared commonalities (e.g., interests, gendered experiences)

during structured social groups, these apparent "skill deficits" were no longer noted, or noted less frequently. As their social environment shifted to better align with their social profile, these supposed deficits shifted. Once things clicked, these girls began to demonstrate social-emotional and social language skills that the researcher had never seen them use before. This realization is what lead to the work of this dissertation, and the desire to dig deeper into what really might be going on in the social lives of adolescent girls with DD. Given the right social opportunities, these girls experienced meaningful social interaction and relationship building that aligned with their own values, strengths, interests and preferences.

Meeting Problems with Solutions: Recommendations

As detailed above, there are a number of areas that we (as educators, researchers, and society) are not getting right. There are problems in the ways that girls with DD are included and excluded from social environments, there are problems in the ways that parents/caregivers are treated, and there are problems in the way that social challenges faced by girls with DD are viewed. However, throughout this study, students and parents provided rich insight into ways that meaningful change can happen. The following section provides a call to action for educators and researchers to shift the way that girls with DD are viewed, treated, included and supported.

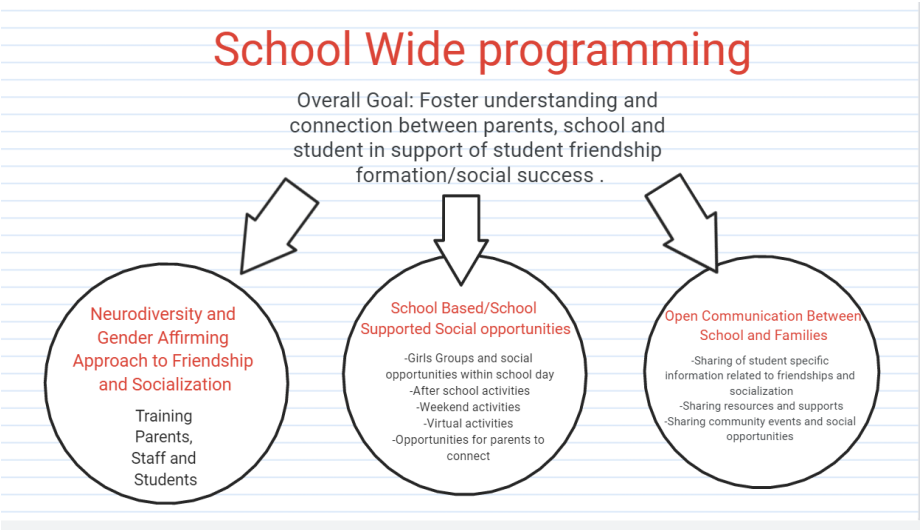
Transforming Environments

Unfortunately, social environments are rarely tailored to adolescent girls with DD. Many girls with DD face feelings of rejection, isolation, and being generally socially inadequate. Researchers have consistently found increased levels of internalizing symptoms (e.g., anxiety, depression) in girls with ASD when compared to female peers

who are neurotypical, and male peers with ASD (Solomon et al., 2011; Oswald et al., 2015). Girls with DD should not assume all of the blame for the social challenges that they have faced. It is the social environment that is inadequate, not the individual. Changing society's view on disability and gender is a tall order, but there are certainly ways that shifts can be made to support adolescent girls with DD. Within school communities, the goal of supporting adolescent girls with DD socially involves multiple people and multiple considerations. Of the utmost importance is a school community that encourages open communication between students, staff and families to ensure the success of all community members. Recommendations for creating a supportive school environment are described in more detail below, and outlined in Figure 6.

Figure 4.

Recommendations for School Wide Programming to Support Adolescent Girls with DD



Educating on Neurodiversity

Students, families and staff members need to be taught about Neurodiversity, and given opportunities to discuss it openly. Rather than focusing on neurotypical peers as mentors for neurodivergent students, schools can focus on encouraging genuine and

mutually supportive peer relationships that do not set students up in a hierarchy, where students with disabilities fall to the bottom every time. Students should be educated on best practices for communicating effectively with their peers of all cognitive and language profiles so that the burden of "making it work" does not fall solely on the student with DD. Similarly, staff members need to understand how they can provide a supportive environment for students with DD without encouraging masking of their disability. Parents and caregivers, though typically the most knowledgeable of all in terms of their child's disability, would also benefit from this kind of training and support. Even with the best of intentions, parents and caregivers may often encourage their children to "be like everyone else". Although this may come from a place of simply wanting their child to fit in and experience social success, this can lead to significant mental health concerns and further social difficulty for girls with DD. Instead, parents and caregivers should be provided with the tools and information that they need to understand their child's social strengths, support needs, interests and preferences so that they can support their child in pursuing the right social opportunities and environments. It is difficult for parents and caregivers to let their child be who they are if they feel that they are not experiencing success and happiness. However, we must go back to changing the environment, not the child. If the people surrounding young girls with DD understand their social profiles, their chances for social success, acceptance and fulfillment are much greater. The responsibility to change cannot continue to rest only on girls with DD. If it is truly our wish to support girls with DD in being socially successful, we should not expect them to change or hide who they are in the process. It is up to the people in their lives to learn about, understand, and support them.

