



Bullying and Individuals with Disabilities: Needs Assessment and Strategic Planning

Alberti Center for Bullying Abuse Prevention

Graduate School of Education | University at Buffalo
alberticenter@buffalo.edu | (716) 645-1532 | gse.buffalo.edu/alberticenter



Prepared for:

NYS Developmental Disabilities Planning Council

Andrew M. Cuomo, Governor

Sheila M. Carey, Executive Director • Rose Marie Toscano, Chairperson

**BULLYING AND INDIVIDUALS WITH DISABILITIES:
NEEDS ASSESSMENT AND STRATEGIC PLANNING**

Amanda B. Nickerson, Ph.D.

Kathleen P. Allen, Ph.D.

Jilynn M. Werth, M.A.

With significant contributions from: Erin Cook, Michele Crandall, Danielle Guttman,
Tiara Handy, Brie Kishel, Joseph Prior, and Samantha Vanhout

University at Buffalo Graduate School of Education
Alberti Center for Bullying Abuse Prevention

November 2014

ACKNOWLEDGEMENTS

The following individuals and organizations deserve special thanks for their support and contributions to this project:

Jessica Aubin, Nicole Bak, Jacqueline Hayes, Robin Hickey, Ashley Pacelli, New York State Developmental Disabilities Planning Council (NYS DDPC)

Frank Cammarata, Executive Director, Erie County Office for the Disabled

Disability Education and Advocacy Network of WNY (DEAN)

Beth Hensel, Rehabilitation Center, Olean, NY

Tina Moreno, Life's WORC Bullying Committee, Garden City, NY

People Inc, Williamsville, NY

Michael Rembis, Ph.D., Director, University at Buffalo Center for Disability Studies

Self-Advocacy Association of New York State

Karen Thayer, Southern Adirondack Independent Living Center, Queensbury, NY

Michael Tinsmon, University at Buffalo Graduate School of Education, Buffalo, NY

Todd Vaarwerk, Independent Living Center, Buffalo, NY

Barb Wale, ARC of Monroe County, Rochester, NY

David Whalen, First Responder Disability Awareness Training, Niagara University

Evan Yankey and Lisa Severino, Metro Developmental Disabilities Regional Office, New York, NY

We also appreciate the many people who generously gave up their time to respond to the survey, attend focus groups, and participate in interviews. Their participation ensured the success of this effort.

TABLE OF CONTENTS

EXECUTIVE SUMMARY	4
INTRODUCTION	6
SUMMARY OF THE LITERATURE.....	7
NEEDS ASSESSMENT PROCESS	17
STRATEGIC PLANNING.....	39
CONCLUSIONS.....	42
REFERENCES	43
APPENDIX A.....	51
Surveys	
APPENDIX B.....	86
Focus Group and Interview Protocols	
APPENDIX C.....	101
Emergent Themes: Findings, Expressed Needs, and Ideas for Activities	
APPENDIX D.....	115
Long Range Strategic Plan: Goals and Activities	
APPENDIX E.....	168
Program Evaluation	

EXECUTIVE SUMMARY

To address the needs and priorities for the New York State Developmental Disabilities Planning Council (NYS DDPC) in relation to the issue of bullying and individuals with intellectual and developmental disabilities, the University at Buffalo's Alberti Center for Bullying Abuse Prevention undertook a broad-based needs assessment and strategic planning effort in partnership with key stakeholders. Beginning with a literature review and planning with key stakeholders, the project team identified several areas to investigate through surveys and focus groups. These included gathering detailed information about bullying victimization and perpetration experiences, effects, and coping, and asking stakeholders about their ideas for the types of activities that the NYS DDPC might initiate and fund to reduce bullying of and by individuals with developmental disabilities.

Survey responses were received from 350 individuals across New York, representing perspectives of parents of children (grades 3-12) with disabilities, adults with disabilities, youth with disabilities, and the general public (service providers, employers, and concerned citizens). Results of the surveys suggested that:

- Individuals with disabilities have experienced bullying (mostly verbal and relational) at rates comparable to or more than their peers
- Children with disabilities are susceptible to being vulnerable socially, as they often believe things that are not true
- Differences appear to be the most common reason for bullying
- The most common effects of bullying include: feeling sad and angry, having problems making friends, and sleeping issues
- It is more common for individuals with disabilities to minimize or ignore the bullying, problem-solve, or internalize as opposed to retaliate against others
- It is not effective for adults to ignore the bullying; instead, taking an active role is helpful
- Self-advocacy and support from peers, families, and staff are critical to preventing and intervening with bullying

Focus groups were held in various locations throughout the state, attended by 68 individuals. In addition, 18 individual interviews were conducted. The core idea of from these focus groups and interviews was that the problem of bullying for people with disabilities is a form of oppression, which can be changed through empowerment. Themes stemming from this core idea of empowerment were:

- **Self-empowerment** of the individual
- **Self-advocacy** as an empowered community of individuals with disabilities
- Networks of **support** that come from family, staff, advocates, educators, service professionals, and others
- **Integration, inclusion, and cultural change** as a broader set of influences such as societal attitudes, political will, and laws and regulations that can promote (or constrain) empowerment, advocacy, and support

The suggestions for the NYS DDPC's strategic planning are organized in three groups, which reflect a social-ecological framework. The community of self-advocates, including self-empowered individuals, is in the center, families and supportive others are in the next expanded context, and all of those people are embedded in a broad social context that includes community, institutions, government, and cultural values and norms.

Based on this framework, three goals were developed, along with suggestions for specific activities:

1. Increase the ability of people with developmental disabilities to prevent and respond to bullying in safe ways
 - Develop, implement, and evaluate programs to assume roles as self-advocates, learn about bullying prevention and intervention, and raise awareness of disabilities across contexts such as self-advocacy groups, workplace, parent groups, and schools
2. Increase supports for people with developmental disabilities and their families to deal with bullying
 - Create online or telephone support networks to assist with bullying of individuals with disabilities
 - Create and disseminate educational programs on bullying for families
 - Create a central location for dissemination of information on bullying and individuals with disabilities
3. Increase awareness of the problem of bullying of individuals with developmental disabilities through education, inclusion, and cultural change
 - Develop educational presentations about individuals with disabilities for community groups
 - Strengthen and support peer relationships through involvement in meaningful activities
 - Develop bullying prevention and intervention knowledge and skills in teachers and direct service professionals
 - Create a public relations or media campaign to promote awareness of the contributions of individuals with disabilities

Detailed information is provided in the full report about the supporting research and recommendations for developing, implementing, and evaluating each of the specific activities corresponding to the three major goals. The importance of evaluating these efforts cannot be emphasized enough, so that the NYS DDPC can evaluate to what extent the activities are meeting their intended goal.

INTRODUCTION

MISSION STATEMENT

The NYS DDPC in collaboration with individuals with developmental disabilities, their families, caregivers and policymakers provides capacity building by promoting policies, plans and best practices that:

- Affirm the dignity, value, respect, contribution and worth of all New Yorkers with developmental disabilities
- Support the full participation of people with disabilities in society
- Uphold equality and self-determination for all
- Promote access to research and information needed for informed decision-making
- Convene individuals with disabilities, family members, service providers and others to learn from each other to promote promising system changes

BACKGROUND

In 2013, the NYS DDPC appropriated \$50,000 for a one year project focused on systematic information gathering, compilation of existing literature, programs and resources, and the development of a long-term strategic plan on bullying prevention for individuals with disabilities. This effort was initiated following a literature search on bullying and people with disabilities by intern, Nicole Bak. Bak concluded that there is a lack of initiatives that are focused on providing individuals with disabilities with the tools necessary to deal with issues surrounding bullying. Hence there is a need for an in-depth investigation of the needs of this population in school and community settings. Additionally, Bak noted that there is a significant lack of literature on bullying and adults with disabilities. The Alberti Center for Bullying Abuse Prevention at the University of Buffalo, SUNY Graduate School of Education was awarded funding to complete a needs assessment that would inform strategic planning at the NYS DDPC on the issue of bullying and individuals with developmental disabilities. Work on this project began in December, 2013.

PROJECT ACTIVITIES AND OUTCOMES

The project work plan called for the following activities:

1. Conduct a comprehensive needs assessment on the impact of bullying for individuals with developmental disabilities across all ages and settings
2. Measure community capacity to address bullying prevention
3. Identify existing resources, supports, and promising practices for bullying prevention
4. Identify and seek input from key stakeholders on bullying of individuals with disabilities, known resources, and prevention avenues. Review resources and input from key stakeholders to clarify what is missing to help guide a strategic plan
5. Develop a strategic plan that focuses on bullying prevention for individuals with developmental disabilities across ages and setting

SUMMARY OF THE LITERATURE

While bullying of youth has been described and discussed in the mainstream media for several years, little has been reported about individuals with intellectual and developmental disabilities who may be involved in bullying. The purpose of this literature review is to consider research on bullying prevention that includes children and adults with developmental disabilities. It starts with a definition of bullying and the related concepts of harassment, child maltreatment, and abuse. A brief introduction to the prevalence of bullying is provided, followed with more details about the prevalence of bullying for individuals with disabilities. The impact and effects of bullying are also reviewed, followed by what is known about resources, supports, and prevention efforts for bullying. The summary of the literature concludes with an examination of needs.

Definition of Bullying and Related Concepts

The Centers for Disease Control and Prevention (CDC) recently developed a uniform definition of bullying to gather comparable data across contexts (Gladden, Vivolo-Kantor, Hamburger, & Lumpkin, 2014, p. 7):

*Bullying is any **unwanted aggressive behavior(s)** by another youth or group of youths who are not siblings or current dating partners that involves **an observed or perceived power imbalance and is repeated multiple times or is highly likely to be repeated**. Bullying may inflict harm or distress on the targeted youth including physical, psychological, social, or educational **harm**.*

In addition to the above definition, Gladden and colleagues described two *modes* of bullying: direct and indirect, and four *types* of bullying: physical, verbal, relational, and damage to property. Bullying can occur in many contexts, including electronically (e.g., cyberbullying). It should be noted that this definition applies to school-aged youth, 5 to 18 years of age, and it does not include aggression or bullying by siblings, or aggression or bullying that occurs within an intimate or dating relationship. Thus, this definition excludes bullying and abuse of youth by adults, and bullying and aggression among adults.

