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Experiences of Bullying for Individuals With Williams Syndrome

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ABSTRACT

Background: Individuals with intellectual disability experience high rates of bullying, but it is not known how people with specific syndromes, such as Williams syndrome (WS), experience and respond to bullying. Given their behavioral profile, including hyper-sociability and heightened anxiety, and their risk for experiencing other forms of victimization, it is important to examine whether individuals with WS experience bullying and to determine how they respond. *Method*: Fifteen individuals with (WS) between the ages of 12 and 37 participated in semi-structured interviews about their understanding of bullying, their experiences of bullying, and how they responded. Interviews were transcribed and coded for themes related to bullying understanding, experiences, and responses. *Results*: Participants were able to describe bullying, often referring to bullies as mean people who want to hurt others. Individuals with WS then reported that they experienced several forms of bullying, including relational, verbal, and physical bullying. In response to bullying, the primary theme that emerged was related to self-advocacy; the participants also provided suggestions about being proud of who you are, and feeling secure within yourself about your strengths and weaknesses. *Conclusions*: Individuals with WS experience bullying but also stand up for themselves in the face of bullying. To inform intervention, future research should further examine the bullying experiences of individuals with WS and how they compare to individuals with other intellectual disability conditions.

Individuals with disabilities are more likely to experience bullying than those without disabilities (Rose, Monda-Amaya, & Espelage, 2011; Sterzing, Shattuck, Narendorf, Wagner, & Cooper, 2012). Bullying is any unwanted aggressive behavior by one individual or group of individuals toward another that involves an observed or perceived power imbalance and is repeated (or is likely to be repeated) multiple times (Gladden, Vivolo-Kantor, Hamburger, & Lumpkin, 2014). There are four types of bullying recognized by the U.S. Department of Education, including (1) physical, (2) verbal, (3) relational, and (4) damage to property (Gladden et al., 2014). Individuals with

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disabilities are likely to experience bullying because they display several of the characteristic risk factors identified as increasing the risk of bullying in the general population. For example, victims of bullying, both with and without disabilities, often have deficits in social and communication skills (Christensen, Fraynt, Neece, & Baker, 2012; Doren, Bullis, & Benz, 1996) and difficulties maintaining peer relationships (Nabuzoka, 2003).

Most studies of bullying of individuals with disabilities have relied on mixed or heterogeneous disability samples (Christensen et al., 2012; Sheard, Clegg, Standen, & Cromby, 2001; Zeedyk, Rodriguez, Tipton, Baker, & Blacher, 2014); yet, a recent review of the bullying literature indicated that victimization rates vary by type of disability, ranging from 0% to 100% (Rose et al., 2011). This wide range suggests that not all individuals with disabilities have similar bullying experiences; rates of bullying may vary because individuals with different disability conditions display distinct cognitive–behavioral profiles (Hodapp & Dykens, 1994). As such, it is highly likely that different disability conditions are associated with different risk factors for, experiences of, and responses to bullying (Bear, Mantz, Glutting, & Yang, 2015; Fisher, Moskowitz, & Hodapp, 2013).

For example, a large body of research has been dedicated to the experiences of bullying of individuals with autism spectrum disorder (ASD), indicating that nearly half (46.3%) to almost all (94%) adolescents with ASD are victims of bullying (Little, 2002; Sterzing et al., 2012). Further, individuals with ASD (compared to those without disabilities and with other forms of disability) are more likely to experience repeated episodes of bullying, multiple forms of bullying, and their experiences are more likely to persist for years (Cappadocia, Weiss, & Pepler, 2012; Kloosterman, Kelley, Craig, Parker, & Javier, 2013). Such experiences are related to increased mental health problems (e.g., depression, anxiety) (Adams, Fredstrom, Duncan, Holleb, & Bishop, 2014; Cappadocia et al., 2012) and poor peer relationships (Fisher & Taylor, 2016).

Alternatively, while individuals with intellectual disability (ID) are also significantly more likely to experience bullying compared to those without disabilities, such victimization is not reported to be more chronic or severe than that experienced by individuals without disabilities (Christensen et al., 2012). Similar to those with ASD, victimization of individuals with ID has been related to social problems, social withdrawal, and relational problems (Reiter & Lapidot-Lefler, 2007); however, there is no significant relationship between victimization and mental health problems (Maïano, Aimé, Salvas, Morin, & Normand, 2016).

Reports of the bullying experiences of individuals with ASD compared to those with ID indicate that the experience of bullying may differ by diagnosis. These differences could have a significant impact on intervention and prevention programs designed to safeguard individuals with disabilities from bullying. Unfortunately, few studies have examined bullying across different types of disabilities or among individuals with specific genetic forms of ID. Considering the behavioral phenotypes associated with specific conditions, however, it seems that

individuals with specific genetic forms of ID might experience and respond to bullying differently.

Williams syndrome (WS) is a genetic disability condition caused by a deletion of ~26 genes on chromosome 7q11.23 (Hillier et al., 2003) and associated with mild to moderate levels of ID (estimated average IQ of 50–60; Searcy et al., 2004). Individuals with WS are usually friendly, socially disinhibited (Jones et al., 2000), and demonstrate extreme interest in interacting with others (Klein-Tasman & Mervis, 2003; Mervis et al., 2003). Despite their sociable nature, individuals with WS have poorly developed social skills and they experience considerable difficulty establishing and maintaining peer relationships (Davies, Udwin, & Howlin, 1998).