Educating on Intersectionality of Gender and Disability

Despite many significant advances, special education programs are still heavily focused on the white, male presentation of DD, particularly ASD. Recent discussion in ASD research highlights the significant gender biases that exist throughout the history of the disorder, including research, diagnosis and treatment (Loomes et al., 2017; Van Wijngaarden-Cremers et al., 2014, Lai et al., 2015). When ASD research is traced back to its earliest published work, studies by Hans Asperger and Leo Kanner in the early 1940s focused on white male research participants, and white males have continued to be the focus of ASD research to this day (Wolff et al., 2004). The information through which diagnostic criteria, evaluation procedures and interventions are informed has been based almost entirely on the male representation of ASD. Given this reality, it is unsurprising that understanding of the female experience of DD is extremely limited, and that girls with DD often move through special education programs that were likely designed for the strengths, support needs, and preferences of their male peers. However, the literature reviewed in this dissertation highlights that there are distinct, gender-based differences across individuals with DD. Rather than assuming that female students have the same social interests, strengths, support needs and preferences as their male peers, educators and researchers need to begin asking girls with DD about themselves. They need to consider the complex interaction between disability and gender (in addition to other intersecting identities), and how this shapes the social experiences of adolescent girls with DD. Rather than assuming that female students will benefit from the same programming as male students, educators and stakeholders must acknowledge the significant contribution that gender makes to one's social experience, and tailor support

accordingly. Giving girls the opportunity to share about their experiences, particularly with other girls their age, has the potential to completely shift the programming provided, and the way that girls with DD view their own potential for social success. Within this study, adolescent girls with DD consistently reported that they enjoyed/benefited from social opportunities with their female peers, and the opportunity to connect with female peers created a safe space for inclusive socialization. Creating opportunities like these weekly "girls' groups" has the potential to provide girls with DD more opportunities for social fulfillment while also providing educators with the opportunity to learn more about the girls' specific social strengths, support needs, goals and preferences. Of course, gender affirming support should be provided across contexts and students should have opportunities to learn alongside peers of all gender identities, but creating this kind of girls social group is one actionable step that can be taken toward providing stronger support for girls with DD.

School Supported Social Opportunities

While public and private schools consistently offer a variety of extracurricular activities such as athletics, clubs and dances, these events may not always be inclusive of female students with DD. Additionally, in special education programs such as non-public schools where students require greater support for social participation, these opportunities are likely more limited. However, girls with DD need opportunities to connect socially, and the responsibility of structuring these opportunities cannot fall solely on parents and caregivers.

After-school and virtual opportunities for connecting with peers over topics of mutual interest are desperately needed for girls with DD. This may be easier for girls who

have interests that are similar to their same-aged peers, like sports or music. However, many girls with DD have unique and focused interests, many of which are not supported by existing social opportunities. Additionally, even if aligned with their interests, existing opportunities may not be supportive of their cognitive, language or sensory support needs. School staff, particularly special education staff, are in a unique position to support adolescent girls with DD in creating and maintaining social clubs and activities that support a variety of student profiles. Many girls with DD struggle to initiate social plans, but may experience greater success given a structured opportunity to socialize with peers around a topic of shared interest. School staff should support students in creating supportive social environments, rather than asking students to change to fit into existing opportunities that were not created for them.

It is not just adolescent girls with DD that need support with social connection, but also their parents/caregivers. Given that the Pew Research Center estimates that only 33% of students receiving special education services under IDEA are female, caregivers of young girls with DD may have a hard time connecting and forming a social network with other caregivers who understand the female experience of DD (Pew Research Center 2020). However, caregiver support is critical to success of the family and individual with DD. Strong support systems show promise in negating some of the impact of social challenges individuals with DD and their caregivers face. In a study on the coping strategies of parents of Black Autistic children, Lewis et al. (2022) found that parents benefited from opportunities to share and discuss experiences with other parents of autistic children, both online and in-person. The parents included in this study shared that they would like more opportunities for this kind of mutual social support.

In addition to supporting adolescent girls with DD in connecting with one another, schools can work toward connecting the parents and caregivers of adolescent girls with DD as well. Many families do not know how to get in touch with other parents of students with DD, and struggle to connect with other caregivers who may share similar experiences. However, we know that the benefit of doing so can be extremely positive and significant. Schools can serve as the point of connection for families so that they can access other families that share some of their experiences. Family nights, virtual meetups, and opportunities for caregiver connection may not only connect caregivers and strengthen their support system, but also increase social opportunities for adolescents with DD. Many caregivers want to get to know the caregivers of their child's friends before allowing them to spend time with another family. Many caregivers simply don't know how to contact other families to organize social events and opportunities. By providing parents and caregivers with structured opportunities for social connection, schools can improve the well-being of the families in their community and support an increase in social opportunity and connectedness for students with DD.

