

In Their Own Words: Perceptions and Experiences of Bullying among Individuals with
Intellectual and Developmental Disabilities

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Abstract

Despite the high incidence of bullying among individuals with intellectual and developmental disabilities (IDD), little research has been conducted with people with IDD as participants reporting their own perceptions and experiences of bullying. To address this shortcoming, we interviewed 18 adults with IDD regarding these issues. Four major themes emerged from our qualitative analysis of the transcribed interviews: (a) bullying is hurtful, (b) why people bully, (c) bullying takes many forms, and (d) bullying can happen anywhere. Though participants' definitions of bullying and explanations for why people bully aligned well with traditional understandings, several reported incidents of bullying were discrepant from the traditional definition, including incidents of abuse and rude behavior. Implications for future research and practice are discussed.

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Bullying has been defined as undesired aggressive behavior perpetrated by a peer involving a real or perceived imbalance of power, and is likely to be repeated over time (Gladden, Vivolo-Kantor, Hamburger, & Lumpkin, 2014). According to Gladden et al., the four subtypes are verbal bullying, physical bullying, relational bullying, and damage to property. Verbal bullying includes aggressive communications, such as teasing, name-calling, and threats. Physical bullying refers to acts of physical aggression (e.g., hitting, kicking). Relational bullying encompasses acts meant to isolate the victim (e.g., excluding the victim from a group, harming the victim's reputation). Finally, damage to property includes actions designed to harm the victim, such as taking an item and refusing to give it back, or destroying the victim's property.

Individuals with disabilities experience higher rates of bullying than typically developing individuals (Rose, Monda-Amaya, & Espelage, 2011). Further, among individuals with disabilities, those with intellectual disability are at greatest risk of being victimized by bullies (Sterzing, Shattuck, Narendorf, Wagner & Cooper, 2012). This increased risk is likely a result of impairments in adaptive behavior that might include gullibility, unawareness of risk, or poor judgment (Edwards & Greenspan, 2010), as well as other impairments in functioning or differences in physical appearance (Fisher, Moskowitz, & Hodapp, 2012). This increased risk of victimization also puts individuals with IDD at greater risk of experiencing common negative effects of bullying, such as anxiety, depression, and low self-esteem that are so prevalent among typically developing victims of bullying (Cook, Williams, Guerra, Kim, & Sadek, 2010; Swearer, Espelage, Vaillancourt, & Hymel, 2010), and those with disabilities who have been victimized by bullies (Cappadocia, Weiss, & Pepler, 2012).

Despite the high incidence of bullying among individuals with IDD, little research has been conducted with people with IDD as participants reporting their own perceptions and experiences of bullying. Documenting the firsthand accounts and perspectives of bullying victims not only privileges their perspectives as valued, but also can inform the development of more effective interventions to address this pervasive problem (Mishna, 2004). Qualitative research methods are particularly suited to eliciting the perspectives of individuals with IDD on their bullying experiences for several reasons. First, such an approach complements the largely quantitative research that has been conducted in the bullying literature (Mishna, 2004). Second, interviews allow for a richer understanding of the subjective experiences of individuals (Finlay & Lyons, 2000), particularly in relation to complex social and psychological experiences associated with bullying. Finally, interviews are suited to exploratory research questions for which well-validated quantitative measures have not yet been developed.

Though a few studies on bullying have included interviews with participants with IDD (e.g., Christensen et al., 2012; Zeedyk, Rodriguez, Tipton, Baker, & Blacher, 2014), to our knowledge only one other study has used qualitative methods to investigate the perspectives of individuals with IDD about this impactful issue. Fisher, Lough, Griffin, and Lane (2017) interviewed individuals with Williams syndrome about their experiences of bullying, revealing multiple themes. Participants described bullying and bullies, and reported experiencing multiple types of bullying. Interestingly, participants responded to bullying with various forms of self-advocacy, rather than with self-blame or desire for revenge, as has been described by individuals with autism spectrum disorder (Fisher & Taylor, 2016). Building on this work, the current study sought to answer the following research questions: What are the perceptions of bullying among individuals with IDD, and what do they report about their own experiences of bullying?