This paradox of social desires and social difficulties has been related to increased social vulnerability (Fisher et al., 2013; Thurman & Fisher, 2015) and experiences of social victimization (Davies et al., 1998; Jawaid et al., 2012). Indeed, 37% of a sample of parents of individuals with WS reported that their child experienced teasing or persuasion (e.g., being talked into doing something questionable) at some point in their lifetime (Fisher et al., 2013). More recently, adults with WS reported experiencing high rates of emotional forms of bullying (Lough & Fisher, 2016). Despite these high rates of bullying reported by parents and individuals with WS, no studies have examined how individuals with WS describe their own bullying experiences and how they respond to bullying. In addition to the other unique characteristics of individuals with WS, these individuals also often have strong communication skills (Mervis et al., 2000), making this population uniquely able to share their perspectives about their own experiences and responses to bullying. Our research question was: How do individuals with WS describe (a) the concept of bullying; (b) their personal experiences of bullying; and (c) their responses to bullying?

Method

Participants and Setting

Participants were recruited at the Williams Syndrome Association (WSA) National Convention, a weeklong meeting for WS families that occurs every two years. Prior to the convention, the WSA sent information about research studies to all families who expressed an interest in participating in research during the convention. Families then contacted the investigator to sign up for participation. For the purposes of this study, any individual with WS aged 12 or older was invited to participate in an interview about friendships and bullying. While there were no specific exclusionary criteria, it was important that participants were able to give verbal answers with enough detail to gain meaningful data from the interviews. All participants were able to answer the questions and were included in the analyses.

In total, 15 individuals with WS (11 female), ages 12–37 (M = 20.07), participated in this study. Five additional individuals had expressed interest in participating, but were not interviewed due to scheduling conflicts. Participants traveled to the convention from all over the United States and interviews took place in a private conference room at the convention hotel.

Procedure and Coding

This study received approval from the university institutional review board. When parents and individuals with WS arrived to the conference room at their scheduled time, they were given a brief overview of the study and asked to sign the consent and assent forms. The parent was then asked to wait outside of the room and the semi-structured interviews were conducted in a one-on-one format with the participant with WS. Using this method, the interviews were focused, open, and brief (less than 30 minutes), but provided participants ample opportunity to share their experiences and for the interviewer to ask follow-up questions (Beail & Williams, 2014).

Open-ended questions about bullying and the participant's response to bullying were developed initially based on the protocol developed by Gamliel, Hoover, Daughtry, and Imbra (2003). Revisions and additional questions were included based on the authors' knowledge of the bullying literature and experience with individuals with ID. Interview questions were adapted to be easily understandable and to avoid problems related to acquiescence, social desirability, and suggestibility (Beail & Williams, 2014; Finlay & Lyons, 2000). As such, the interview began with rapport-building questions about friendships in general. Next, following recommendations from Finlay and Lyons (2000), broad questions about bullying were asked, with more specific questions used as follow up. Examples include: "Have you ever been picked on or has anyone ever teased you at [school or work]?" and "If you had a friend that was being bullied, what would you tell them to do?" (Please see the Appendix for the full interview protocol). Interviews were recorded and later transcribed.

We used inductive category development to derive codes from the interviews and to sort those codes into themes. Initially, the second author read all of the transcripts to become familiar with the data and then derived codes by highlighting phrases that defined bullying, described an instance of bullying, or provided a suggestion for ways to respond to bullying. After identifying preliminary codes from five transcripts, the second author then coded the remaining transcripts and re-coded the first five using the identified codes and adding new codes when data did not fit into an existing code. Codes were then sorted into themes based on how they were related and linked (Hsieh & Shannon, 2005). This process was repeated until theoretical sufficiency was achieved (i.e., the data no longer revealed new concepts and insights). The first and second author discussed the general category definitions; categories and resulting codes were refined by the

second author. The first author then reviewed all category definitions and coded transcripts. Their high level of agreement with codes (90%) suggests the credibility of findings. Any disagreements were discussed until consensus was achieved.

Results

Definition of Bullying

Rather than providing a definition of bullying to participants during the interview, we wished to determine how participants with WS themselves defined bullying. Therefore, we first asked them to tell us what it means to be bullied or teased. Overall, participants indicated that they understood the concept of bullying and they were able to give examples related to universal definitions of bullying and teasing. In general, participants described bullying and teasing by either providing descriptions of what bullying looks like or by describing the characteristics of a bully.

What Bullying Looks Like

Participants described bullying through providing examples of bullying behavior. For example, one participant described, "It means to like say mean things about people…hitting, pushing, and all that" (female, age 12). Another said, "It's when like somebody doesn't like you and tries to hurt you….Like when someone calls you names and lies to you" (female, age 14). Finally, one participant discussed the emotional reaction to being bullied, "To get bullied means that your friend is hurting your feelings. Makes you mad, makes you sad" (male, 14).

Characteristics of the Bully

Participants also explained bullying as being mean to another individual or that a bully is not a nice person. For example, one participant stressed that a bully is not a friend, "Bullied is like someone who's not nice…and not a real friend" (female, 18). Another participant stated,

> When…that means when someone makes fun of you…they just…when you get bullied, they want to um…hurt you, be mean to you, be very…very, very rude towards you, and say mean stuff about you, and just…just, just be rude towards you. (female, 25)

Finally, two participants discussed how different minority groups experience bullying. For example, one participant stated:

> bullying is something that has been going on for y–…for ages, and ages. You can go back in history and lots of people and groups have been picked on for their… for their faith, their disabilities, their beliefs, their ah…judgment on things. (male, 24)
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> Similarly, another participant described:

because like people, like people judge people because of their um, like race, or religion, or um skin color, or like how, like or how…or how they're raised, like what…if they have disabilities or not. Like, people bully people because they're just mean. (female, 15)

Experiences of Bullying

To get a general sense of their bullying experience, participants were first asked whether they had ever been bullied or teased; all participants indicated they had been bullied at some point in their lives. To elicit more details about their experiences, we then asked about specific ways in which they might have been bullied. Most examples of bullying were verbal in nature, such as being teased for their physical characteristics (the way they look, talk, walk) and being made fun of or being called cruel names. Other examples related to relational bullying, such as being excluded from a group, and physical bullying or threats of physical violence (see Table 1).