Open Communication

Though highly relevant to a student's educational experience, socialization is a challenging component of student success to support, as it occurs across such a wide range of contexts with so many different communication partners. For this reason, open communication between students, staff and families is even more important. Student preference, family values, culture and availability of social resources all impact the way that a student interacts with their social world across settings. It is important that all parties involved understand the student and how they wish to interact with their social

world. No two students will be exactly the same, and open communication is needed to ensure that support is individualized, meaningful, and effective. It is easy for all to feel as though they do not have the information that they need to ensure social success. Parents and caregivers may feel that they lack information on peers that their child spends time with at school, or how to get in touch with other families. They may be unsure of the kinds of social support that are provided to their child at school. School staff may feel that they lack information about the student's social life outside of school, as it may be difficult for students with cognitive and language support needs to explain their social life in detail, and it may be difficult to carve out time to check in with parents and caregivers, specifically about social functioning. Most importantly, the students themselves may feel that they lack information on how to successfully find and participate in meaningful social opportunities. If communication increases between all groups involved, the potential for growth is significant.

Creating More Meaningful Opportunities

If we begin to view social challenges as opportunity deficits, the question of how to create meaningful social opportunities follows. A number of factors are at play when creating social opportunities for adolescent girls with DD. Given the findings in this study, the following recommendations are highlighted:

1) Give students the option to opt in or out of the group. Not only does this ensure that the group is something that they want to do, it respects students' ability to exit a situation that may not be gender/identity affirming for them.
2) Have a staff member structure the groups with input from students/caregivers.
3) Have a staff member that students are comfortable with present throughout the group. The staff member should be available to enter and exit the conversation

as needed to provide space for authentic student interaction while also providing support in teachable moments (e.g., social breakdowns, problem solving).

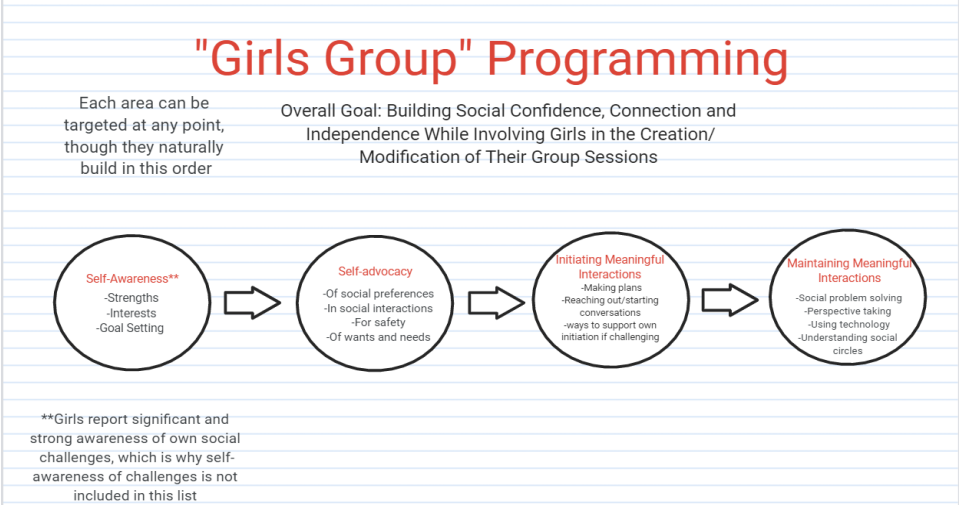
4) Build groups based on existing/emerging friendships first. It was noted through this work that many students were able to build relationships with their peers with little to no staff support in the moment once the social opportunity was structured for them. For many, the executive functioning and social skills needed to initiate the interaction is the biggest barrier, and they just need help "getting started".
5) After considering any existing friendships, consider grouping based on common interests and any special interests. Particularly for autistic students, this can be a great way to ensure mutually beneficial and meaningful interactions.
6) Finally, consider language and cognitive support needs in different groups. These groups are a great opportunity for students with diverse learner profiles to interact, so this does not need to drive the make-up of groups. However, it is important for each participant to feel that they can access the language being used in their group, which may be easier to do in groups of students with relatively similar cognitive/language profiles.

Figure 7 outlines recommendations for creating a girls group similar to the one from this study that creates a safe social space for girls with DD to develop their own sense of identity, belonging and connection. Girls with DD need to experience more

opportunities for safe, supported and positive connection with their peers.

Figure 5.

Recommendations for Girls Group Programming



These recommended topics stray from what one might think of for a typical "social skills group". They do not focus on specific social behaviors or skills, and they certainly do not encourage students to practice social behaviors that are aligned with neurotypical social standards. Instead, these topics focus on meaningful support for girls with DD to grow confidence within their social relationships and themselves. Additionally, these recommendations encourage the involvement of girls in the development of their own group sessions to ensure that group sessions are enjoyable, meaningful and effective.