Method

Participants

We utilized purposeful sampling in order to study the perspectives of individuals who could serve as “information-rich cases” that “yield data on major study questions” (Patton, 1999, p. 1197). Specifically, participants were recruited through a non-profit that provides services for individuals with IDD (e.g., employment services; services for those living independently, with their families, with support, and in Intermediate Care Facilities). Settings in which participants received services were on a spectrum of segregated to fully inclusive. All participants received services through the non-profit, and had a variety of conditions (e.g., autism spectrum disorder, cerebral palsy, Down syndrome, intellectual disability). Participants included 18 adults (50% female) aged 18-63 ($M = 43$ years), with four participants not disclosing their ages.

Procedures

Upon receiving Institutional Review Board approval, research team members explained the study to clients with IDD and staff at the non-profit, and answered their questions. Then, a researcher met individually with interested individuals with IDD in a private setting to further explain participation in the study and ensure that prospective participants met the inclusion criteria. Inclusion criteria were that participants must (a) be 18 years or older, (b) have IDD, and (c) have receptive and expressive language skills in English sufficient to provide informed consent and respond to interview questions; all interested individuals met the inclusion criteria.

The informed consent process involved a researcher reviewing the study procedures with prospective participants, and asking them to answer questions to verify that they understood their rights as research participants that had been described (e.g., Do you have to answer the [interview] questions?). All participants demonstrated their understanding through their answers,

and provided informed consent or assent. For those with a legal guardian (n=8), the researchers contacted the guardian to explain the study; all guardians provided their informed consent.

Data collection. A researcher interviewed participants individually in a private setting using a semi-structured interview protocol based on questions developed by Gamliel, Hoover, Daughtry, and Imbra (2003). The researchers revised these questions and added further questions based on their experience with individuals with IDD, the bullying literature, and recommendations for interviewing individuals with IDD. For example, a point of revision from Gamliel et al.'s protocol was that the research team decided not to provide a definition of bullying during the interview, and instead added questions about participants' understanding of bullying (e.g., What does it mean to be bullied?), as that addressed a critical aspect of our research question. The researchers also adapted interview questions to be understandable and to avoid methodological challenges of interviewing participants with IDD that have been documented in the literature (e.g., acquiescence bias, social desirability bias; Finlay & Lyons, 2000; Perry, 2004). The protocol was used in a related study; for protocol, see Fisher et al., 2017.

The protocol began with rapport-building questions about school or work experiences, preferences for free time, and friendships. Next, participants were asked open-ended questions about what bullying is, in order to ascertain their understanding of bullying prior to asking questions about specific types of bullying or their own past or present experiences with bullying. The protocol then included a series of questions about different types of bullying. Initial questions were general (e.g., Has anyone ever teased you at [school or work]?), followed by specific probes (e.g., Has anyone ever teased you about the way you look?).

As a semi-structured protocol, the number of questions posed was not standard, but depended upon a participant's responses. For example, if a participant answered negatively to a

certain question, then follow-up questions were not asked; conversely, if a participant answered affirmatively or provided information that warranted follow-up, then more questions were asked. However, the protocol included 12 overarching questions posed to all participants. Interviews were recorded, transcribed, and uploaded to a qualitative data analysis program. On average, interviews were 29 minutes in duration.

Data analysis. The research team used an inductive approach to data analysis (Thomas, 2006). The first author read all transcripts and created an initial coding framework. The first author then met with the team to receive feedback and refine the framework. The team used the initial coding framework to iteratively code transcripts and met regularly to review these. Specifically, team members individually coded one or two transcripts within the qualitative analysis software, and reviewed the transcripts coded by other team members. In addition to applying codes to the transcripts, team members noted their questions regarding specific excerpts and the appropriate codes to use. The team met regularly to review coded transcripts and discuss questions about how to code an excerpt; discussion generated revisions to the coding (e.g., combining codes, adding new codes, and deleting or refining existing codes).