Bullying overlaps with other aggressive and harassing behaviors (Espelage, Basile, & Hamburger, 2012). Harassment, as defined by the New York State Dignity for All Students Act (New York State Education Department [NYSED], 2012) is conduct, verbal threats, intimidation, or abuse that creates a hostile environment. This behavior has or would have the effect of unreasonably and substantially interfering with a student's educational performance, opportunities or benefits, or mental, emotional or physical well-being, or fear for physical safety. This harassment includes but is not limited to actions based on a person's actual or perceived race, color, weight, national origin, ethnic group, religion, religious practice, disability, sexual orientation, gender, or sex (NYSED, 2012). Harassment differs from bullying in that it does not have to include intent to harm, be directed at a specific target, or involve repeated incidents.

Bullying is sometimes conceptualized as a form of abuse. However, child abuse is defined as a non-accidental injury to a child inflicted or allowed to be inflicted by the person responsible for the child's care (e.g., parent, clergy, coach, teacher). Abuse includes but is not limited to malnutrition, sexual molestation, deprivation of necessities, emotional maltreatment, or cruel punishment (CDC, 2009).

Adults and children with disabilities may also suffer from abuse according, defined as the maltreatment of an individual receiving services which would endanger the physical wellbeing of the person through

action or inaction (New York State Office for People with Developmental Disabilities [OPWDD], 2011). These definitions differ from bullying primarily in relation to the position of the perpetrator as someone in a custodial or service provider role.

Prevalence of Bullying

Estimates of the percentages of students involved in bullying in the general population range from 13% to 75%, a wide divergence likely due to the use of different measurement tools and various definitions of bullying (Swearer, Siebecker, Johnsen-Frerichs, & Wang, 2010). The most consistent prevalence rates from large national surveys indicate that 30% to 32% of youth report involvement in bullying as a perpetrator, a victim, or both (Dinkes et al., 2009; Nansel et al., 2001). This breaks down to approximately 10.6% as victims, 13.0% as bullies, and 6.3% as bully-victims; Nansel et al., 2001).

Prevalence of Bullying and Peer Victimization of Youth with Disabilities

The majority of research on the prevalence of bullying among individuals with disabilities has been conducted with school-aged youth (ages 5 to 18), although in this review we examine the available literature taking a life-course perspective on bullying of individuals with disabilities. A study of young children with disabilities and their experiences of peer victimization used a secondary data set of 1,270 children between the ages of 3 and 5 who were followed for three years from the Pre-Elementary Education Longitudinal Data Set (Son, Parish, & Peterson, 2012). According to parent report across the three years of the study, 19% of three and four year olds experienced one or more types of victimization, and 25% of five year olds experienced one or more types of victimization. By the time children were six years old, 30% had experienced one or more types of victimization.

Despite varying results across studies, a generally consistent finding is that school-aged students with disabilities are at increased risk for bullying than their peers without disabilities (Blake, Lund, Zhou, Kwok, & Benz, 2012; Carter & Spencer, 2006; Estell et al., 2009; Rose, Espelage, & Monda-Amaya, 2009; Rose, Monda-Amaya, & Espelage, 2011; Van Cleave & Davis, 2006; Whitney et al., 1994). A national study using data from the Special Education Elementary Longitudinal Study and the National Longitudinal Transition Study-2 found that the rate of bully victimization for students with disabilities was 24.5% in elementary school, 34.1% in middle school, and 26.6% in high school (Blake et al., 2012). Findings by Chad Rose and colleagues (Rose, Espelage, & Monda-Amaya, 2009; Rose, Monda-Amaya, & Espelage, 2011) have concluded that the rate of victimization for students with disabilities is in excess of 50% for students with disabilities, which is 5 times the rate of that reported for the general population by Nansel and colleagues (2001). Whitney, Smith, and Thompson (1994), in a study conducted in the United Kingdom, found that 61% of middle school students with special needs were bullied, compared to 46% of their peers without disabilities and that 59% of high school students with special needs were bullied compared with 16% of high school students without special needs.

Although the rates for bullying perpetration are lower than those for victimization, bullying perpetration appears to be more common among students with disabilities than those without (Carter & Spencer, 2006; Estell et al., 2009; Rose et al., 2009; Whitney et al., 1994). In the Whitney and colleagues' (1994) study, just under one-third of students with special needs engaged in bullying compared to about one-sixth of those without special needs. Reiter and Lapidot-Lefler (2007), in their study of 12-21 year-old students with mild developmental and intellectual disabilities, found that half of their sample was involved in

bullying perpetration. It should be noted that much of the bullying (which sometimes provoked students to bully back) was related to their special needs, and most of the children with disabilities who reported bullying others also indicated that they were victims of bullying (i.e., provocative victims, bully-victims; Carter & Spencer, 2006; Reiter & Lapidot-Lefler, 2007; Whitney et al., 1994; Van Cleave & Davis, 2006).

The results about prevalence rates of other aggressive and abusive behaviors consistently indicate that individuals with disabilities may be particularly susceptible to such maltreatment. In a study of special education teachers ($N=90$), 96.7% of participants reported that they observed more than one incident of school-related disability harassment that included epithets, slurs, mimicking, mockery, and staring (Holzbauer, 2008). In a study of disability harassment in secondary schools, Holzbauer and Conrad (2010) found that students with disabilities in grades 6-12 experienced cultures of marginalization, denigration, and intimidation. These researchers further identified six major types of disability harassment: pigeonholing, abandonment, manipulation, belittlement, fear, and violation. Furthermore, there is an association between bullying and maltreatment (Hong, Espelage, Grogan-Kaylor, & Allen-Meares, 2012), and children with disabilities are more than three times more likely than those without disabilities to experience maltreatment (9% of children without disabilities compared to 31% of children with disabilities experiencing maltreatment; Sullivan & Knutson, 2000).

Bullying Across Disabilities: Types and Degrees of Vulnerability

As stated by Rose, Swearer, and Espelage (2012, p. 3), “Understanding bullying among students with disabilities is more complex than making a dichotomous distinction between students with and without disabilities or placing students into arbitrary groups based on a common characteristic.” Indeed, some studies have not found differences in bullying and victimization for students with and without disabilities (Rose & Espelage, 2012), whereas others have found bullying more common for those with disabilities than those without, but have not found differences based on whether the disabilities are visible or non-visible (Carter & Spencer, 2006). Instead, Rose and Espelage (2012) suggest the risk factors associated with the disability (e.g., aggressiveness, anger, hostility, low impulse control, hyperactivity, poor social information processing, poor social skills, low self-esteem, social rejection) are what contribute to the bullying phenomenon, not merely the presence or absence of a disability.

In studies examining the prevalence of bullying by type of disability, students with ADHD and those with emotional and behavioral problems have been shown to be particularly susceptible to victimization (Blake et al., 2012; Reiter & Lapidot-Lefler, 2007; Rose & Espelage, 2012; Swearer, Wang, Maag, Siebecker, & Frerichs, 2012; Turner, Vanderminden, Finkelhor, Hamby, & Shattuck, 2011). When Turner and colleagues (2011) controlled for confounding variables such as demographic characteristics, parent disorders, and other youth disabilities, the only children who were at high risk of peer assault and bullying were youth with ADD/ADHD, who were found to be 40% more likely to be exposed to peer assault or bullying in the past year than their peers without disabilities.

Blake and colleagues found that students with ADHD, ASD (autism spectrum disorder), and emotional disturbances are at greater risk for victimization than students with other disabilities, perhaps because their behaviors are perceived as annoying, disruptive, provocative, and aggressive by their peers. Swearer, Wang, Maag, Siebecker, and Frerichs (2012) also found that students with behavioral disorders were the most likely of all students (with and without disabilities) to both bully others and be bullied. Bullying

others was also associated with being hyperactive and displaying behavior problems for adolescents with mild developmental and intellectual disabilities (Reiter & Lapidot-Lefler 2007). In contrast to these findings about behavioral disorders, Turner and colleagues (2011) found that youth with physical disabilities or developmental, or learning disorders did not experience any more peer assault or bullying than their peers without disabilities. However, Blake and colleagues (2012) found that students with orthopedic impairments in high school were particularly susceptible to bullying victimization.

Research is conflicted about whether prevalence rates of bullying and victimization are higher based on placement in special education settings, with some research finding higher rates of bullying victimization in more restrictive special education placements (Norwich & Kelly, 2004; Rose et al., 2009), and other studies indicating that inclusive placements predict greater involvement in bullying than segregated placements (Sterzing, Shattuck, Narendorf, Wagner, & Cooper, 2012; Zablotsky, Bradshaw, Anderson, & Law, 2013). These data raise questions regarding the quality of inclusion classrooms, and suggest that the school climate in terms of being welcoming and inclusive could contribute to these differences.

Bullying Prevalence among Adults with Intellectual and Developmental Disabilities

In a comprehensive literature search for bullying and related constructs (e.g., harassment, abuse, maltreatment), we were able to locate only three studies that focused on adults with disabilities. The National Survey on Abuse of People with Disabilities conducted by Baladerian, Coleman, and Stream (2012) gathered information from 7,289 people (20.2% had a disability, 47.4% were a family member of a person with a disability, and others were service providers, professionals, and response personnel) about abuse (bullying was subsumed under the framework of “abuse”). Of the people with disabilities who responded, 73% had been victims of bullying, and 38% said the bullying lasted for years. People with autism and individuals with mental health conditions were victims of bullying at significantly higher rates than people with other types of disabilities. Most (72%) reported that the bullying occurred at school, 42.4% said in the neighborhood or the home, 36.8% reported at work, and 8.8% said it happened on a sports team. Most (65.4%) people with disabilities who were victims of abuse or bullying did not receive counseling or therapy, although when therapy was provided, 83% of people with disabilities who were victims said that it was helpful to them.