Self-Awareness

In order for girls with DD to feel successful in their social relationships, they need to have some understanding and awareness of their own strengths, needs, goals and preferences in social relationships. Educators should work with students to identify their

own strengths and needs so that they can advocate for them in social situations. They can support students in identifying their own social goals and preferences, keeping in mind that these might look very different from neurotypical social goals and preferences. While many teenage girls look for friendships that involve a significant amount of conversation, that may not be what is most meaningful to all girls with DD, and that is ok. Girls should be aware of the type of social interactions and settings that are most enjoyable for them so that they can experience as much success as possible. If loud places are difficult, going to a concert with a friend would not set the interaction up for success. A trip to a coffee shop and library, however might be a great way to spend time with a friend. Girls with DD should be supported in identifying what they want out of social relationships and what is most comfortable and meaningful for them. This will allow them to seek out social opportunities that will be most successful given their unique interests, goals and preferences.

Self-Advocacy

While the first step is having awareness of social strengths, needs, goals, preferences, etc., the next step is speaking up and advocating for them, in whatever way the individual communicates most effectively. It is evident across research in special education that self-advocacy is a critical skill for ensuring successful transition into adulthood across vocational and social contexts (Mazzotti et al., 2021; Southward & Kyzar, 2017). Of course, forming and maintaining meaningful social relationships is an important aspect of transition into adulthood. Girls with DD should be explicitly taught the skills needed to self-advocate, and provided support and tools that will allow them to do so effectively. The importance of this is twofold. First, the ability to successfully self-

advocate will allow the adolescent girl with DD to make requests for meeting wants and needs that will provide greater opportunity for overall wellness, setting her up for a stronger ability to interact socially in a way that is positive and mutually beneficial. Second, self-advocacy skills will allow her to navigate social relationships more effectively by allowing her to share her preferences, boundaries and interests with communication partners. The likelihood of authentic connection within social relationships is much higher when girls with DD are able to share openly about what they want and need.

Initiating and Maintaining Meaningful Interactions

Throughout this study, one of the most consistently reported difficulties that most closely aligns with being a "social skills target" is difficulty initiating interactions and social plans with others. Even this is likely highly influenced by past experiences and current unmet needs (e.g., executive functioning supports), but it is one of the few "skills" that I confidently recommend targeting through groups after completing this study. Some girls with DD may never be big initiators, and that may simply be a part of their personality and social profile. However, many do want to initiate, but do not have the knowledge and skills that they need to do so. Areas of difficulty reported by girls with DD and their families included initiating conversations, initiating activities with friends (e.g., "Do you want to play a video game next?"), generating ideas for social hangouts, following the steps to make a social plan (e.g., who to invite, where to go, what activities to do), and following the steps to carry out a social plan (e.g., inviting a friend, buying the items needed for the plan). All of these skills are important for setting girls up to

successfully initiate with their peers in ways that will provide additional contexts for social emotional growth.

In addition to initiation, many girls with DD and their parents reported difficulty with "keeping a conversation going". This is a common difficulty for individuals with DD for a variety of reasons, and is not necessarily a problem, it may simply be a part of their neurodivergent social profile. However, if girls feel that they are struggling and want to learn how to maintain conversations more effectively, or if they are struggling to maintain interactions because problems consistently arise, there should be a space for girls with DD to target important skills that will support them in maintaining interactions more effectively. Social problem solving skills, perspective taking skills, skills for navigating technology based communication, and exposure to a variety of question and comment structures can all support girls with DD to maintain positive and successful interactions with others. Although these skills are important, groups should not be formed to focus only on these skills. It is common for speech/language and behavioral services to specifically target conversation maintenance without including self-awareness and self-advocacy. This poses significant risk of encouraging students to practice skills that may lack meaning to them, or worse, encourage them to mask their neurodivergent social profile. Instead, skills for initiating and maintaining social interactions should be an aspect of overall group programming, and should be introduced after girls with DD have been given opportunities to focus on self-awareness and self-advocacy.

There is, of course, one major caveat to applying these findings to groups outside of the participants in this study. One of the central tenets of this work was co-construction of recommendations, with open dialogue between participants and the researcher. If one

walks away from reading this dissertation ready to begin running groups such as these, it is important that they first consider the important steps to take to ensure that their groups also align with PAR. Educators/leaders will need to dedicate time upfront to collect information from adolescent girls with DD about their social preferences, interests, strengths, support needs, and goals for a group such as this. Rather than a curriculum to be applied across groups of students, these recommendations serve as a general framework that can be used, along with the input of students and families, to shape individualized and unique social opportunities for groups of students. These groups are successful because students have a say in how they are created, how time is spent within the groups, and how both of these concepts change over time. It is important to ensure that this critical component of group programming is not lost, and students are consistently given opportunities for their voices to be heard.