After the transcripts were coded, the first author reviewed all coded transcripts again, and identified broad themes representing codes that described a group of similar ideas (LeCompte & Schensul, 1999). The first author presented these to the research team members and a peer debriefer, who provided feedback and agreed that thematic saturation had been achieved. Further analysis was conducted after receiving feedback on a prior draft manuscript, with research team members revisiting the themes and ultimately coming to consensus. This triangulation among research team members strengthens the quality and credibility of the findings (Patton, 1999), and helps to ensure that saturation has been adequately achieved (Fusch & Ness, 2015).

Results

Four themes emerged from our analysis: (a) bullying is hurtful, (b) why people bully, (c) bullying takes many forms, and (d) bullying can happen anywhere. Two themes were divided into subthemes; for themes, subthemes, and representative quotations, see Table 1.

Bullying is Hurtful

In discussing what bullying is, participants offered both general definitions and specific examples of incidents that they considered to be bullying, all of which fell under the umbrella theme *bullying is hurtful*. Most participants' answers about the definition of bullying described actions that a bully might take that would hurt the victim, either physically or emotionally. One participant explained his understanding, thus: "[A bully] would be someone that's not being kind to the person or not thinking of their feelings. It means they don't care" (male, age 63). When defining bullying, many respondents gave general examples of bullying, with most falling into the categories of verbal bullying (e.g., name-calling, teasing), or physical bullying (e.g., pushing, throwing spitballs). For example, one participant said, "[Bullies] can pick on people, trip people" (male, age 18). In addition, a few participants described examples of relational bullying (e.g., being left out of a group) in their responses.

Why People Bully

In discussing what bullying is and their own experiences of bullying, some participants provided explanations about *why* people engage in bullying. Within this theme, two subthemes emerged: (a) bullies have challenges, and (b) bullies focus on differences.

Bullies have challenges. Several participants characterized bullies as individuals who struggled with challenges in their own lives that then caused them to engage in bullying behavior. For example, a few participants explained that they thought bullying was a result of the

bully's own insecurities; in that line of thinking, one respondent stated, "[A bully] doesn't feel comfortable about themselves. And maybe out to get insecure feelings...if they don't care about themselves or their bodies...so they, like, hurt somebody else" (female, age 28). Another speculated that bullying stems from loneliness or social isolation, suggesting, "Maybe because they don't have any friends, and that's why they bully people" (female, age 33).

Bullies focus on differences. Some participants also commented on the characteristics of victims and that their differences relate to why bullies choose them as victims. One participant focused on physical characteristics that would make an individual more vulnerable to bullying, such as being younger and physically smaller than the bully. A few participants also noted that differences with regard to physical appearance or behavior might make a person more likely to be victimized by a bully. One participant commented, "Anybody who has a different disability, or ability, or has autism, or other, other things...They get picked on because they have a disability, and it's not their fault; they were born that way" (female, age 33). Others also noted that differences related to disability status could make someone more vulnerable to bullying; one participant suggested, "The kind of person that has an obvious disability as opposed to an invisible disability [is more likely to be bullied]" (female, age 28).

Bullying Takes Many Forms

In response to questions about their own bullying experiences, participants provided examples of bullying taking many forms. Many examples fit Gladden et al.'s (2014) definition of bullying, including (1) verbal bullying, (2) physical bullying, and (3) relational bullying. Participants also described examples of other aversive experiences that do not align with the standard definition of bullying. Although the examples within these categories do not fit the

traditional definition, participants considered them to be bullying; we categorized them as (4) abuse, (5) rude behavior, and (6) other.

Verbal bullying. By far the most common experience among participants was verbal bullying, with 15 of the 18 participants reporting this type. Participants recounted memories of being yelled at, being threatened, and being called names (e.g., “bitch,” “ugly”). One participant described being bullied because of his race/ethnicity, saying, “You know, they talk about my color, you know, race. They called me Mexican and so stupid, ah . . . they called me a bunch of names. I can’t remember” (male, undisclosed age). Participants also reported being made fun of or teased because of physical characteristics related to their disabilities (e.g., scars, using a wheelchair); for example, one participant reported, “They called me a granny for how I walked-- I did not like that” (female, age 35). Several participants also described others teasing them for limitations in different activities (e.g., stuttering, challenges with reading).