Verbal Bullying

Participants described times when they were either made fun of or called names. Some participants with WS were teased for the way they looked; for example, one participant said, "I get teased about my big ears. My….they call me elf ears" (male, 24). Another reported, "They would just make fun of me that my eyes are really big…they would call me snake eyes, or…um, bug eyes" (female, 20). Others were teased for the way they talk, for example, "they like to make fun of me and say '[participant] has a funny voice'" (female, 13). Finally, some participants were teased for the way they walk, such as "When I was younger I couldn't walk normal. Like I couldn't walk, you know, on my own two feet. I always walked on my tippy toes because my joints weren't very strong enough yet, and they'd ask me, 'why do you walk that way?'" (female, 20).

Participants described other forms of verbal bullying as well, most often in the form of being called names. For example, one stated, "I got picked on like

Table 1. Percentage who responded that they had experienced each form of bullying.

	Total (N = 15)	Participants aged 18 and under (n = 7)	Participants aged over 18 (n = 8)
Participant reported being bullied for…	100	100	100
(a) how they look	66.7	71.4	62.5
(b) how they talk	40	42.9	37.5
(c) how they walk	13.3	14.3	12.5
Participant reported having experienced…			
(a) being left out of a group	60	85.7	37.5
(b) physical violence/being threatened with physical violence	53.3	57.1	50
(c) verbal bullying (e.g., teasing, name-calling)	80	85.7	75

every single day…they would say like 'you're retarded,' 'you're stupid,' 'you're dumb,' 'you're not going to make it in life'" (male, 24); another described, "I've been called so many nasty names like I've been called ugly…..They called me a slut and a bitch" (female, 25). Others were called names related to their appearance, such as "Um…a lot of people like called me names…like doll face" (female, 14) and "I used to get called ah…the word, the word beaver" (male, 25).

Relational Bullying

Participants described experiences in which they were purposefully excluded from a group, such as "I wanted to be like popular. But, then like I was trying to sit with like somebody, and like everyone would like leave me and g-, go sit at the next table" (female, 15). Another participant indicated that her peers would say, "you're not good enough to play with me and my friends" (female, 20) or, "Oh look, it's that kid, [participant's name], what's he doing here?" (male, 25).

Physical Bullying

Participants also described instances of physical bullying and threats of violence. One participant described a physical encounter:

> I did get pushed down, and I fell and I scraped my hands and my knees…..And I went to the nurse's office 'cause these two boys were bullying me at my public school, and they pushed me down, really hard, and I got…my face was like all bloody and stuff. (female, 13)

Another participant indicated that a bully attempted physical aggression, but her father stepped in. This participant stated, "He tried to grab my hair. And pull my arm, but my dad's like 'No. You're not getting near my daughter; you're not touching her'" (female, 27).

Finally, some participants stated they had been threatened by bullies, such as: "When a kid in middle school tried to threaten my family. And I tried and stop it, but he was like 'he's going to go kill my family'" (female, 19), and:

> I had this one girl, um, she wasn't very nice to me. Not kind at all to me. I would, like she, she bullied me. Like, she….I had, um, a crush on a boy, and she told me go talk to him or she'll kill me. (female, 15)

Response to Bullying

In the final part of the analyses, we examined how the participants with WS responded when they were bullied. Responses were drawn from questions about how they responded to the specific examples of bullying they provided, and from questions about what advice they would give to others who were experiencing bullying. While participants described the expected emotional responses to the bullying they encountered (e.g., "I cry" [female, 37] and "I

sometimes lash out at them, but I don't mean to do that" [female, 13]), a more surprising theme emerged as well; the primary higher-order theme that emerged from the thematic analysis was one of self-advocacy.

Participants shared ways in which they would advocate for themselves, both in describing how they responded to bullying in the moment and in how they described what they would tell others to do in response to bullying. Participants displayed self-determination by speaking up for their rights and empowering themselves to stand up to the bully.

Advocacy in the Moment

In response to bullying, participants often described instances in which they stood up to bullies and advocated for themselves. In describing how they responded to bullying, the sub-theme of "standing up for myself" emerged.

Standing Up for Myself. Participants often described ways in which they stood up for themselves, either by confronting the bully or by seeking assistance from others. For example, one individual stated: "I said, 'The words you used really hurt my feelings'" (female, 37). Another reported: "I said, 'Why are you making fun of me; it's not right….I don't make fun of you, so why are you doing it to me?'" (female, 14). Another participant described that she would "…just confront the person and just like tell them exactly how I feel about them doing that to me" (female, 25).

In terms of seeking assistance, participants told a parent, teacher, or principal about the bullying. One participant described, "I've told the principal, I've told my mom and dad, um, I have told my friends, um I have….I have stuck up for myself" (female, 15). Another participant indicated that friends have been helpful, "I told one of my friends, and um, they took care of it" (female, 25).

Advocacy Advice for Others Who Are Bullied

The participants were energized and enthused when asked about the advice they would give to others who experienced bullying, conveying suggestions about changing others' perspectives, being proud of who you are, and feeling secure within yourself about your strengths and weaknesses.