Methodological Recommendations

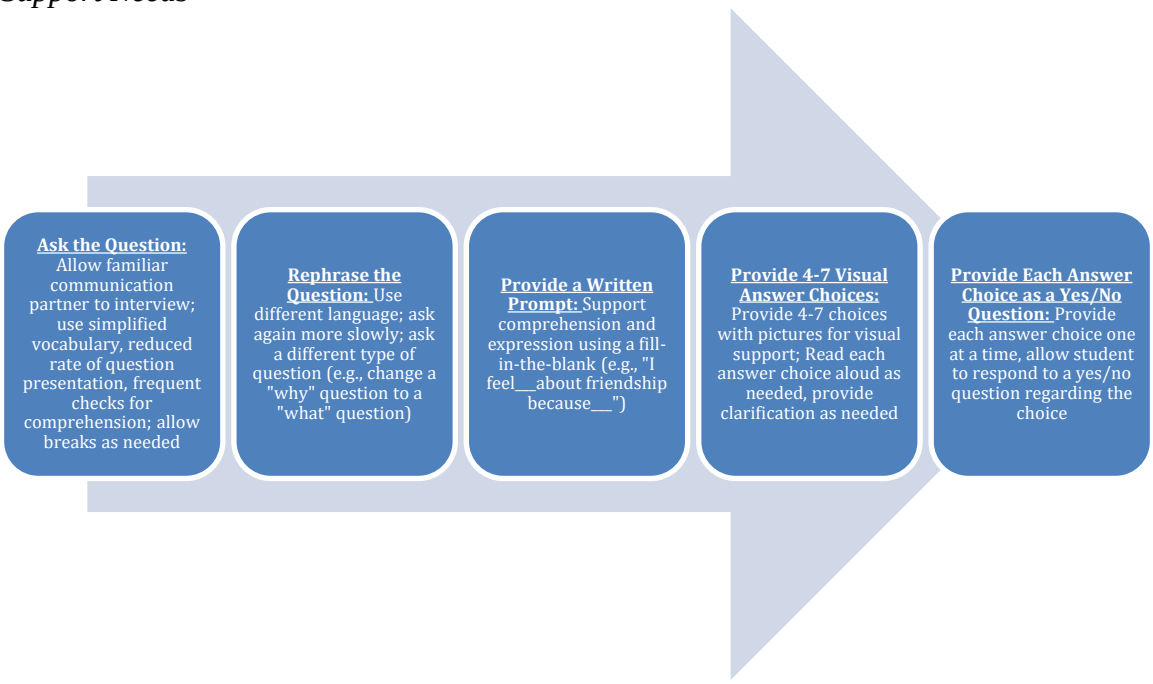
It is critical to ensure that all voices, including those that are often marginalized, are highlighted and supported in the world of research. Critical to applying the principles of PAR to research is removing barriers to research participation for individuals who might otherwise be blocked from sharing their authentic voices and experiences (Baum, 2006). Individuals with developmental disabilities often find themselves studied but not listened to, asked questions but not given the power to ask questions, or left out of the research entirely. Without their input, support, and authentic approach to the research, researchers run the risk of conducting research that is inaccurate, insensitive, or that lacks meaning for those with real lived experiences. In this study, a number of novel methodological practices were implemented, and allowed the researchers to involve

adolescents with cognitive/language support needs as active members of the research process. First, interviews took place with a familiar and trusted adult. The interviewers were both licensed speech-language pathologists who worked with the group of students being interviewed on a weekly basis. Both interviewers were familiar with effective language strategies for supporting individuals with cognitive/language support needs, while also possessing a strong understanding of each individual participant's cognitive/language profile, history, and social communication preferences. This familiarity provided a deeper understanding by the interviewer, and likely increased comfort by both parties throughout the interview process. Participants were likely more available to share personal stories and insights given the existing relationship with both interviewers as trusted adults/staff members.

Additionally, interviewers were trained in strategies for supporting interactions with individuals with cognitive/language support needs. Although this background training certainly supported the interview process, researchers do not need to be Speech-Language Pathologists to successfully involve individuals with cognitive/language support needs as active voices and participants in their research. An overview of strategies implemented in this study are reviewed in Figure 3 below.

Figure 6.

Supports Used to Ensure Access to Interviews for Participants with Cognitive/Language Support Needs



Through implementation of these specific strategies and adjustments, adolescents with developmental disabilities were active participants in this research process. It is critical that researchers consider the problems that lie in traditional research practices, not individuals, that create barriers to participation for marginalized communities.

Recommendations for Future Research

This dissertation is one of the few studies that have focused on adolescent girls with DD and friendship. The overall recommendation for future research is simple: to increase attention to this critical topic. Specific recommendations for future research are outlined below.

More research on girls with DD as a whole is desperately needed. For years, research has continued to focus on the male presentation of DD, and researchers are only beginning to untangle this long-standing problem in Special Education and Disability

Studies research (D'Mello et al., 2022; Watkins 2014). More first-person perspectives are needed not only in research on girls with DD, but in research on DD more broadly. Individuals with cognitive and language support needs have long been left out of the research on their own experiences, which likely leads to impractical, imprecise, or even inaccurate findings and recommendations. Researchers should revisit topics of existing research by involving individuals with DD in the process in new ways. It is the hope of this researcher that the interview methods described in this dissertation might serve as a resource for future researchers to involve individuals with DD in interview and research processes more consistently and effectively.