In a Canadian study of 17 individuals (ages 21-63) with disabilities as a result of a severe, chronic condition attributable to mental and physical impairment and limitations in major areas of life, Marini, Fairbairn, and Zuber (2001) found that 23% experienced physical victimization, 42% cognitive victimization, 15% social victimization, and 31% emotional victimization. They also looked at bullying perpetration, finding the following prevalence rates: 12% physical, 25% cognitive, 12% social, and 2% emotional. In a study conducted in the United Kingdom with adults with profound or severe disabilities, Sheard, Clegg, Standen, and Cromby (2001) found that 19% of people with “problem behaviour” picked on others and 11% with “problem behavior” were “picked on by others.” This study was limited in that it did not clearly define bullying, but rather it was part of a constellation of behaviors.

Impact/Effects of Bullying

Students with disabilities involved in bullying are more likely to be at-risk for depression, delinquency, anger, hostility, and lowered self-esteem (Rose, Forber-Pratt, Espelage, & Aragon, 2013). In addition,

Andreou, Didaskalou, and Vlachou (2013) found that students with disabilities who are victimized or bullied at school experienced an increased sense of loneliness at school and greater difficulties in social interactions with peers, as well as high levels of social exclusion. Davis and Nixon (2010) found that students who receive special education services were somewhat more likely to report severe trauma as a result of peer victimization when compared to students who did not receive special education services. Farmer and colleagues (2012) found that fifth grade students who received special education services were more likely to be identified as a bully-victim or a victim, and they were also at an increased risk for emotional and behavioral problems. Overall, when compared to general education students, individuals with disabilities appear to experience effects such as social exclusion, loneliness, and trauma. Oftentimes their attempts to combat the bullying only seems to elicit additional bullying behavior from their peers.

Resources, Supports, and Successful Prevention Practices

Bullying Prevention for Youth

Although not focused on individuals with disabilities, studies of bullying prevention programs have shown that they can increase awareness, knowledge, and teacher reports of increased ability to intervene, but they do not necessarily produce substantial reductions in bullying behaviors and victimization (Merrell, Gueldner, Ross, & Isava, 2008; Smith, Schneider, Smith, & Ananiadou, 2004). Meta-analyses conducted by Tofti, Farrington, and Baldry (2008) and Tofti and Farrington (2009) have found more promising results, indicating that bullying prevention programs in schools reduced bullying and victimization by 17-23%. Programs that were most effective followed a whole-school approach, had multiple components, and were based on sound theory (often social-ecological theory). Elements that were part of programs that reduced bullying included: parent training, improved playground supervision, disciplinary measures, school conferences, information for parents, classroom rules, classroom management, and videos. The total number of elements, their duration, and their intensity for students and teachers were significantly associated with reducing bullying. Elements that were part of programs that reduced victimization included: videos, disciplinary methods, work with peers, parent training, cooperative group work, and playground supervision. The duration of the program for children and teachers, and the intensity of the program for teachers were associated with reducing victimization.

Bullying Prevention for Youth with Disabilities

There is a lack of empirically validated bullying prevention and intervention strategies for students with disabilities, and few studies address intervention strategies for individual subgroups of students with disabilities (Rose et al., 2011). Whitney and colleagues (1994) reported on a project conducted in Sheffield, UK, in the early 1990s (Smith & Sharp, 1994) that included information about the effects of the program on youth with disabilities. This initiative, which was modeled after the Olweus program in Scandinavia (Olweus, 1993), included: (1) developing a school-wide policy, (2) implementing a classroom curriculum, (3) training for lunchroom supervisors, (4) improved playground supervision, and (5) working directly with students involved in bullying (Smith & Sharp, 1994). Whitney and colleagues (1994) found that students with disabilities reported a decrease in bullying victimization and perpetration following the implementation of the intervention. In addition, following the intervention, students with disabilities reported that they had more friends..

In another study, eleven school nurses conducted a 12-session, bi-weekly support/discussion group intervention for 65 students between the ages of 8 and 14 with a wide range of disabilities (e.g., mental health problems, behavioral and developmental concerns, ADHD, cerebral palsy, pervasive developmental delay, physical conditions such as severe allergies, epilepsy, cardiomyopathy). They used materials from the *Stop Bullying Now* campaign (see <http://www.stopbullying.gov/kids/index.html>). After the program, students reported being significantly less bothered by teasing and bullying, and possessed significantly improved self-concepts (Vessey & O'Neill, 2011).

Raskauskas and Modell (2011) provide several recommendations for how bullying prevention programs can be modified to better meet the needs of students with disabilities. In terms of the needs assessment or use of surveys on prevalence of bullying, these authors assert that the definition should be understandable; and that alternate methods of response (paper and pencil, electronic, verbal) should be provided. To make program content more accessible, it is advised that staff working with students with disabilities should be trained on how to recognize and respond to problem behaviors; assess policies to ensure that they are effective for a wide spectrum of disabilities; take into account language and communication difficulties; and provide several ways to report bullying (hand signal, anonymous report). Furthermore, Raskauskas and Modell (2011) recommend matching bullying content and training with positive behavior support and educating students about tolerance, empathy, respect, and responding to bullying. In terms of program delivery, it is suggested that (1) additional examples be integrated into the content, (2) concrete examples be provided, and (3) concepts be repeated. In addition, it is recommended that opportunities are provided to practice identifying, responding to, and reporting bullying, and that materials are accessible (e.g., large print, audio recording, Braille).

School-Wide Bullying Prevention Strategies

Anti-bullying strategies that aim to alter the school environment and provide a framework to guide the school's actions to address bullying have been shown to be effective. The Supporting Early Adolescent Learning and Social Success (SEALS) approach (Farmer et al., 2011) integrates academic engagement, behavior management, and social dynamic management interventions for students with developmental disabilities. Research on this approach has suggested that although it can promote productive peer contexts, many youth with elevated risk factors, bullying involvement, and social roles that support their problem behavior may not respond to universal strategies and will likely require selected and indicated interventions to address their needs (Farmer et al., 2012).

Other programs include Positive Behavior Interventions and Supports (PBIS), Positive Behavior Support (PBS), and applied at the school-wide level, School-Wide Positive Behavior Support (SWPBS; Good, McIntosh, & Gietz, 2001; Sugai, Horner, & Algozzine, 2011). These proactive programs focus on improving the school climate and have been shown to reduce office referrals and improve academic outcomes (Good et al., 2001; Sugai et al., 2011). Based on three tiers of support, the programs not only teach students the rules and how to behave, but also reward students for use of the behaviors and provide increasing levels of support. Within the framework of these programs, bullying prevention and intervention strategies can be embedded. The Bully Prevention in Positive Behavior Support (BP-PBS) program was developed specifically to address bullying, victimization, and bystander behavior using PBIS. Evaluation revealed that bullying behaviors decreased, while prosocial and protective victim and

bystander behaviors increased even among children in the tertiary, or most intensive level of intervention (Ross & Horner, 2009).

The Achievement for All Program Model utilizes school wide strategies to assess, track progress, and intervene to support youth with special needs (Humphrey, Lendrum, Barlow, Wigelsworth, & Squires 2013). The model aims to improve attendance and behavior, reduce exposure to bullying, develop positive relationships, and increase participation in school life among youth with special needs (Humphrey et al., 2013). Structured, open, on-going dialogue with parents is included to address children's learning and their life at school (Humphrey et al., 2013). Also unique to this program is the ongoing support, training, and technical assistance provided to schools using this model (Humphrey et al., 2013). Evaluation findings indicate that the program was effective in promoting positive relationships and preventing/stabilizing bullying and problem behaviors.

The literature on the effects of bullying perpetration and victimization and the information on universal programming is more advanced than the evidence regarding secondary and tertiary levels of prevention and intervention for bullying, particularly for students with exceptionalities. However, the following evidence highlights interventions for youth who may not respond to the universal level of intervention, or who may need additional support.

Interventions to Improve Social Skills and Peer Relations

Traditionally, the predominant approach for intervening with children who are rejected by peers has been social skills training designed to teach positive peer interaction skills and increase awareness of how one's social behavior affects others (Coie & Koeppl, 1990). This training should be individualized to the behaviors that are related to the rejection (i.e., aggressive-disruptive or sensitive-isolated), as social skills interventions targeting specific deficits are more effective for their targeted group than for other groups (Bienert & Schneider, 1995; Lochman, Coie, Underwood, & Terry, 1993). For example, problem-solving skills training discussed below can be used for rejected children who also exhibit aggressive behavior. For more socially withdrawn children, interventions typically include social skills instruction focused on making friends, increasing positive pro-social strategies, regulating anxiety, and building assertiveness (Bienert & Schneider, 1995; Gazelle & Ladd, 2002). Early research on coaching children in peer interaction skills through the use of direct instruction, practice with peers, and review of skills has resulted in increased peer acceptance post-intervention and at follow-up, in contrast to control and comparison conditions (Ladd, 1981; Oden & Asher, 1977).

More recent research suggests that social skills training for children with autism is beneficial in that increasing social skill levels are a protective factor against bullying (Bohlander, Orlich, & Varley, 2012; Reichow & Volkmar 2010). For example, using *Social Stories* with children with ASD has been found to decrease undesirable behaviors and increase prosocial behaviors (Ali & Frederickson, 2006; Karkhaneh et al., 2010; Kokina & Kern, 2010; Reynhout & Carter, 2011; Test, Richter, Knight, & Spooner, 2011). A teaching interaction procedure may be more beneficial for some students (Leaf et al., 2012). This approach teaches social skills by first introducing the skill, providing a rationale, describing cues and characteristics when the skill should be displayed, then divides the skill into smaller behavioral components that can then be modeled, role played, and practiced. Corrective feedback, praise, and consequences can also be provided based on the participant's performance (Leaf et al., 2012).

For children who demonstrate aggressive behaviors, problem-solving skills training can be used to teach how to identify alternative interpretations for others' behaviors, increase awareness of physiological signs of anger, improve social problem solving skills, and learn strategies for coping with conflict (Lochman & Lenhart, 1993). Problem-solving training has been shown to lead to decreases in disruptive and aggressive behavior and increases in prosocial behavior compared to control and comparison conditions (Kazdin, Bass, Siegel, & Thomas, 1989; Lochman, Burch, Curry, & Lampron, 1984).