Changing Perspectives. Another technique suggested by participants was to try to engage bullies in a discussion that might help them think and act differently. Participants highlighted the need to try to get the bully to understand what it was like to live their life from their perspective.

I would tell them, 'Would you like to spend a day in my shoes? Would you like to have to go the heart doctor and get your heart checked every four years, hoping that your heart doesn't have to have heart surgery? Would you like to get tested so many times?' Like 'would you like to be born with it?' I'm not just disabled, you know, I'm a person! I'm not like an alien from outer space! (female, 20)

For those who bully people, just think about what the person's feeling. Think…if you stepped into their shoes one day, how, how would you see their life? Just step into their shoes and just think about why you're hurting them. (female, 15)

Have Belief About Self-Worth. Interviewees had a strong sense of self-worth. One participant spoke of trying to stay grounded in positive attributions of themselves, and having the confidence to acknowledge that what the bullies were saying was inaccurate:

Kids who have special needs are really important …don't let anyone tell you different. I had people tell me different and I believed them…things can hurt you, things can make you feel down, but just remember that you're bigger, you're tougher than the person who's bullying you. (female, 15)

Another participant also spoke of focusing on positive personal character-istics, and having the confidence to challenge what bullies say: "I would tell him or her that what [bullies] say doesn't really matter. It's about you and your thoughts, and your feelings…If they tell you you're ugly, no you're not ugly…you're a kind person" (female, 15).

Stay True to Yourself. There was also some discussion around "difference" and what it means to be different. The participants emphasized that the world is made up of differences, and people should feel no pressure to conform to be something that they are not. Linked in with the earlier theme of self-worth, this sub-theme is rooted in confidence: "You know you may be different. You know everybody's different. We're not all the same; we don't do the same things, but like, be yourself, don't pretend. Don't be something that you're not" (female, 20).

Keep a Positive Outlook. Finally, participants suggested it was important to have a positive disposition. The participants suggested that people who are being bullied should focus on the things that make them happy, not those that make them sad:

You're gonna to get teased by people and you just have to know that you are who you are…and no one can change you. You have to make changes yourself. So, if someone is picking on you, just think of the good things of life and things that make you happy and not worry about what they say. (male, 24)

Discussion

Little is known about how specific subgroups of individuals with disabilities, such as those with WS, define, experience, and respond to bullying. Understanding the bullying experience of individuals with specific behavioral profiles will help to inform the development of more targeted bullying prevention and intervention programs. Indeed, Evans, Fraser, and Colter (2014) emphasize that bullying prevention programs must focus on specific at-risk populations rather than addressing heterogeneous groups of individuals. Thus, this investigation provides a first account of the bullying experiences of a sample of individuals with WS and how they respond to bullying.

First, rather than providing a definition of bullying, this study sought to determine how the participants with WS would define bullying in their own words. Their perception of bullying was related to what bullying looks like (e.g., specific actions a bully might take) and the characteristics of a bully (e.g., someone who hurts another person). Such responses indicated that the participants with WS understood the concept of bullying and were aware of when bullying takes place.

Second, the participants with WS reported they experienced several forms of bullying, including verbal, relational, and physical bullying, and they were able to provide detailed descriptions of their experiences. While previous research found that adults with WS experience several forms of victimization, including persuasion, theft, and physical or sexual abuse (Davies et al., 1998; Fisher et al., 2013; Lough & Fisher, 2016; Rosner, Hodapp, Fidler, Sagun, & Dykens, 2004), this is the first account of the specific forms of bullying they have experienced. These findings highlight the need for additional research exploring the bullying experiences of individuals with WS. To estimate the prevalence of bullying of individuals with WS, future research should capitalize on the use of validated self-report assessments that are triangulated with parent or teacher reports and direct observations (Nowell, Brewton, & Goin-Kochel, 2014), and should compare bullying experiences to those with other forms of disability (e.g., ASD).

It is also important for future research to determine *why* individuals with WS are targets for bullying. Results from the current study indicate that individuals with WS describe experiences of bullying similarly to reports of those with ASD, as has been reported in previous studies (e.g., Adams et al., 2014; Fisher & Taylor, 2016; Rose et al., 2011). Thus, while individuals with WS and ASD seem to display contrasting social profiles—hypersociability in WS (Jones et al., 2000) and social withdrawal in ASD (Bellini, 2006)—they seem to share certain key risk factors for bullying victimization. For example, despite the highly sociable nature of individuals with WS, they often have trouble making and maintaining friendships (Davies et al., 1998). Difficulty with friendships is a known risk factor for increased bullying among individuals with ASD and without disabilities (Card & Hodges, 2007; Cook,

Williams, Guerra, Kim, & Sadek, 2010; Rowley et al., 2012), and could likely be related to the increased vulnerability of those with WS as well. Future research should examine how friendship and social difficulties experienced by individuals with WS are directly related to their bullying experiences.

Further, in both the typically developing and the ASD literature (as opposed to those with ID), bullying experiences have been linked to mental health problems, including anxiety, depression, and low self-esteem (Adams et al., 2014; Cappadocia et al., 2012; Cook et al., 2010; Hawker & Boulton, 2000; Swearer, Espelage, Vaillancourt, & Hymel, 2010). Individuals with WS often experience high levels of anxiety (Dykens, 2003), and anxiety has been related to impairments in social functioning for individuals with WS (Riby et al., 2014). Similar to those with ASD, then, it is possible that the heightened anxiety experienced by those with WS could also be related to their experience of bullying. Future research should examine how anxiety and social functioning of individuals with WS relate to bullying experiences.