In order to determine what kinds of programming and support would be beneficial for girls with DD in forming and maintaining positive social relationships, it is critical that more research is done with girls with DD involved in the actual research process and providing first person perspectives. Although this dissertation addressed this topic, it included only a small group of individuals from a specific geographical area, with a relatively similar cognitive profile. Replicating this study across a variety of locations and disability profiles would make for a stronger and more individualized approach to supporting friendship opportunities for girls with DD.

Additionally, more research is needed to strengthen the developed theory and determine whether or not it is accurate and meaningful for groups of girls with DD and parents/caregivers outside of this sample. Researchers might determine a) whether or not the developed theory holds true for different populations; and b) whether or not programming based on the developed theory leads to positive and meaningful social outcomes for girls with DD. Additionally, development of a formal "girls group"

curriculum and research on the outcomes of implementing the curriculum would be an important next step in evaluating and disseminating important information and resources. This project is only a first step in the process of addressing the strengths and support needs of girls with DD in their social and friendship experiences.

Although social and friendship experiences are critical to development and growth of adolescent girls with DD, this topic is only one of the many factors that impact girls with DD daily. It is important for researchers to gather more information from adolescent girls with DD on their experiences with topics such as self-care, mental health, sexuality education, vocational/post-secondary education preparation, and more. Although some research has addressed these topics for individuals with DD more broadly, it is rare for researchers to consider the impact of gender on findings. Additionally, much of the research on outcomes focuses on employment, but we see from studies that take a more holistic approach that social needs play a large role in overall outcomes (Chiang et al., 2013; Muller et al., 2013). Continued research on the social and friendship experiences of individuals with DD during their transition into adulthood is a critical component of outcomes research that is too rarely considered.

Conclusion

Participants in this study provided honest, vulnerable, and meaningful accounts of their lived experiences as adolescent girls with DD and parents of adolescent girls with DD. As researchers, we might consider that the most important thing we can do to support those we aim to support is to take a seat and listen.

This qualitative study utilized a constructivist grounded theory approach to search for better understanding of the social experiences of adolescent girls with DD. The 12

student participants and 13 parent participants provided a range of experiences with some common threads. Analysis of data provided a path toward understanding these experiences in relation to the social environments that girls with DD have grown up in. The generated theory refutes the myth that girls with DD are not interested in social opportunities and friendships. It posits that environments that have never been tailored to girls with DD, paired with unrealistic expectations on parents/caregivers to create the right social environments, leads to significant social challenges for girls with DD and their parents/caregivers.

This dissertation makes a few distinct contributions to existing research. This work includes data gathered from interviews with individuals with cognitive/language support needs, something that many researchers have claimed impossible. To support this process in future research, this dissertation includes specific recommendations for supporting individuals with DD and cognitive/language support needs to actively participate in research and interviews. Given the information provided by adolescent girls with DD and their parents, this work highlights a different way of thinking about social challenges of girls with DD. Rather than viewing challenges as pure skill deficits, it is time to shift the viewpoint toward acknowledgement of the many environmental deficits that have forced girls with DD into uncomfortable or even negative social situations. Through supporting the social and friendships strengths, support needs and preferences of adolescent girls with DD from a young age, as well as supporting their parents/caregivers, immensely positive change is possible.

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Appendices

Appendix A: Student Interview Protocol

Who are your closest friends? Where did you meet them?

My friends are_____, _____, _____,_____, _____

I met them at_____.

School

Sports/Clubs

Religious Group

Family

Online

Somewhere else

What do you like to do with your friends?

I like to _____ because_____.

Share stories/interests

Talk-Share feelings

Do Activities

Hang out at school

Go places in community

Call/facetime

Go to my house/their house

Text

(If you chose ACTIVITIES or GO PLACES, please share a few examples)

What do you like to talk about with friends?

I like talking about____because_____.

Music Movies Celebrities Food/Restaurants Our own lives

Sports Friendship My feelings

OTHER

Something else!

\

What is easy about making friends with other girls?

It is easy to make friends with other girls because_____.

We have similar feelings

We like to do similar things

We have similar experiences in life

We like to talk about similar things

It's easier to talk to girls rather than boys

Girls are nicer to me than boys

I feel more comfortable with other girls

What is difficult about making new friends?

It is difficult to make new friends sometimes because_____.

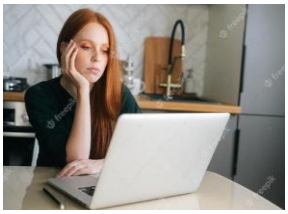
We argue/I feel frustrated

We have different interests

I don't know what to say

It's hard to find a time to hang out

I feel nervous/stressed



I'm not really interested in new people

What do you wish teachers helped you with in your friendships?

I wish teachers helped me learn_____ because_____.

How to have conversations

How to make plans

How to text/call/social media

How to solve problems

How to be a good friend

How to feel confident with friends

Making friends in school

Making friends outside of school

What do you wish teachers would not be involved in?