Interventions with Peers

There are a variety of intervention techniques in which peers can play a central role, particularly in relation to generalizing the newly learned more prosocial skills of rejected children. Because social rejection is often a precursor to victimization (Brock et al., 2005) allowing children to acquire and practice appropriate social skills within the context of a positive peer group may be helpful.

Reinforcing peers for making positive comments about rejected children's behavior has been successful in breaking the cycle of peers' negative perceptions and reactions towards victims (Ervin, Miller, & Friman, 1996). Teachers can be involved in this by using story time and discussion about prosocial behavior and inclusive play, which have been found to increase children's self-reported acceptance and liking of others (Favazza & Odom, 1997; Harrist & Bradley, 2003). More targeted interventions aimed at promoting peer acceptance include incidental teaching of social behavior, where an adult models appropriate social behavior or encourages peers to model appropriate social responses (Brown et al., 2001), which, in combination with positive teacher feedback, is slightly effective in improving rejected children's reputations (White, Sherman, & Jones, 1996).

Social integration and friendship interventions, in which a child with social difficulties is paired with a same-sex peer or a group of socially responsive and competent students to engage in activities that allow frequent interactions, have benefited children with disabilities (e.g., ADHD, Hoza, Mrug, Pelham, Greiner, & Gnagy, 2003), and led to more frequent contact between students with and without disabilities, improved attitudes of peers without disabilities, and increased liking of children with disabilities (Favazza & Odom, 1997; Odom et al., 1999). Indeed, when high social status peers initiate social contact with rejected children, it improves the social behaviors of rejected children and influences the attitudes and behaviors of the peer group (Sasso & Rude, 1987).

Interventions have also been developed to bolster peer support systems for victims of bullying such as befriending, circle of friends, and peer counseling (Cowie & Wallace, 2000). These involve training a small group of peer helpers in intervention skills to offer support to victims under the supervision of adults (Sharp & Cowie, 1998). Evaluations of peer support systems implemented for at least one year in several schools in the United Kingdom have yielded mixed findings. Reported benefits included increases in peer helpers' confidence, sense of responsibility, involvement, and communication, improvement in the overall school climate (Cowie, 1998; Naylor & Cowie, 1999), and victims' increased strength to overcome the problem (Naylor & Cowie, 1999). Drawbacks of these approaches included peer helpers reporting experiencing some hostility from the peer group (Cowie, 1998), limited success in reducing levels of bullying (Naylor & Cowie, 1999), and the underrepresentation of male leaders and boys as both peer helpers and system users (Naylor & Cowie, 1999). The befriending approach, through after-school clubs, buddying, and peer telephone listening services, allows peer helpers to offer companionship to children suffering from distress, including bullying (Cowie & Wallace, 2000). The befriending approach,

implemented over the course of an academic year in Italian middle schools, countered the normally observed increase of negative attitudes and reactions among peers towards bullying victims that was found in the control group, although it did not reduce the rate of bullying incidents (Menesini, Codecasa, Benelli, & Cowie, 2003). Victim support groups that allow targets to receive support, encouragement, and friendship, in addition to teaching skills to cope have also been recommended (Arora, 1991; Rigby, 1996), although there is virtually no empirical support for these approaches (Nickerson, Brock, Chang, & O'Malley, 2006).

Peer advocacy programs can also be used to develop a group of students who are committed to supporting those who are bullied by interacting with them in prosocial and protective ways. The role of supportive peers and positive peer relationships is not only critical to acceptance into peer ecologies, but also serves as a protective factor against bullying (Bourke & Burgman, 2010; Humphrey & Symes, 2011; Hebron & Humphrey, 2014). Other intervention techniques attempt to turn bystanding peers into active helpers, with the assumption that peers are critical change agents in reducing peer victimization (Hawkins, Pepler, & Craig, 2001; O'Connell, Pepler, & Craig, 1999). Through anti-bullying educational curricula, this aspect may focus on raising the peer group's awareness of the bullying problem, promoting a sense of responsibility, instilling empathy for victims' suffering, and encouraging peer involvement to reduce the bullying problem (Cowie & Sharp, 1994; Sharp & Smith, 1993) using techniques such as drama, role-play, literary stimuli, films and video, group discussion, and problem solving (e.g., the Quality Circle method; Cowie & Sharp, 1994). The implementation of curricular-based approaches has been effective in raising peers' awareness of the problem of bullying and changing attitudes (Gini, 2004; Stevens, Van-Oost & de-Bourdeaudhuij, 2000), but has been less effective in changing children's behaviors within the peer group (Gini, 2004).

In addition to the role of peers, O'Brennan and colleagues (2014) found that staff who had close relationships with students, their colleagues, and the school, were more comfortable intervening with at-risk students in bullying situations. However, research has found that students with ASD receive the same amount of social support from teachers as students without disabilities (Humphrey & Symes, 2011; Hebron & Humphrey, 2014). In addition, they receive less support from classmates and friends than other students with and without disabilities (Humphrey & Symes, 2011, Hebron & Humphrey, 2014). This suggests that programming needs to be responsive to differential social needs of students with exceptionalities and to create classroom social contexts that enhance the social opportunities, supports, and position of all students (Estell et al., 2009).

Bullying Prevention for Adults

There is limited research about anti-bullying approaches for adults with disabilities. The one exception was a study by McGrath, Jones, and Hastings (2010), who offered a ten week anti-bullying program to 42 participants in two work centers in Ireland. Eighteen participants in a third work center were a wait-listed comparison group. Initially, 43% reported victimization, 28% reported perpetration, and 15% reported being a bully-victim, and reporting of being bullied decreased significantly after the intervention, although reports of bullying did not decrease.

Conclusions and Needs

Overall, results from the literature review suggest that bullying (both victimization and perpetration) is more common for youth with disabilities than for those without, particularly as related to behaviors and risk factors associated with the disability. However, virtually nothing is known about peer-to-peer bullying among adults with intellectual and developmental disabilities. As such, there is also a lack of empirically validated measures to assess bullying and victimization among youth and adults with disabilities.

Although the field has made some progress in identifying elements of successful prevention approaches for bullying, there remains a significant gap in empirically validated bullying prevention and intervention strategies for students with disabilities, and very few studies address intervention strategies for individual subgroups of students with disabilities.

From this review, there emerged several needs for research. In terms of youth, it is important to examine the predictive nature of type of disability and class placement for bullying involvement and students with disabilities. In addition, research is needed to examine the bully-victims (students who are both bullied by others and who bully), and to explore whether the bullying perpetration is an attempt to protect themselves from bullying. We also need to know more about the effects of bullying involvement on individuals with disabilities, in terms of how it can be measured, treated, and prevented. Exploring to what extent these effects are similar or different to people without disabilities is also important. The larger issue of maltreatment and abuse of individuals with disabilities, and how this relates to bullying, is also an area in need of study. Future research should also look at the connection between bullying involvement and school disciplinary practices with regard to students with disabilities. As the research advances, it will be important to identify mediators of the relation between bullying victimization and adverse outcomes. In particular, examining the mediating role of positive and healthy school, work, and living environments will be important. Finally, it is clear that evaluation research needs to include individuals with disabilities in both the design and implementation of the evaluation, and data should be gathered from these individuals about their experiences with (Jacobson, Assam, & Baez, 2013).

NEEDS ASSESSMENT PROCESS

PRELIMINARY ACTIVITIES

Preliminary discussion with the NYS DDPC staff determined that information on bullying and people with developmental disabilities should be collected formally through surveys, focus groups, and interviews, as well as informally through participation in various conferences and presentations involving individuals with developmental disabilities. These informal activities included:

- *Spread the Word to End the Word* Panel Discussion, Buffalo, NY, March 6, 2014
- *Developmental Disabilities Awareness Day Conference*, Presentation on Bullying, Niagara Falls, NY, May 22, 2014
- *SANYS* Conference Presentation on Bullying by Self-Advocates, Batavia, NY, June 5, 2014

In order to determine what types of information stakeholders wished to have collected through surveys, focus groups and interviews, two conference calls were held on January 21 and 24, 2014. These conversations involved staff from the NYS DDPC and the Alberti Center and included individuals with developmental disabilities, family members of individuals with disabilities, direct care providers, and service providers.

As a result of these initial meetings, quantitative (i.e., survey) and qualitative (i.e., interview and focus group) approaches were designed to reach a large number of stakeholders to obtain broad and in-depth information about the issue of bullying and individuals with disabilities, as well as potential ways to address prevention and intervention.

QUANTITATIVE DATA COLLECTION

Phase 1: Survey Development and Institutional Review Board Approval

An extensive search within the literature on bullying was conducted to find existing measures and scales with established psychometric properties, and preliminary surveys were developed. On April 7, 2014, Katy Allen met with the Children's Subcommittee of the NYS DDPC to determine if the questions chosen were suitable for the various constituencies, and if they adequately and accurately addressed the issues and concerns of the committee. Based on the feedback from this meeting, the surveys were revised to (1) make them shorter, (2) simplify the language, and (3) add questions regarding cyberbullying and bystander behavior. Four surveys were developed reflecting the interests and needs of different sectors within the developmental disability community. These surveys were developed for: (1) school-aged youth with intellectual and developmental disabilities, (2) adults (18 and older; not in grades 5-12) with developmental disabilities, (3) parents of children (grades 3-12) with disabilities, and (4) the general public (employers, service providers, concerned citizens). Appendix A includes all four surveys. Because the work being done for the NYS DDPC qualified as research, an application was submitted to the University of Buffalo's Institutional Review Board (IRB) for review. The application was divided into two parts, one containing the survey component of the study and the other containing the interview and focus group component of the study. The application for the survey component was submitted to the IRB

on April 29, 2014 (resubmitted with requested changes on June 4, 2014). Approval of the survey component was granted on June 6, 2014.