Finally, when asked how they respond to bullying or how others should respond to bullying, the theme of *self-advocacy* emerged. Rather than focusing on self-blame or ways to get revenge (as has been described by a sample with ASD; Fisher & Taylor, 2016), individuals with WS discussed ways to remain true to oneself and to face the situation with positivity. Across interviews, participants remained positive, took a self-advocacy approach, and were empowered to take a stand against bullying. Although it is not clear from these interviews if this strategy of self-advocacy was effective at stopping future occurrences of bullying, previous research indicates that students without disabilities describe self-advocacy as an effective strategy to stop bullying (Frisén, Jonsson, & Persson, 2007; Llewellyn & Northway, 2008). Future research should examine if self-advocacy is also effective at reducing bullying for individuals with WS.

The findings from the current study offer a first glimpse into the experiences of individuals with WS who have been bullied; however, there are some limitations which merit consideration. First, all participants actively chose to participate in this study, raising the possibility of selection bias. It is possible that participants chose to participate in this study specifically because they wanted to share information about their bullying experiences. Alternatively, it is possible that individuals with WS with more severe communication impairments, who were bullied, chose not to participate in this interview-based study because of the difficulties associated with communicating their experience. From the ASD literature, we know that individuals with social communication difficulties face an elevated risk of bullying, yet this sample did not include those with impaired communication. Multi-informant methods should therefore be considered in order to represent all levels of functioning. Further, as all participants were attending a national convention, it is possible that those attending the convention were not representative of the broader WS population.

Second, due to the nature of the semi-structured interview, participants' reports of bullying were not confirmed with others or through direct observation. However, the specificity of participants' responses, and their differential responses to questions in the interview (e.g., responding affirmatively to some questions and negatively to others), minimizes any concerns related to acquiescence bias. Ultimately, the purpose of this study was to learn about participants' subjective experience of bullying and their response to this.

A third limitation is that there was no comparison or control group. All participants in this sample reported that they had experienced at least one form of bullying. To identify syndrome-specific protective factors, future research should compare individuals with WS who have experienced bullying to those with WS who have not experienced bullying. The inclusion of a cross-syndrome comparison group would also be insightful in highlighting similarities and differences in protective and risk factors across syndromes. Finally, because of the qualitative nature of this study and the small sample size, no comparisons were made to examine gender, age, or race differences. While future research should examine whether there are demographic differences, previous research has shown these variables to not be related to victimization of individuals with WS (Fisher et al., 2013).

The limitations of the current research are similar to those in the wider field of research on bullying and disabilities. Indeed, Schroeder, Cappadocia, Bebko, Pepler, and Weiss (2014) highlighted that bullying of individuals with disabilities has only recently become a focus of research, and as such, there are many areas to improve on in order to enhance our understanding. For example, in their review of 17 research studies on bullying of children with ASD, the authors found less than half (47%) included any control group, and few included a typically developing control group (29%), a disability comparison group (12%), or both (6%). Additionally, only two studies included semi-structured qualitative interviews.

Thus, while the larger field of disability bullying research has limitations to address in order to improve the rigor of the evidence base, it remains important to first establish an initial understanding of the phenomenon before conducting larger-scale studies. Effective disability-specific bullying-prevention programs cannot be developed until it is clear how and why individuals with specific forms of ID experience bullying. Research must move beyond a focus solely on the prevalence of bullying, comparing individuals with disabilities to those without disabilities. Rather, to develop appropriate prevention programs, research must examine how individuals with specific types of disabilities experience bullying (Fisher, 2016; Fisher & Taylor, 2016; Rose & Espelage, 2012), and then address those risk factors in bullying prevention programs. To date, only one study has examined the impact of a bullying prevention program on bullying of students with disabilities (Espelage, Rose, & Polanin, 2015), and two have been developed to decrease bullying of students with disabilities (Humphrey,

Lendrum, Barlow, Wigelsworth, & Squires, 2013; Saylor & Leach, 2009). None of these programs examined how unique disability characteristics were related to the success of the program.

Results from this study highlight three important directions for the development of bullying interventions. First, despite their sociable nature, individuals with WS are not immune to bullying, and interventions should be developed to help them avoid, respond to, or cope with bullying. Second, the participants' insightful responses to bullying should be further examined. Individuals with WS reported standing up to bullies (either directly or indirectly). If a self-advocacy approach can serve as a way to decrease future occurrences of bullying, then such training should be incorporated into bullying prevention programs. Finally, additional research should examine the bullying experiences of individuals with other genetic forms of ID, including Down syndrome. If specific subgroups of individuals with ID experience and respond to bullying differently, then interventions should be tailored to address issues specific to these groups (Evans et al., 2014). Additionally, if certain subgroups of individuals with ID do not experience bullying, it will be important to determine the specific protective factors.

In conclusion, listening to the voices of people with WS has allowed for new insight into their understanding of, experiences of, and responses to bullying. Researchers should continue to listen to their voices as they strive to develop interventions that might decrease this form of victimization for individuals with WS and other disabilities.