I wish teachers would not be involved in____because____.

How to have conversations

How to make plans

How to text/call/social media

How to solve problems

How to be a good friend

How to feel confident with friends

Making friends in school

Making friends outside of school

What is hard about making friends with other girls?

It is hard to make friends with other girls because_____.

We have different feelings

We like to do different things

We have different experiences in life

We like to talk about different things

It's harder to talk to girls rather than boys

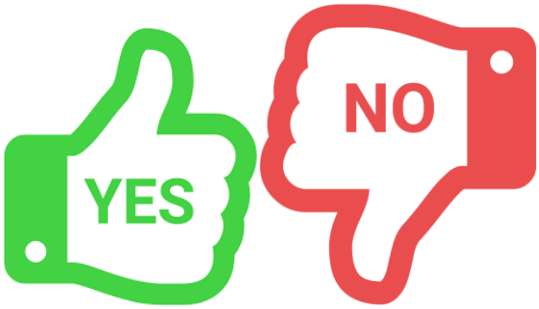
Girls are not nice to me

I feel more comfortable with boys

Do you want to make new friends?

Yes, I do want to make new friends.

No, I don’t want to make new friends.



If you could choose, what would you like to do with friends?

I would like to _____ because_____.

Talk-Share stories/interests

Talk-Share feelings

Do Activities

Hang out at school

Go places in community

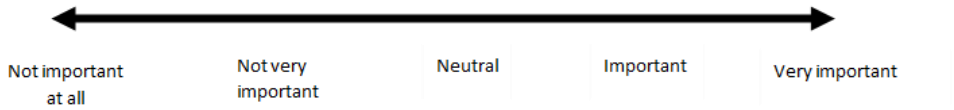
Call/FaceTime

Go to my house/their house

Text

How important are friendships to you?

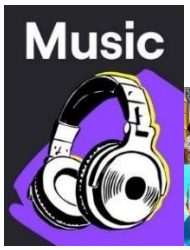
Friendships are _____ to me.



Why (are they important, not important, etc.)?

What do you want to talk about more in groups?

I would like to talk more about____because_____.



Music Movies

Celebrities Food/Restaurants

My own life Friendship

Sports

My feelings

Something else!

What do you like about group?

I like ____ in group because ____.

Spending time with classmates

Talking about things I am good at

Talking about things I like

Playing games

Getting out of class

Spending time with other girls

OTHER

Something else!

What do you dislike about group?

I don't like _____ in group because _____.

The topics we talk about

The other people in my group

Missing class

The games we play

The activities we do

Something else!

Do you want to make more friends who are girls?

Yes, I want to make more friends who are girls.

No, I don’t want to make friends who are girls.

How do you feel about being a girl?

I feel _____ about being a girl because _____.

Proud

Scared

Happy

Annoyed

Worried

Neutral

Are there any women/girls in your life that you admire? Why do you admire them?

Appendix B: Parent Interview Protocol

We are really grateful that you are taking the time to talk with us and share your experiences and thoughts! This project is aimed to gather parent and student perspectives about the unique social strengths, challenges, and experiences of girls with developmental disabilities. Julia (or) Kelly and I have been running weekly groups to target social language and social relationships amongst girl students in the MLN high school program, and we want to better understand how we can tailor those groups to address the skills and topics that you and your student find most relevant and meaningful. We know that girls with developmental disabilities may have very different social experiences from their non-girl classmates, and we want to better understand those experiences.

We appreciate your willingness to talk about this with us, and want this to be an open conversation about your experiences, there are no right or wrong answers to our questions. All of your responses will be private, your name and your student's name will not be attached to any information that you provide—we will only provide personal information to other Ivymount staff if it will help to better serve your student's individual needs. This is really an opportunity for us to make sure that we are providing the support in school that you think is most beneficial to your student's social emotional development.

I have a few major questions that I want to ask-if we have extra time, I may circle back to different topics to ask additional questions.

I would like to get your permission to record our session-it will not be shared outside of the research team, I just need to record so that I can transcribe our conversation after the fact. Are you ok with me recording this session?

Question	Examples to Share if Needed	Informal Observation of Parent	Follow-up questions asked?
Tell me about the social goals that you have for your student now. When they graduate?	**Examples: Make new friends, maintain friendships, organize hangouts, participate in hangouts, participate in clubs**		
What aspects of social relationships would you like for your student to be learning about in school?	**Examples: Making friends, keeping friends, conversation, activities, planning social events, solving problems**		
Are there any aspects of social relationships that you would you prefer to teach at home?	**Examples: What makes a good friend, how to solve problems with friends, how to disagree**		
Do you think that your child is interested in forming girl friendships specifically?	**Examples: Do they seem to want to connect with other girls, or gender doesn't impact their decision?**		
What do you think your student's social goals are?			