Phase 2: Survey Dissemination and Response

Participants were recruited via an email invitation in late June and early July 2014 to complete a survey that gathered information on bullying experiences (victimization and perpetration) of individuals with intellectual and developmental disabilities. The surveys also asked about strategies to deal with bullying (prevention and intervention) and their effective. Emails were sent via listservs through the NYS DDPC to a variety of professional associations and institutions that serve individuals with disabilities and their families, parents of children with disabilities, as well as to service providers currently living or employed in NYS. Paper copies of the surveys were also distributed at participants’ request. Survey data were collected from June through August of 2014.

The demographic information about the survey respondents including youth with disabilities (Table 1), adults with disabilities (Table 2), parents of children with disabilities (Table 3), and the general public (Table 4) are provided below:

Table 1

Demographics of School-Age (Grades 5-12) Youth Survey Participants (N = 5)

Gender	
Male	100%
Female	0%
Age	
Mean	12.60
Stand. Dev.	1.34
Maximum	11
Minimum	14
Race	
White	100%

Table 2

Demographics of Adult (Ages 18 and Older, Not in Grades 5-12) Survey Participants (N = 34)

Gender	
Male	56%
Female	44%
Age	
Mean	38.53
Standard deviation	11.79

Race	
White	100%
Disability status	
Learning Disability	29%
Intellectual Disability	17%
Physical Disability	8%
Vision or Hearing Impaired	6%
Traumatic Brain Injury	13%
Autism/Asperger's	13%
Cerebral Palsy	13%

Note. Response options of less than 5% of the sample were not reported.

Table 3

Demographics of Parent/Guardian Survey Participants (N = 142)

Gender	
Male	10%
Female	90%
Child Age	
Mean	13.26
Standard deviation	3.16
Race	
White	90%
Hispanic	5%
Child's disability status	
Autism	41%
Intellectual Disability	17%
Other Health Impaired	7%
Multiple Disabilities	12%
Relationship to child	
Biological mother	77%
Adoptive mother	11%
Class placement	
Regular classroom most of the day	62%
Regular classroom half the day	9%
Regular class less than half day	17%
Separate school	11%
1:1 Aide	
Yes, all day	35%
Yes, part of day	23%
No	42%

Note. Response options of less than 5% of the sample were not reported.

Table 4*Demographics of General Survey Participants (N = 169)*

Participant relationship with individual with disabilities	
Mental health professional	31%
Administrator	24%
Educator	20%
Service coordinator	7%
Direct care worker	7%
Interaction with individuals with disabilities	
Direct	92%
Indirect	8%
Number of individuals with disabilities interacted with daily	
1-5	48%
6-10	26%
11-15	7%
16-20	5%
More than 20	13%
Setting	
Special education	33%
Day program/volunteer setting	29%
Individuals' apartment or home	25%
General education	25%
Residential placement	25%
Community-based setting	21%
Employment site	20%
Population	
Adults	47%
Youth	
Infants/preschoolers	17%
Elementary school children	37%
Middle school adolescents	31%
High school-age adolescents	36%

Note. Response options of less than 5% of the sample were not reported. This survey asked participants to reference their general experiences and not focus on one individual as the other surveys did.

Part 1 of the surveys asked about the respondent's demographics (e.g., age, gender, race/ethnicity). For adults with disabilities, this section also asked about the nature of their disability (e.g., cerebral palsy, down syndrome, autism). Parents/guardians were asked about their child's demographics, disability, and educational services (e.g., inclusion, time with 1:1 aide), while those who completed the general survey provided information on the population (e.g., age group, disability status, amount of people, and time spent per day) and setting in which they work (e.g., general education, day program). Questions were drawn from the *2012 Survey on Abuse of People with Disabilities* (Disability and Abuse Project of

Spectrum Institute) and the *Bullying and School Experiences of Children with ASD Survey* (Interactive Autism Network, 2013).

Parts 2 and 3 ask about bullying victimization and perpetration. The youth, adult, and parent surveys were modeled after *The California Bullying Victimization Questionnaire* (CBVQ; Felix et al., 2011) and the *Peer Victimization Scale* (Livingston, 2014). The CBVQ has evidence of good test-retest reliability (.80 to .83) and predictive validity (Felix et al., 2011). The general survey was modeled after the *Current Bullying Prevention/Intervention Practices in American Schools* (Sherer & Nickerson, 2010). These measures assess relational (e.g., ignored, left out, gossiped), physical (e.g., hit, kicked, shoved) verbal (e.g., teased or put down), and cyber (e.g., teased or isolated through electronics) bullying. Additionally, parents were asked about their child's social vulnerability in terms of gullibility (i.e., being tricked into things and being bullied) and credulity (i.e., believing others' statements to their own detriment; *Social Vulnerability Scale [SVS]*; Soronoff, Dark, & Stone, 2011). The SVS demonstrates good internal consistency (Cronbach's alpha = .94) and test-retest reliability ($r = .85$; Soronoff et al., 2011). Parents and individuals with disabilities (youth and adults) were asked where and when bullying occurred and the impact (e.g., I felt sick, sad, or angry; Swearer, 2001) on the target. Adults with disabilities, parents, and general survey respondents also reported reasons (i.e., jealousy, behaviors, differences) for victimization (*When Bad Things Happen at School* survey; Visconti, Sechler, & Kochenderfer-Ladd, 2013). Adults and youth with developmental disabilities, and parents were also asked about coping strategies (questions adapted from Kochenderfer-Ladd & Pelletier, 2008). Visconti and colleagues (2013) found that composite scores for coping strategies and reasons for victimization had good reliability (Cronbach's alpha ranging from .66 to .86).

In parts 3 and 4 of the surveys, respondents are asked about resources (e.g., reading written or web-based anti-bullying resources; attending anti-bullying presentation or seminar), strategies (e.g., creating more laws; avoiding contact between the bully and target), and programs used to prevent and intervene in bullying and their effectiveness adapted from a variety of sources (e.g., Cooper & Nickerson, 2013; IAN, 2013; Sherer & Nickerson, 2010).

Surveys were adapted to fit a larger population of individuals with disabilities (youth and adults), parents, and service providers. McDonald and Patka (2012) support making the surveys understandable through the use of simple and short language. This was achieved by consulting experts in the disability field, including the NYS Developmental Disabilities Planning Council, and creating consent forms at low reading levels. The research team used the Readability Tool in Microsoft Word to assess readability. We made several modifications in an attempt to make the language understandable while also keeping the required content intact.

QUALITATIVE DATA COLLECTION

Phase 1: Focus Groups/Interviews Protocol Development and Institutional Review Board Approval

In order to provide more in-depth information about these issues and to capture perspectives that could not be gained through surveys, seventeen focus groups were held across NYS in Buffalo, New York City, Albany, Rochester, Olean (Southern Tier), and Glens Falls (North Country). Based on literature in the field of bullying and information on individuals with developmental disabilities, protocols for semi-structured interviews and focus groups were developed (see Appendix B). The interview and focus group

component of the study was submitted to the IRB on May 12, 2014 (resubmission on May 28, 2014), and approval was granted on June 5, 2014. Interviews and focus groups were conducted from June through August of 2014.

Phase 2: Focus Group and Interview Implementation

Sixty-eight people attended focus groups and 18 individuals participated in individual interviews (6 in person, 12 phone/Skype). Participants were recruited via email as described above. Kathleen Allen, Ph.D. and Amanda Nickerson, Ph.D. led a full-day training session for all research team members involved in conducting interviews and focus groups. The training included a discussion of risk assessment (guidelines for talking with people about concerns, managing immediate problems, and assessing risk of threat to self or others); procedural issues including human subjects protections; the purpose of focus groups, including viewing videotapes and role-play practice; procedures for interviews; and how to write memos, field notes; and how to conduct qualitative analysis. Interviews and focus groups were conducted with the following stakeholders:

Table 5

Stakeholder Groups that Participated in Interviews and Focus Groups (N=86)

	Adults with disabilities	Youth with disabilities	Employers, administrators, organizational leaders	Service providers	Family, friends, advocates	Multiple roles
Number of Participants	35	5	10	17	5	13

Note. Youth were children in grades 5-12 (ages 12 and older). Adults were individuals with disabilities ages 18 and older (not in grades 5-12). Service providers were defined as anyone who provides any type of service to a person with a disability. Individuals who fit into two or more of the groups (e.g., family member, employer) were categorized as multiple roles.

ANALYTIC PROCEDURES

Quantitative Analysis

Prior to conducting analyses, data were screened and cleaned, including removing individuals who did not fit the criteria of the desired population (i.e., parents of children with a disability [grades 3-12], youth [grades 5-12] and adults [18 and older, not in grades 5-12] with a disability, and service providers). Next, questions that allowed participants to write in a response were reviewed and coded. If needed, new categories were created based on frequent responses and similar themes.

Because many of these scales were adapted for this population, we conducted Principal Component Factor Analyses using the Maximum Likelihood Method with promax rotation in *SPSS Version 20.0* (IBM, 2011) to determine factors, or subscales, within each scale. We then calculated descriptive statistics (i.e., means and standard deviations for subscales, frequencies for items with discrete choices such as yes or no). When calculating descriptive statistics, response options of “Not applicable” and/or “I don’t know” were removed from the calculations as to not inflate and distort the descriptive statistics.

Percentages for bullying victimization and perpetration were analyzed using the criterion of bullying 2-3 times per month or more according to previous guidelines about bullying being repeated (Branson & Cornell, 2009; Cornell, Klein, Konold, & Huang, 2012; Cornell & Sheras, 2003). Those who indicated bullying behavior less than this criterion were not included in the percent calculations. For subscales about effective prevention and intervention strategies, responses of “Have not tried” were separated from effectiveness (*not at all effective* to *very effective*) responses to create factors within a scale. Independent samples t-tests were used to compare mean scores of each factor between respondent groups (i.e., parents, adults, or service providers).

Qualitative Analysis

The interviews and focus groups were either audio-taped, video-taped, or both. In a number of cases, two or more members of the research team were present for the interview or focus group. While limited time and resources precluded the ability to analyze the data with the precision and fidelity of a particular qualitative methodology, the analysis of the interview and focus group data was guided by a grounded theory approach (Charmaz, 2006; Corbin & Strauss, 2008). Each video and/or tape recording was reviewed by at least two members of the research team. Those who had participated in the actual interview or focus group or watched/listened to it after the fact, took notes, and generated memos on participant comments. This phase of the data analysis approximated the process of doing line by line coding and the development of categories.