Physical bullying. The next most common type of bullying, reported by half of participants (n=9), was physical bullying (e.g., hitting, kicking, tripping, throwing spitballs). The research team also included attempts to engage in such activities within this subtheme. For example, one participant described an encounter, thus: “He gets mad at me. He throws a fist at me” (male, age 59). Another described an attempt at physical aggression, recounting, “When I was walking home he would just corner me in a corner and...try to beat me up” (female, age 31); this participant reported that she later stood up to the bully and he broke her arm.

Relational bullying. Fewer (n=5) participants reported being left out of a group or excluded from an activity. One participant recounted being excluded from playing a game, and another reported being excluded from a social group. She remembered, “Umm, I was in the classroom, and they were around the table, and they’re like...I wanted to sit there, and [they

said] like, ‘You, over there’ [indicating go away]” (female, age 41). Two participants answered in a way that does not fit well into the definition of relational bullying developed by Gladden et al. (2014). One participant reported being socially isolated because he was a bully himself. Another reported wanting to join a Special Olympics team and not being allowed to, though it was unclear why this was the case. Nevertheless, we coded them under the theme of relational bullying because they were in response to questions about being left out of a group or activity.

Abuse. Four participants responded to interview questions with accounts of experiencing different forms of abuse in the past (e.g., emotional, physical, sexual). Two participants recounted incidents perpetrated by family members (e.g., parents, step-parents and siblings, foster parents and siblings). For example, one participant recounted a memory of his stepmother, saying, “It...it just didn’t feel right. I mean she’d...grab our hair, push us into walls, break doors down” (male, age 18). As a follow-up, the interviewer asked whether the participant considered his stepmother to be a bully, and he responded affirmatively. In addition, two female participants described being physically or sexually assaulted by their ex-boyfriends in the past.

Rude behavior. Four participants recounted incidents in which they experienced rude behavior, with the majority relating to housemates in their group homes. This subtheme included a wide range of behaviors relating to the use of shared space and items (e.g., disagreements related to the bathroom, television). One participant described a particular concern, thus: “[My housemate] goes in the restroom and leaves the door open...but he can’t do that. I like to have... I like that door shut” (male, age 59). The interviewer followed up with questions, clarifying whether the participant perceived his housemate’s behavior as a form of bullying, which he did. Within this subtheme, we also included participants’ descriptions of other behaviors they found to be generally objectionable (e.g., others being bossy) or annoying (e.g., others eating loudly).

Other. The vast majority of incidents described by participants fell into one of the five categories described above. However, two participants reported experiencing other forms of victimization: damage to property and sexual harassment. One reported that his property was being stolen, and another recounted that she had been sexually harassed. A final participant described an experience she had in which a staff member dismissed her reports of being bullied by a peer; this participant characterized the staff member's behavior as bullying.

Bullying Can Happen Anywhere

In recounting experiences of bullying, participants would sometimes provide information about the context and setting of the event; the overarching theme emerging from these data is that *bullying can happen anywhere*. Although it was not always clear from participants' descriptions, we did note whether participants described being alone during a bullying incident, or whether others were present. This information was available for 20 incidents described by participants. In the majority of cases (60%, n=12), participants reported being alone during the bullying incident. Although not always the case, the more severe instances of abuse or physical bullying more often occurred when individuals were alone.

We coded the setting of bullying incidents into six categories; the most commonly reported setting was school (72%, n=13), which included all levels of school and aftercare programs. The next most common setting where bullying occurred was group homes (39%, n=7). In similar numbers (33%, n=6), participants reported bullying at the non-profit at which the interviews were conducted, and at supported employment settings where they received services through the non-profit. Several incidents occurred in participants' family homes (22%, n=4). Finally, two participants reported (11%) bullying occurred in settings that provided supports for individuals with IDD (e.g., Special Olympics), and two reported bullying in community settings.

Discussion

Individuals with IDD (compared to those without disabilities and to other types of disabilities) are at the greatest risk of being bullied; yet, limited research is available describing their bullying experiences. The current study used qualitative research methods to document the accounts and perspectives of individuals with IDD as they described bullying in their own words. Four major themes emerged from the interviews, providing both alignment and departure from earlier research on bullying of individuals with IDD.