Tell me about what your student enjoys socially	**Examples: who they like the be with, where they like to go, what they like to do**		
Tell me what is easiest for you to support socially			
Do you think there anything that is easier to support your student with because they are a girl?			
Tell me about what challenges your student socially			
Tell me what challenges you when supporting your student socially			
Is there anything that is particularly challenging to support your student with because they are a girl?			

Additional Goals Questions If Extra Time

What would you like for your student to be doing in a weekly social group?

What do you think your student's social goals are now. For when they graduate?

What types of social experiences would you like for your student to have now? When they graduate?

What types of social experiences do you think your student would like to have now? When they graduate?

What types of social relationships would you like for your student to engage in now? When they graduate?

What types of social relationships do you think your student would like to have now? When they graduate?

Additional Strengths Questions If Time

What do you think makes your student a good friend?

Tell me what you like about supporting your student socially

Tell me about what aspects of socialization are easy for your student.

Additional Challenges Questions If Time

What do you think your student needs additional support with?

Tell me about concerns you have related to socialization now

Tell me about concerns you have related to socialization in the future

Tell me about what has challenged your student in the past

Appendix C: Consent/Assent Forms

INFORMED CONSENT

Title: Using the Unique Perspectives of Adolescent Girls with Developmental Disabilities and their Caregivers to Inform Social Language Groups

Ivymount School would like to invite you and your child to take part in an in-house study. Please review this form and return to Ivymount School by 8/26/22. If you have any questions or concerns, feel free to contact Kelly Offutt, M.A. CCC-SLP at koffutt@ivymount.org.

WHY IS THIS STUDY BEING DONE? This project aims to gather information about the social goals, strengths, challenges and experiences of adolescent girls with developmental disabilities from the perspectives of adolescents themselves and their parents/caregivers. This information will be used to refine the curriculum and structure of a social language group that is currently being implemented to support the unique social experiences of adolescent girls with developmental disabilities. Results of the study may also be presented at conferences and/or published.

WHAT IS INVOLVED IN THE STUDY? Regardless of whether or not you/your student participate in this study, your student will continue to receive the opportunity to participate in a social language group once a week. Topics of the social language group will utilize existing research on the social support needs of girls with developmental disabilities. For those students participating in the study, data collection will involve individual, paired, or small group interviews to collect information on their personal social goals, strengths, challenges and experiences. You will be asked to participate in a virtual or phone interview to gather input about your social goals for your child, including social outcomes after high school, supports provided in social opportunities, strengths, and needs. Parent/caregiver interviews will be conducted virtually or by phone and will last up to one hour. If you do not wish to participate in an interview, you are still able to provide permission for your student to participate in interviews at school. If you do not wish to provide permission for your student to participate, you are still able to participate in virtual interviews with the researchers/clinicians. You are free to consent to your child taking part in the student interviews, your participation in parent/caregiver interviews, both, or neither.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT, AND WHAT WILL HAPPEN IF YOU DECIDE NOT TO PARTICIPATE? Participation in the study is completely voluntary. Your decision as to whether you and/or your child participates will not affect your child's current or future treatment at Ivymount School or in the Multiple Learning

Needs Program. If you do decide to take part in this study, you and your child are free to change your minds and stop being in the study at any time.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART IN THIS STUDY?

Possible benefits to your child for taking part in this study may include improved instruction as a result of findings. If/when findings are made public, your participation may also indirectly benefit other children with similar profiles.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS? This study will not include anything out of the ordinary for you or your child. The only possible risks or discomfort you or your child might experience as a result of this study is discomfort related to being interviewed or recorded.

WILL YOUR INFORMATION BE KEPT PRIVATE? Although results of the study may be presented at conferences and/or published, participants' names and identities will not be associated with any findings reported as a result of this study.

WHO DO YOU CONTACT IF YOU HAVE QUESTIONS OR CONCERNS? You may contact Kelly Offutt at koffutt@ivymount.org with any questions or concerns about the research or your child's participation in this study. You may also contact Susan Holt, Executive Director of Ivymount Corporation, at 301-469-0223.

AGREEMENT

I have read the information provided above. I understand that if I have any questions, I may contact the researcher at any time. By signing this form, I am agreeing that **my child will take part in this study** and that I can withdraw from the study at any time by contacting the researcher

_____

Name of Participating Child

_____

Name of Parent/Guardian

_____

Signature of Parent/Guardian Date Signed

I have read the information provided above. I understand that if I have any questions, I may contact the researcher at any time. By signing this form, I am agreeing that **I will take part in this study** and that I can withdraw from the study at any time by contacting the researcher

_____

Name of Parent/Guardian/Caregiver

_____

Signature of Parent/Guardian/Caregiver Date Signed

STUDENT ASSENT FORM

I, _____ , understand that my parents have said it is okay for me to take part in a study about my social interests, strengths, challenges and goals. We will also talk about what I want to learn in speech groups. If I have any questions about this study, I can ask either Ms. Offutt or Ms. Donovan.

I am taking part because I want to. I have been told that I can stop at any time, and nothing will happen to me if I want to stop.

_____

Signature

_____

Date