Using these notes and memos, research team members then went through a process where codes and categories were explored for emergent themes. The team discussed each person’s conceptualization of the data, and by consensus developed emergent themes and a core category.

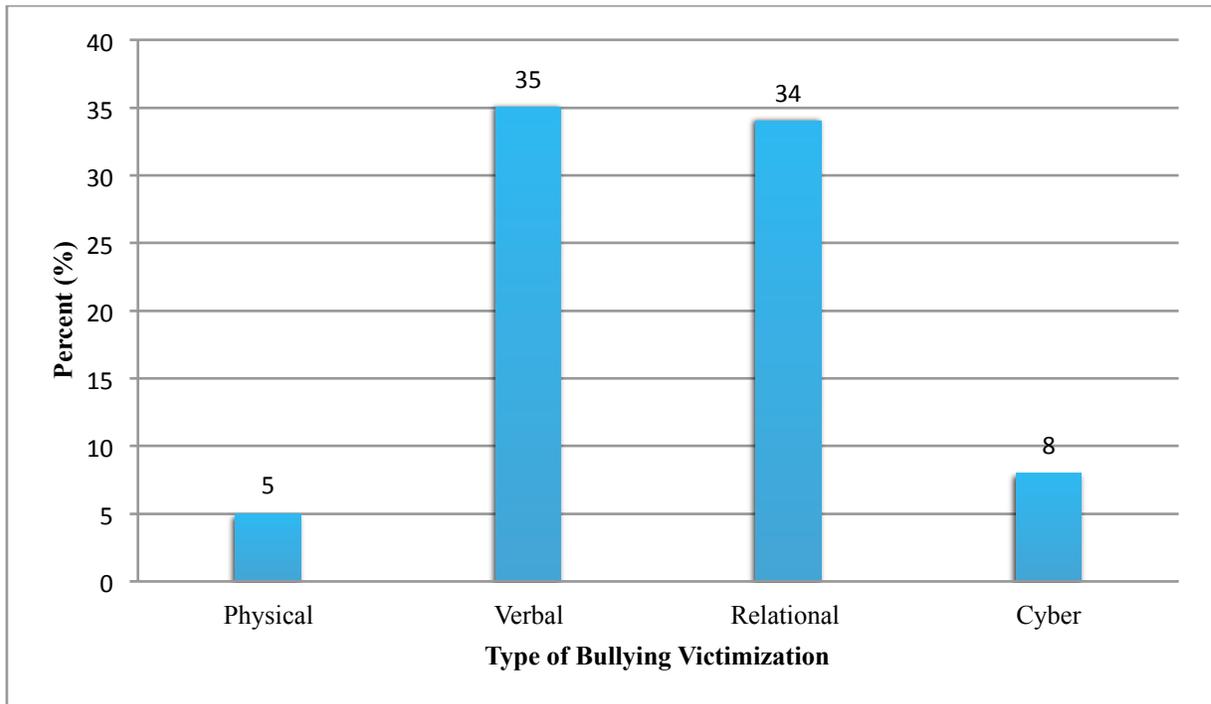
KEY FINDINGS

QUANTITATIVE FINDINGS

Bullying Victimization

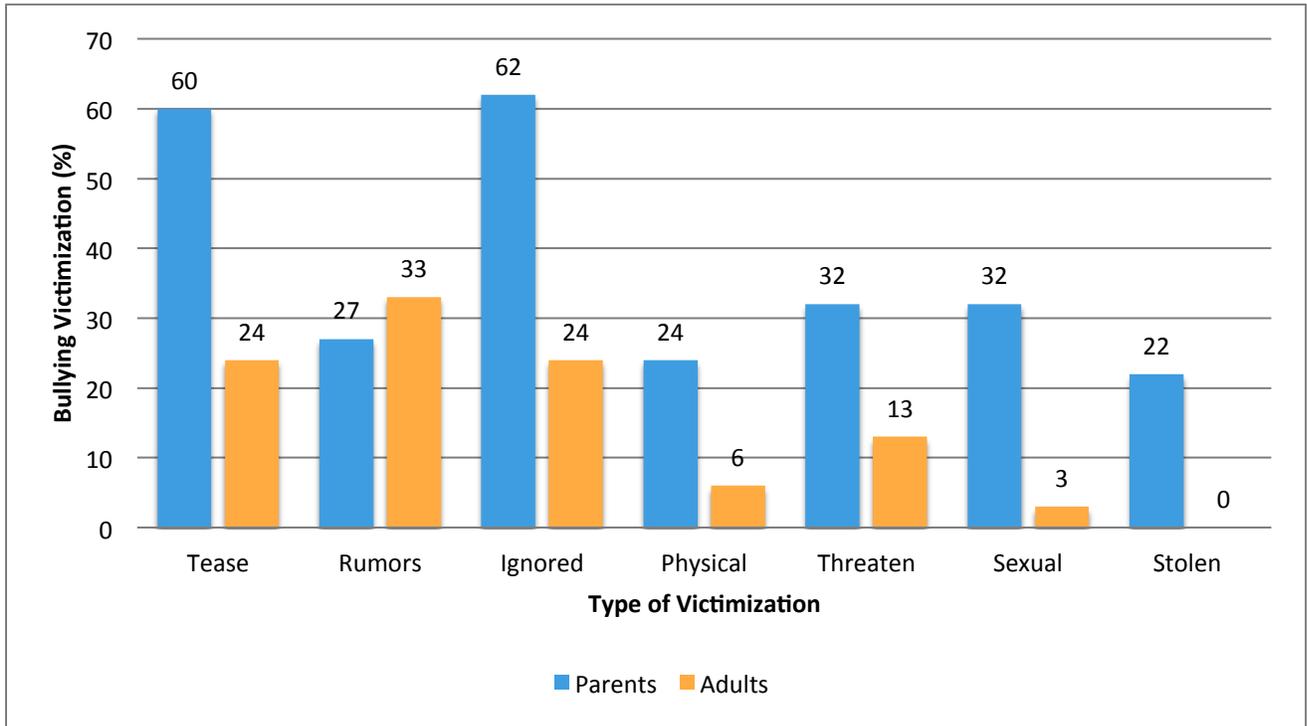
As shown in Figure 1, service providers and others who interact with individuals with disabilities (youth and adults) reported verbal (e.g., teased, put down, insulted) and relational (e.g., ignoring, excluding, rumor spreading) forms of bullying victimization to be more common than cyber (teased, harassed, or socially isolated through electronics) and physical (e.g., hit, kicked, shoved) bullying.

Figure 1. Bullying Victimization Reported by Service Providers as Occurring “Often” or “Always”



Similarly, parents of children with disabilities and adults with disabilities reported that being teased, ignored, and having rumors spread were the most common types of bullying victimization. Parents reported that teasing/name calling and being left out/ignored happened more often than adults reported these behaviors happening to them. Approximately two-thirds of parents surveyed reported that their child was left out of a group or ignored, as well as teased and called names. Parents reported that the least common bullying victimization their child experienced was having things stolen or damaged (22%). While one in three adults with disabilities reported they experienced rumor spreading, none reported having their things stolen or damaged. Overall, parents of children in grades 3-12 reported that their child experienced more bullying than adults reported experiencing, with the exception of rumor spreading.

Figure 2. Bullying Victimization Reported by Parents (of Children Grades 3-12) and Adults with Disabilities



Note. Percentages are reported for parents endorsing behaviors occurring 2 or more times in the past month or adults with disabilities endorsing behaviors occurring “a lot (once a week).”

Parents also reported how often their child engaged in everyday behaviors that involve social judgments and indicate social vulnerability (Soronoﬀ et al., 2011). Social vulnerability is defined by their child’s likelihood of believing others’ statements despite reliability of the source (i.e., credulity) and being tricked into things or bullied (i.e., gullibility; Soronoﬀ et al., 2011). Parents reported less gullibility ($M=2.39$, $SD=0.94$) than credulity ($M=3.00$, $SD=1.06$), meaning that although youth with disabilities may believe others’ statements to their own detriment, their peers may be less likely to take advantage of this and trick a student with a disability. As shown in Figure 3, the most commonly reported credulous behaviors were believing what he or she is told regardless of the source of reliability (48%), prior deception (42%), and being easily fooled (42%). Less common experiences were being tricked into giving up valuable objects (12%), and giving into suggestions to say something that he or she could get into trouble for (21%). Parents also reported gullible behaviors (see Figure 4) such as their child being taunted or insulted to the point of distress (37%), saying something because he or she doesn’t understand social rules and gets in trouble (35%), and being provoked by others and the only one who gets into trouble (31%). Parents reported that being tricked into buying lunch/treats for another child (8%) and being tricked into taking the blame when it’s not his or her fault (11%) were less common.