Individuals with IDD described bullying as hurtful and they were able to provide several examples of bullying they had experienced. Through their descriptions, it became apparent that most of the participants' experiences of bullying were consistent with the definition of bullying developed by Gladden et al. (2014), and with prior research on bullying of individuals with IDD (e.g., Mañano et al., 2016). Specifically, similar to previous research, the majority of participants reported high rates of verbal bullying (Cappadocia et al., 2012; Fisher et al., 2017). Also, consistent with Gladden et al.'s definition, participants described experiences of both physical and relational bullying (Reiter & Lapidot-Lefler, 2007; Zeedyk et al., 2014).

However, relational bullying was the least reported by participants. This finding contrasts with reports of other studies of individuals with IDD. For example, Fisher and colleagues (2017) interviewed individuals with Williams syndrome and found that 60% of participants reported being left out of a group. Given the characteristic hypersociability of individuals with Williams syndrome, the increased incidence and salience of relational bullying in this group is not surprising. Further, within the current study, several examples of relational bullying provided by participants departed from the traditional definition. For example, one participant described being excluded from Special Olympics; though departing from traditional conceptualizations of

relational bullying, the participant reported this as a bullying incident. Such examples highlight the importance of directly interviewing individuals with IDD about their experiences of bullying.

Another notable finding is related to participants who recounted examples that did not fit Gladden's et al.'s (2014) definition of bullying in other ways. For example, some participants described instances of abuse and others recounted memories of people being rude or inconsiderate to them (e.g., poor manners, bossy behavior). While we did not consider these to be examples of bullying per se--because they were not instances of peer victimization--we found it surprising that participants recounted these events in the context of an interview about bullying and we felt they were important to address. While the research literature adheres to a strict definition of bullying, these examples indicate that some individuals with IDD have a broader conceptualization of bullying, again highlighting the value of open-ended interviews among individuals with IDD in characterizing their perceptions and experiences of bullying.

Participants described their experiences of bullying as happening in a variety of different contexts, indicating that victimization can happen anywhere. Consistent with the literature, participants' memories of bullying largely were in school settings (e.g., Christensen et al., 2012; Ross, Horner, & Higbee, 2009). Given the older age of many participants, this finding highlights the salience of these bullying experiences at school, even years later. Extending beyond the current research, our participants also reported experiencing bullying in their group homes and the non-profit at which the interviews were conducted. These findings indicate that, just as bullying is more likely to occur in segregated school settings (Rose et al., 2011), such experiences might continue into segregated settings outside of school as well.

Implications for Research and Practice

Though bullying prevention has become a buzzword in recent years, this study

documents that bullying continues to be a pervasive problem impacting individuals with IDD. Some efforts to address bullying among individuals with IDD have been developed, including a national campaign to end the use of the word *retarded* (Spread the Word to End the Word, n.d.). Also, as an effort to teach individuals with IDD to respond to verbal bullying, Stannis (2015) used behavior skills training to teach participants a four-part response to bullies. These efforts are laudable, and should be extended to prevention of physical and relational bullying, as well. However, we note that for this approach to be effective, staff and parents must be responsive to an individual's reports of bullying. Bullying interventions need to be designed holistically, such that those supporting individuals with IDD receive training in how to identify, prevent, and address bullying and other forms of victimization.

With regard to the context of bullying, most reported incidents occurred in schools. This is not unique to individuals with IDD, and points to the need for continued attention to bullying prevention in educational settings. Many anti-bullying efforts in schools have been developed and implemented. However, we are unaware of how such efforts involve students with IDD, a population often segregated and left out of school-wide curricula and initiatives. For those schools that actively involve students with IDD in bullying prevention initiatives, attention must be given to ensuring that these initiatives and curricula are appropriately tailored to meet the learning needs of this population. In addition to the school setting, this study revealed that bullying continues to be a problem among adults in group homes and other settings. The vast majority of bullying research has been conducted with children, and these findings indicate a need for attention to older populations, as well. Future research should also explore whether individuals with IDD who live and work in segregated settings experience higher rates of bullying than those in inclusive community settings.