References

Adams, R. E., Fredstrom, B. K., Duncan, A. W., Holleb, L. J., & Bishop, S. L. (2014). Using self- and parent reports to test the association between peer victimization and internalizing symptoms in verbally fluent adolescents with ASD. *Journal of Autism and Developmental Disabilities*, 44, 861–872. doi:10.1007/s10803-013-1938-0

Beail, N., & Williams, K. (2014). Using qualitative methods in research with people who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 27, 85–96. doi:10.1111/jar.2014.27.issue-2

Bear, G. G., Mantz, L. S., Glutting, J. J., & Yang, C. (2015). Differences in bullying victimization between students with and without disabilities. *School Psychology Review*, 44, 98–116. doi:10.17105/SPR44-1.98-116

Bellini, S. (2006). The development of social anxiety in adolescents with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 21, 138–145. doi:10.1177/10883576060210030201

Cappadocia, M. C., Weiss, J. A., & Pepler, D. (2012). Bullying experiences among children and youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42, 266–277. doi:10.1007/s10803-011-1241-x

Card, N. A., & Hodges, E. V. E. (2007). Victimization within mutually antipathetic peer relationships. *Social Development*, 1, 479–496. doi:10.1111/j.1467-9507.2007.00394.x

Christensen, L. L., Fraynt, R. J., Neece, C. L., & Baker, B. L. (2012). Bullying adolescents with intellectual disability. *Journal of Mental Health Research in Intellectual Disabilities*, *5*, 49–65. doi:10.1080/19315864.2011.637660

Cook, C. R., Williams, K. R., Guerra, N. G., Kim, T. E., & Sadek, S. (2010). Predictors of bullying and victimization in childhood and adolescence: A meta-analytic investigation. *School Psychology Quarterly*, *25*, 65–83. doi:10.1037/a0020149

Davies, M., Udwin, O., & Howlin, P. (1998). Adults with Williams syndrome. Preliminary study of social, emotional and behavioural difficulties. *The British Journal of Psychiatry*, *172*(3), 273–276. doi:10.1192/bjp.172.3.273

Doren, B., Bullis, M., & Benz, M. R. (1996). Predictors of victimization experiences of adolescents with disabilities in transition. *Exceptional Children*, *63*, 7–18.

Dykens, E. M. (2003). Anxiety, fears, and phobias in persons with Williams syndrome. *Developmental Neuropsychology*, *23*, 291–316. doi:10.1080/87565641.2003.9651896

Espelage, D. L., Rose, C. A., & Polanin, J. R. (2015). Social-emotional learning program to reduce bullying, fighting, and victimization among middle school students with disabilities. *Remedial and Special Education*, *36*, 299–311. doi:10.1177/0741932514564564

Evans, C. B. R., Fraser, M. W., & Colter, K. L. (2014). The effectiveness of school-based bullying prevention programs: A systematic review. *Aggression and Violent Behavior*, *19*, 532–544. doi:10.1016/j.avb.2014.07.004

Finlay, W. M., & Lyons, E. (2000). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment*, *13*, 319–335. doi:10.1037/1040-3590.13.3.319

Fisher, M. H. (2016). Heightened social vulnerability among adults with intellectual and developmental disabilities: Findings, perspectives, and needed interventions. In J. R. Lutzker, K. Guastaferro, & M. Graham (Eds.), *Maltreatment of people with intellectual and developmental disabilities*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Fisher, M. H., Moskowitz, A., & Hodapp, R. M. (2013). Differences in social vulnerability among individuals with autism spectrum disorder, Williams syndrome, and Down syndrome. *Research in Autism Spectrum Disorders*, *7*, 931–937. doi:10.1016/j.rasd.2013.04.009

Fisher, M. H., & Taylor, J. L. (2016). Let's talk about it: Peer victimization experiences as reported by adolescents with ASD. *Autism: International Journal of Research and Practice*, *20*, 402–411. doi:10.1177/1362361315585948

Frisén, A., Jonsson, A., & Persson, C. (2007). Adolescents' perception of bullying: Who is the victim? Who is the bully? What can be done to stop bullying? *Adolescence*, *42*, 749–761.

Gamliel, T., Hoover, J. H., Daughtry, D. W., & Imbra, C. M. (2003). A qualitative investigation of bullying: The perspectives of fifth, sixth and seventh graders in a USA parochial school. *School Psychology International*, *24*, 405–420. doi:10.1177/01430343030244004

Gladden, R. M., Vivolo-Kantor, A. M., Hamburger, M. E., & Lumpkin, C. D. (2014). *Bullying surveillance among youths: Uniform definitions for public health and recommended data elements, Version 1.0*. Atlanta, GA: National Center for Injury Prevention and Control Centers for Disease Control and Prevention and US Department of Education.

Hawker, D. S. J., & Boulton, M. J. (2000). Twenty year's research on peer victimization and psychosocial maladjustment: A meta-analytic review of cross sectional studies. *Journal of Child Psychology and Psychiatry*, *41*, 441–455. doi:10.1111/1469-7610.00629

Hillier, L. W., Fulton, R. S., Fulton, L. A., Graves, T. A., Pepin, K. H., Wagner-McPherson, C., . . . Minx, P. (2003). The DNA sequence of human chromosome 7. *Nature*, *424*(6945), 157–164. doi:10.1038/nature01782

Hodapp, R. M., & Dykens, E. M. (1994). Mental retardation's two cultures of behavioral research. *American Journal on Mental Retardation*, *98*, 675–687.