Figure 3. Credulity (Form of Social Vulnerability) Reported by Parents of Children (Grades 3-12) with Disabilities as Occurring “Often” or “Always”

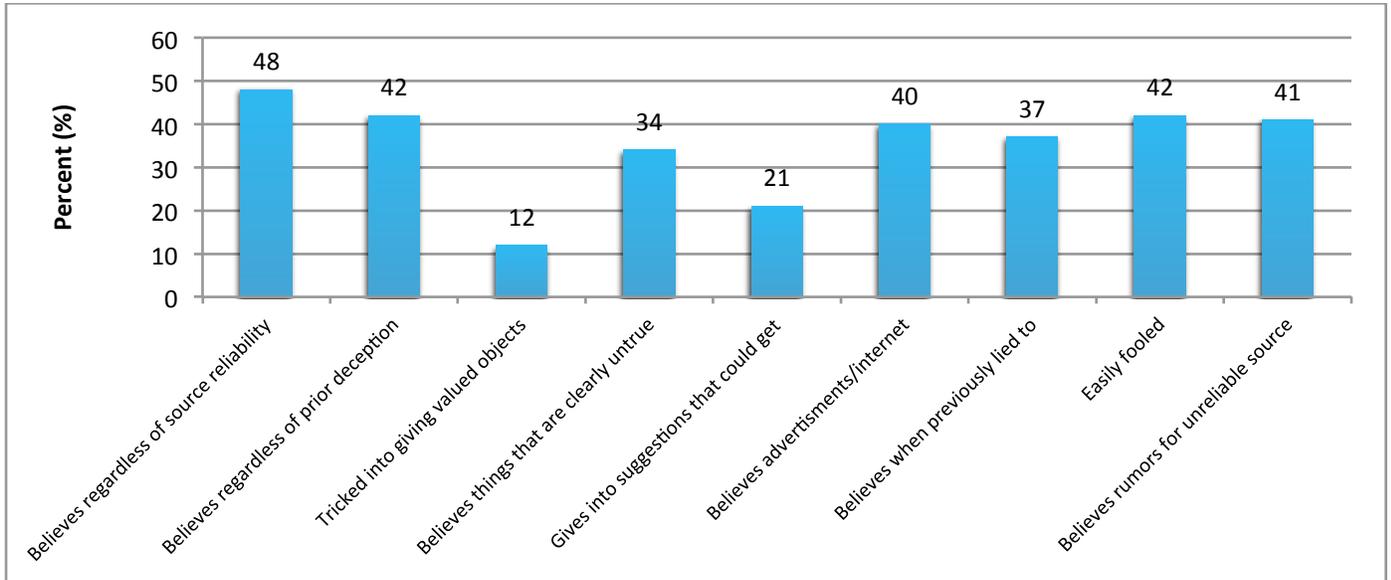
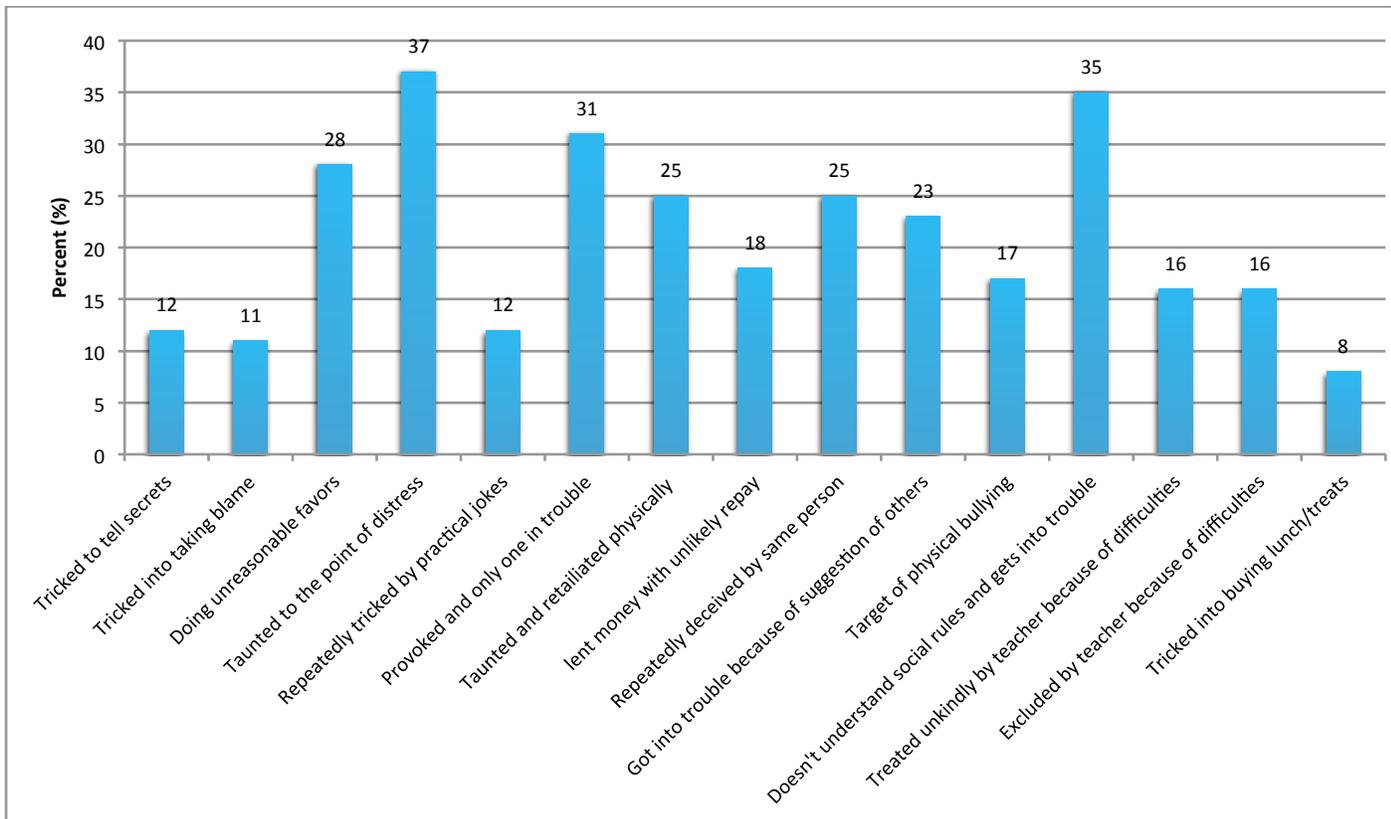


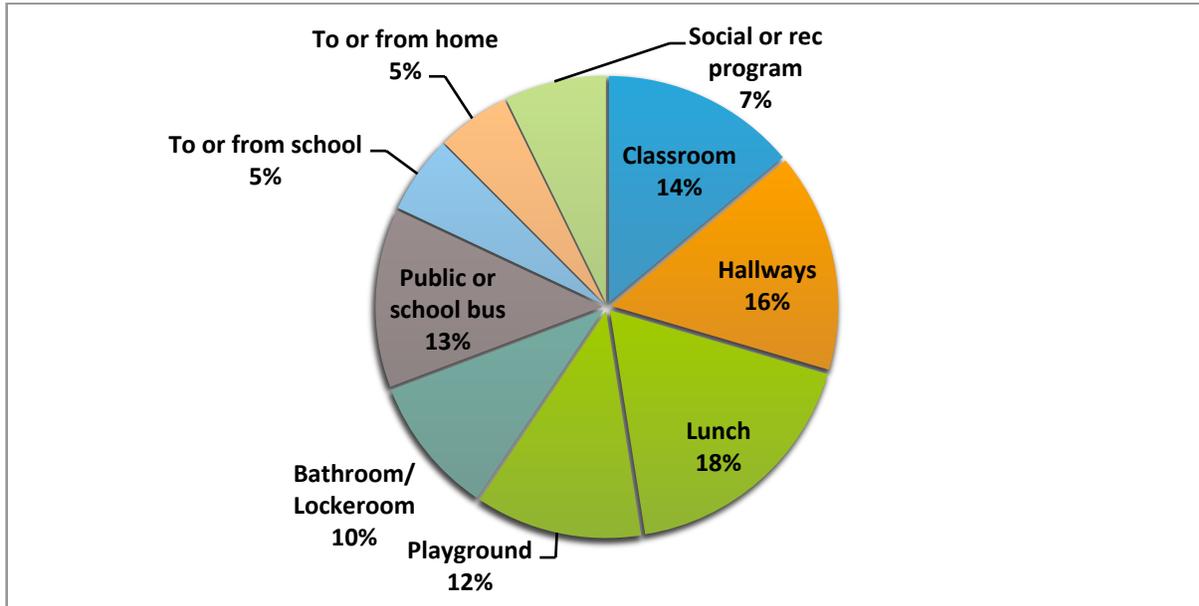
Figure 4. Gullibility (Form of Social Vulnerability) Reported by Parents of Children (Grades 3-12) with Disabilities as Occurring “Often” or “Always”



When and Where Victimization Occurs

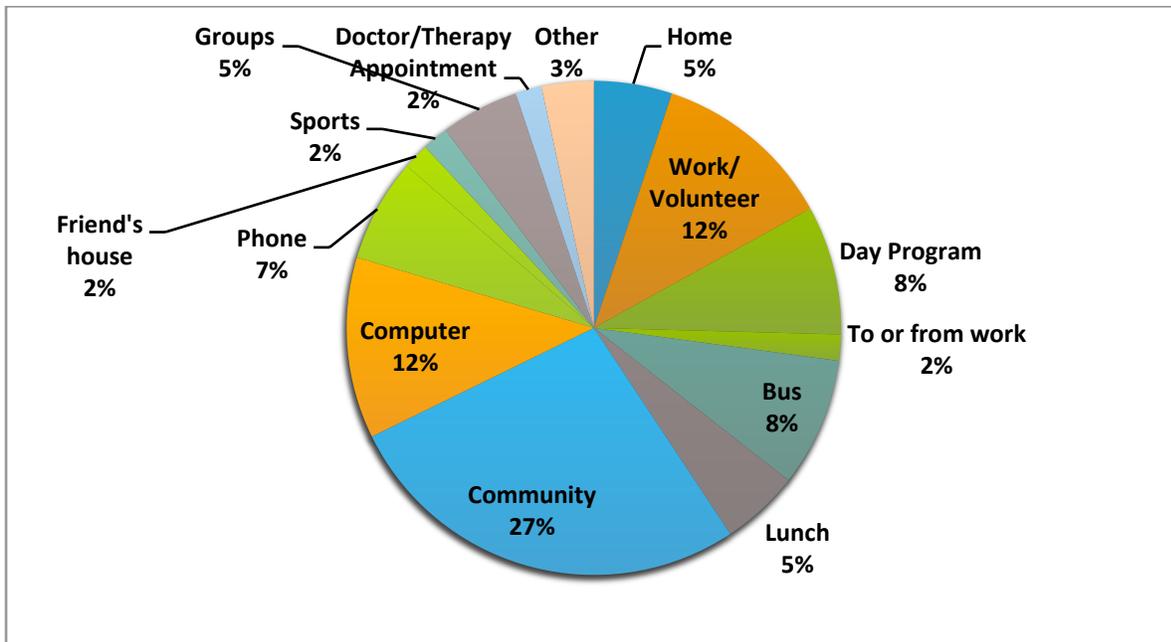
As shown in Figure 5, the majority of parents reported that bullying victimization happened at school. Bullying occurred most often at lunch [18%], in hallways [16%], and in classrooms [14%].