Our findings also point to critical areas of need that extend beyond the subject of bullying, and more broadly apply to the support needs of individuals with IDD to experience satisfying lives. Beyond learning how to respond to bullying, individuals with IDD need to receive training in how to recognize, avoid, and report abuse. Informed by this study's findings, many individuals with IDD would also benefit from learning problem-solving and self-advocacy skills such that they are better equipped to navigate interpersonal challenges with housemates, staff members, and others in their lives. Though various national organizations (e.g., Best Buddies, Special Olympics) and researchers in the field of special education have developed programs and interventions on teaching self-advocacy, these often focus on specific skills, such as public speaking around disability awareness or on self-advocacy within specific contexts, such as individualized education program (IEP) meetings. The current study points to a need for training in self-advocacy skills to resolve interpersonal conflicts.

Finally, the research team noted that participants were eager to share their experiences during the interviews, and seemed to not have many opportunities to do this otherwise. Future research should continue to empower individuals with IDD to share their stories to further develop the firsthand accounts of issues impacting their quality of life. In parallel, practitioners should consider how to better elicit information about the satisfaction (or dissatisfaction) of individuals with IDD receiving services in schools or via the adult service system.

Limitations

In considering these findings, several limitations must be addressed. Like many other interview studies, participant reports were not corroborated by others, or by conducting observations. Second, participants were informed of the study's focus in advance; though this was necessary to secure informed consent, those who had experienced bullying may have been

more likely to participate than those who had not. However, concerns related to selection bias are minimized given that our findings were consistent with prior research documenting high levels of bullying among individuals with IDD (e.g., Sterzing et al., 2012). Third, though we had planned to conduct member checks to gather feedback from participants on the themes we identified from their interviews, unanticipated challenges precluded us from doing so.

Finally, we did not collect or report demographic data beyond age and gender. The sensitive nature of participants' experiences of victimization, which included accounts of abuse and assault, necessitates careful protection of identifying information. This is of particular concern because of the low-incidence populations involved. In the region where the research was conducted, several race/ethnicity categories compose 2% or less of the population. Further, participants with IDD in this study include individuals with low-incidence disabilities. Documenting these demographic data in conjunction with age and gender would provide identifiable information about participants in some cases, and therefore would violate assurances of confidentiality provided to participants. Nevertheless, this lack of demographic information remains a limitation. Relatedly, we acknowledge several participants did not disclose their ages; though not ideal, we respect their right not to answer any of the questions we had posed.

Despite these limitations, the current study offers unique insight into the perceptions and experiences of bullying among people with IDD. Documenting their experiences of bullying and other forms of victimization is a first step in expanding and refining interventions for them, as well as their parents, staff, and peers. By providing individuals with IDD an opportunity to share their challenges and perspectives in their own words, this study has empowered them to inform future research and practice efforts that will hopefully improve the quality of their lives.

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Table 1. *Interview Themes, Subthemes and Representative Quotations*

Theme	Subtheme	Representative Quotation
Bullying is hurtful	--	“[Bullying is] telling [people] to feel bad about themselves, and they start crying.” (female, age 33)
Why people bully	Bullies have challenges	“[Bullies think] like, ‘Oh, like, I hate myself. Okay, I go, like, bully the other person.’” (female, age 41)
	Bullies focus on differences	“Some of my pals get picked on ‘cause they’re different, or different backgrounds that get bullied, or religion. Now, they’re transgender, so it’s even worse now.” (male, age 44)
Bullying takes many forms	Verbal bullying	“He used to tease me and stuff, and say mean words to me. I don’t want to say.” (female, age 31)
	Physical bullying	“Those kids are like bullying me and throw stuff at me.” (female, age 41)
	Relational bullying	“Most people don’t [exclude me]. There’s some, but not many. Because I choose not to be a part.” (male, age 63)
	Abuse	“[My foster-brother] not around anymore. And he knocked out my tooth once.” (female, age 49)
	Rude behavior	“I help her bring groceries in, not say thank you. I told the staff. Next time, not help her...” (female, undisclosed age)
	Other	“She just told me I tattled... That was not even right of her to say that. I was just advocating for myself.” (female, age 33)
Bullying can happen anywhere	--	“I stutter sometimes...and, he’s all making fun of me, in front of the whole class.” (male, undisclosed age)