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*, 1277–1288. doi:10.1177/1049732305276687

Humphrey, N., Lendrum, A., Barlow, A., Wigelsworth, M., & Squires, G. (2013). Achievement for all: Improving psychosocial outcomes for students with special education needs and disabilities. *Research in Developmental Disabilities*, *34*, 1210–1225. doi:10.1016/j.ridd.2012.12.008

Jawaid, A., Riby, D. M., Owens, J., White, S. W., Tarar, T., & Schulz, P. E. (2012). "Too withdrawn" or "too friendly": Considering social vulnerability in two neurodevelopmental disorders. *Journal of Intellectual Disability Research*, *56*, 335–350. doi:10.1111/jir.2012.56.issue-4

Jones, W., Bellugi, U., Lai, Z., Chiles, M., Reilly, J., Lincoln, A., & Adolphs, R. (2000). Hypersociability in Williams syndrome. *Journal of Cognitive Neuroscience*, *12* (Supplement 1), 30–46. doi:10.1162/089892900561968

Klein-Tasman, B. P., & Mervis, C. B. (2003). Distinctive personality characteristics of 8-, 9-, and 10-year-olds with Williams syndrome. *Developmental Neuropsychology*, *23*(1–2), 269–290. doi:10.1080/87565641.2003.9651895

Kloosterman, P. H., Kelley, E. A., Craig, W. M., Parker, J. D. A., & Javier, C. (2013). Types and experiences of bullying in adolescents with an autism spectrum disorder. *Research in Autism Spectrum Disorders*, *7*, 824–832. doi:10.1016/j.rasd.2013.02.013

Little, L. (2002). Middle-class mothers' perceptions of peer and sibling victimization among children with Asperger's syndrome and nonverbal learning disorders. *Issues in Comprehensive Pediatrics Nursing*, *25*, 43–57.

Llewellyn, P. & Northway, R. (2008). The views and experiences of people with intellectual disabilities concerning advocacy: A focus group study. *Journal of Intellectual Disabilities*, *12*, 213–228.

Lough, E., & Fisher, M. H. (2016). Parent and self-report ratings on the perceived levels of social vulnerability of adults with Williams syndrome. *Journal of Autism and Developmental Disorders*, *46*, 3424–3433. doi:10.1007/s10803-016-2885-3

Maïano, C., Aimé, A., Salvas, M.-C., Morin, A. J. S., & Normand, C. L. (2016). Prevalence and correlates of bullying perpetration and victimization among school-aged youth with intellectual disabilities: A systematic review. *Research in Developmental Disabilities*, *49-50*, 181–195. doi:10.1016/j.ridd.2015.11.015

Mervis, C. B., Morris, C. A., Klein-Tasman, B. P., Bertrand, J., Kwitny, S., Appelbaum, L. G., & Rice, C. E. (2003). Attentional characteristics of infants and toddlers with Williams syndrome during triadic interactions. *Developmental Neuropsychology*, *23*(1–2), 243–268. doi:10.1080/87565641.2003.9651894

Mervis, C. B., Robinson, B. F., Bertrand, J., Morris, C. A., Klein-Tasman, B. P., & Armstrong, S. C. (2000). The Williams syndrome cognitive profile. *Brain and Cognition*, *44*, 604–628. doi:10.1006/brcg.2000.1232

Nabuzoka, D. (2003). Teacher ratings and peer nominations of bullying and other behaviour of children with and without learning difficulties. *Educational Psychology*, *23*, 307–321. doi:10.1080/0144341032000060147

Nowell, K. P., Brewton, C. M., & Goin-Kochel, R. P. (2014). A multi-rater study on being teased among children/adolescents with autism spectrum disorder (ASD) and their typically developing siblings. *Focus on Autism and Other Developmental Disabilities*, *29*, 195–205. doi:10.1177/1088357614522292

Reiter, S., & Lapidot-Lefler, N. (2007). Bullying among special education students with intellectual disabilities: Differences in social adjustment and social skills. *Intellectual and Developmental Disabilities*, *45*, 174–181. doi:10.1352/1934-9556(2007)45[174:BASESW]2.0.CO;2

Riby, D. M., Hanley, M., Kirk, H., Clark, F., Little, K., Fleck, R., . . . Allday, M. (2014). The interplay between anxiety and social functioning in Williams syndrome. *Journal on Autism and Developmental Disorders*, *44*, 1220–1229. doi:10.1007/s10803-013-1984-7

Rose, C. A., & Espelage, D. L. (2012). Risk and protective factors associated with the bullying involvement of students with emotional and behavioral disorders. *Behavioral Disorders*, *37*, 133–148.

Rose, C. A., Monda-Amaya, L. E., & Espelage, D. L. (2011). Bullying perpetration and victimization in special education: A review of the literature. *Remedial and Special Education Research*, *32*, 114–130. doi:10.1177/0741932510361247

Rosner, B. A., Hodapp, R. M., Fidler, D. J., Sagun, J. N., & Dykens, E. M. (2004). Social competence in persons with Prader-Willi, Wiliams, and Down's syndromes. *Journal of Applied Research in Intellectual Disabilities*, *17*, 209–217. doi:10.1111/j.1468-3148.2004.00200.x

Rowley, E., Chandler, S., Baird, G., Simonoff, E., Pickles, A., Loucas, T., & Charman, T. (2012). The experience of friendship, victimization, and bullying in children with an autism spectrum disorder: Associations with child characteristics and school placement. *Research in Autism Spectrum Disorders*, *6*, 1126–1134. doi:10.1016/j.rasd.2012.03.004

Saylor, C. F., & Leach, J. B. (2009). Perceived bullying and social support in students accessing special inclusion programming. *Journal of Developmental and Physical Disabilities*, *21*, 69–80. doi:10.1007/s10882-008-9126-4

Schroeder, J. H., Cappadocia, M. C., Bebko, J. M., Pepler, D. J., & Weiss, J. A. (2014). Shedding light on a pervasive problem: A review of research on bullying experiences among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *44*, 1520–1534. doi:10.1007/s10803-013-2011-8

Searcy, Y. M., Lincoln, A. J., Rose, F. E., Klima, E. S., Bavar, N., & Korenberg, J. R. (2004). The relationship between age and IQ in adults with Williams syndrome. *American Journal on Mental Retardation*, *109*, 231–236. doi:10.1352/0895-8017(2004)109<231:TRBAAI>2.0.CO;2

Sheard, C., Clegg, J., Standen, P., & Cromby, J. (2001). Bullying and people with severe intellectual disability. *Journal of Intellectual Disability Research*, *45*, 407–415. doi:10.1046/j.1365-2788.2001.00349.x

Sterzing, P. R., Shattuck, P. T., Narendorf, S. C., Wagner, M., & Cooper, B. P. (2012). Bullying involvement and autism spectrum disorders: Prevalence and correlates of bullying involvement among adolescents with an autism spectrum disorder. *Archives of Pediatric and Adolescent Medicine*, *166*(11), 1058–1064. doi:10.1001/archpediatrics.2012.790

Swearer, S. M., Espelage, D. L., Vaillancourt, T., & Hymel, S. (2010). What can be done about school bullying? Linking research to educational practice. *Educational Researcher*, *39*, 38–47. doi:10.3102/0013189X09357622

Thurman, A. J. & Fisher, M. H. (2015). The Williams syndrome social phenotype: Disentangling the contributions of social interest and social difficulties. *International Review of Research in Developmental Disabilities*, *49*, 191–227.

Zeedyk, S. M., Rodriguez, G., Tipton, L. A., Baker, B. L., & Blacher, J. (2014). Bullying of youth with autism spectrum disorder, intellectual disability, or typical development: Victim and parent perspectives. *Research in Autism Spectrum Disorders*, *8*, 1173–1183. doi:10.1016/j.rasd.2014.06.001

Appendix

Williams Syndrome Friendships and Bullying Interview

1. First, why don't you tell me a little bit about yourself?
   (a) What's your name?
   (b) How old are you?
   (c) What do you like to do in your free time?
   (d) Do you go to school or work?
       (i) [If work] where do you work?
       (ii) [If school] what grade are you in? What's your favorite subject?
2. Tell me about your friendships at your [school or job].
   (a) Do you have many friends?
   (b) What do you like to do with your friends?
   (c) How did you get to be friends with them?
   (d) How often do you see them?
   (e) How often do you talk to them?
       (i) Do you talk to them on the phone?
       (ii) Do you email with them?
       (iii) Are you friends with them on Facebook?
   (f) What makes them your friends?
3. Can you tell me, what does it mean to be bullied?
4. What does it mean to be picked on or teased?
5. Can you describe a person who bullies?
6. Can you describe a person who might get bullied or picked on?
7. Have you ever been picked on or has anyone ever teased you at [school or work]?
   (a) Has anyone ever teased you about the way you look?
   (b) Some kids get teased for the way they talk. Has that ever happened to you?
   (c) The way you walk?
   (d) What about the way you act? Has anyone ever teased you for things that you do?
   (e) [If information not already provided] Tell me more about one of these times. What
       happened the last time this happened to you?
           (i) Who was there?
               1. Were there other kids or adults around?
           (ii) Where did it happen?
           (iii) What did they say?
           (iv) How did you feel at the time?
           (v) How many times would say something like this happens to you?
   (f) I would like to know how you act when you feel you are being teased or picked on.
       (i) What did you do about it?
       (ii) Did your actions stop the person from teasing you?
       (iii) Did anyone else try to stop the person from teasing you?
       (iv) How did you feel afterward?
8. Has anybody left you out of a group to make you feel bad at [work or school]?
   (a) Tell me more about one of these times. What happened the last time this happened
       to you?
           (i) Who was there?
               1. Were there other kids or adults around?
           (ii) Where did it happen?
           (iii) What did they say?

(iv) How did you feel at the time?

(v) How many times would say something like this happens to you?

(b) I would like to know how you act when you feel you are being left out of a group.

(i) What did you do about it?

(ii) Did your actions stop the person from leaving you out?

(iii) Did anyone else try to stop the person from leaving you out?

(iv) How did you feel afterward?

9. Has anyone close to your age ever hit you, beat you up, or threatened to beat you up?

(a) [If yes] Tell me more about one of these times. What happened the last time this happened to you?

(i) Who was there?

1. Were there other kids or adults around?

(ii) Where did it happen?

(iii) What did they say?

(iv) How did you feel at the time?

(v) How many times would say something like this happens to you?

(b) I would like to know how you act when someone hits you.

(i) What did you do about it?

(ii) Did your actions stop the person?

(iii) Did anyone else try to stop the person?

(iv) How did you feel afterward?

10. Has anyone ever said mean things to you or mean things about you? Has anyone ever made fun of you or called you names?

(a) [If yes] Tell me more about one of these times. What happened the last time this happened to you?

(i) Who was there?

1. Were there other kids or adults around?

(ii) Where did it happen?

(iii) What did they say?

(iv) How did you feel at the time?

(v) How many times would say something like this happens to you?

(b) I would like to know how you act when you feel people are being mean to you or making fun of you.

(i) What did you do about it?

(ii) Did your actions stop the person from being mean or making fun of you?

(iii) Did anyone else try to stop the person from being mean or making fun of you?

(iv) How did you feel afterward?

11. Now I want to know how we can stop people from doing these things to you and to other people like you.

(a) What do you think you would do if any of these things happened to you again?

(b) What have you done or what do you think you could do to stop these things from happening again?

(c) Do your friends help stop these things from happening?

(d) Do your friends protect you from being bullied?

(e) Do you feel like you can talk to your friends about the people who do this to you?

12. If you had a friend who was being bullied, what would you tell them to do? Why?