Figure 5. Where Victimization Occurs as Reported by Parents of Children (Grades 3-12) with Disabilities



In contrast, adults with disabilities reported that victimization most commonly occurs within the community (27%), on the computer (12%), and at work or day program (12%), as shown in Figure 6.

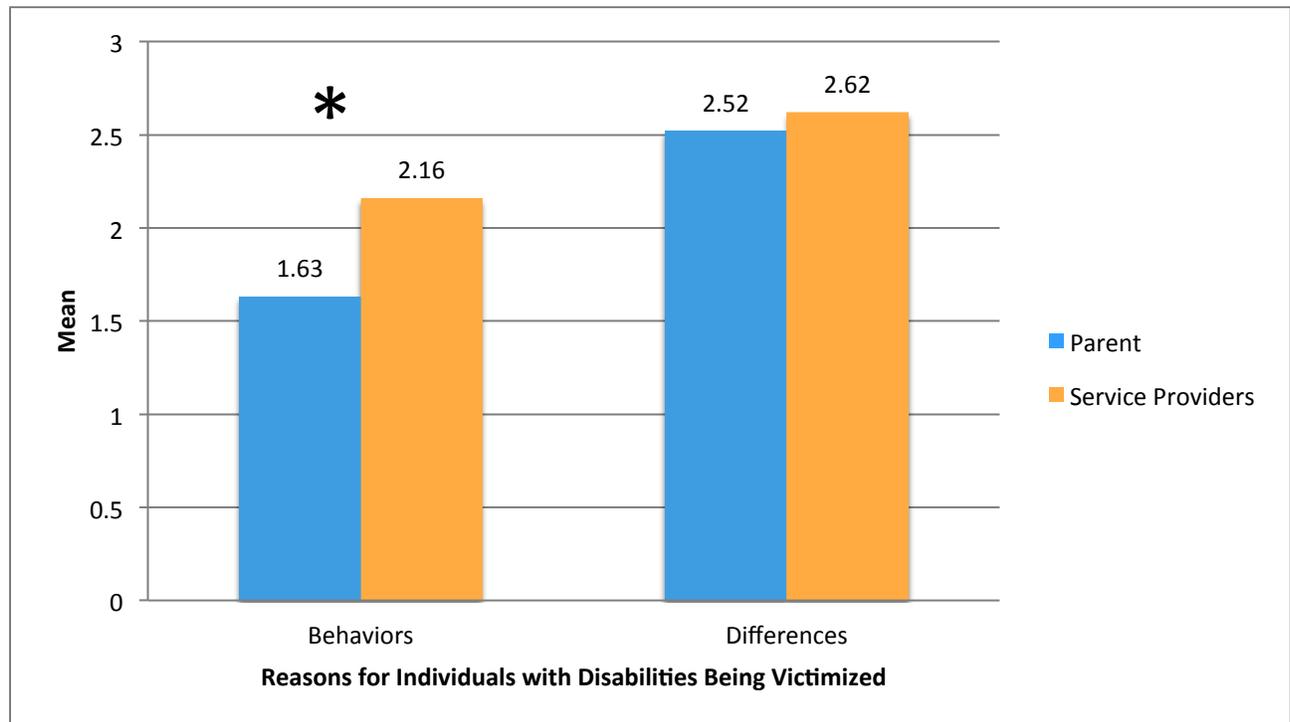
Figure 6. Where Victimization Occurs as Reported by Adults with Disabilities



Reasons People with Disabilities are Victimized

When parents and services providers were asked the reason for being bullied, two themes emerged: differences (being different from others, not as cool, having different friends) and behaviors performed by the target (i.e., bugging or annoying others, making others mad, doing something mean). Parents and service providers reported differences to be the most common reason. The means indicate that parents and service providers believe that differences is “sometimes” or “usually” the reason an individual with disabilities is bullied. Service providers were more likely than parents to indicate the bullying may have occurred because of behaviors performed by the target, as shown in Figure 7.

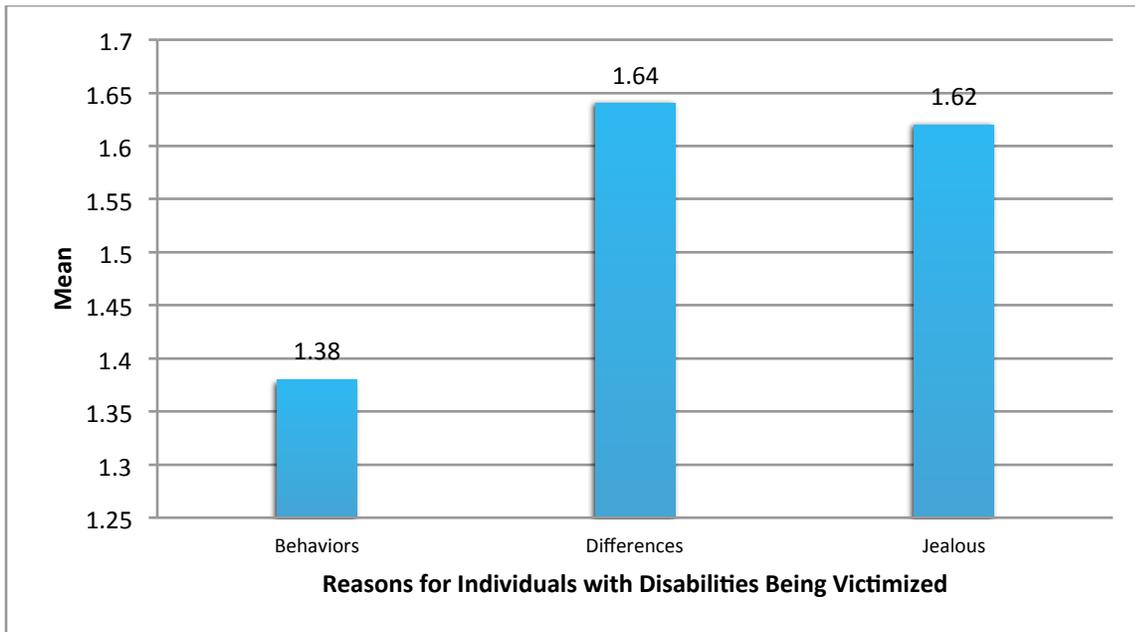
Figure 7. Reasons for Individuals with Disabilities Being Victimized as Reported by Parents of Children (Grades 3-12) with Disabilities and Service Providers



Note. Responses are on 4-point Likert-type scale from 1 (*Never*) to 4 (*Always*). * is a significant difference between the two means reported by parents of children with disabilities and service providers.

When adults with disabilities were asked the reason for their own victimization, they also reported that being different was the most common reason for being bullied, followed by their own behaviors, and jealousy (e.g., they want to be like me, want the things I have). Interestingly, adults with disabilities reported all three of these reasons for being bullied within the “never” to “sometimes” range (see Figure 8). This suggests that there may be other reasons adults with disabilities believe they are bullied that were not measured in this study.

Figure 8. Reasons for Individuals with Disabilities Being Victimized as Reported by Adults with Disabilities

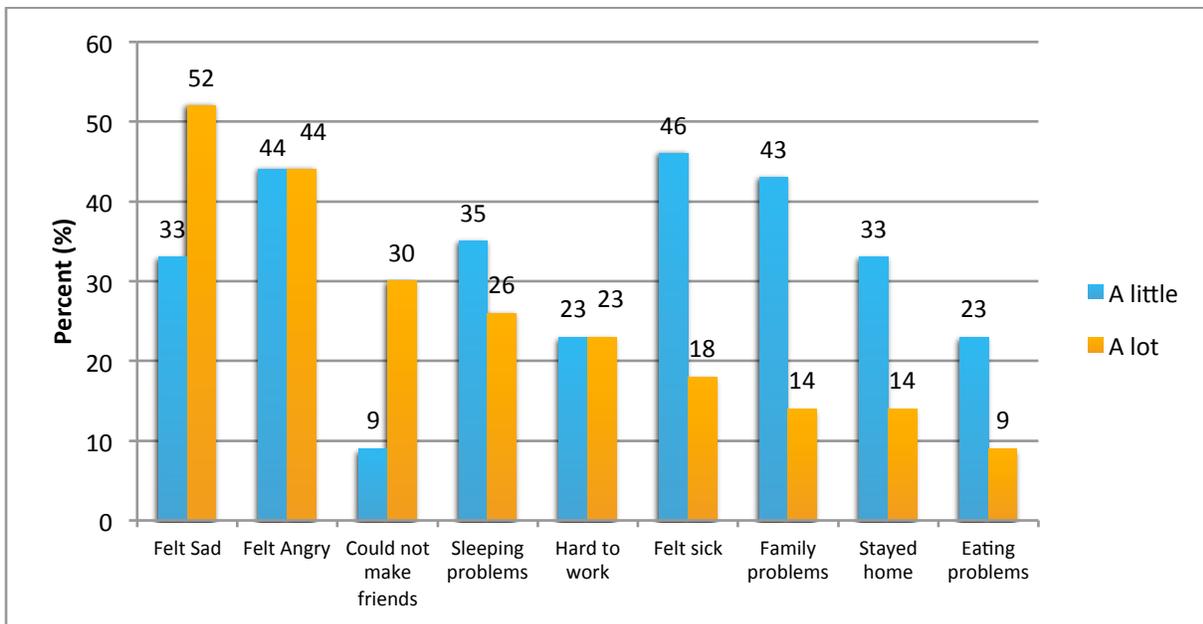


Note. Responses are on 3-point Likert-type scale ranging from 1 (*Never*) to 3 (*Always*).

Effects of Bullying and Coping Strategies Used by Individuals with Disabilities

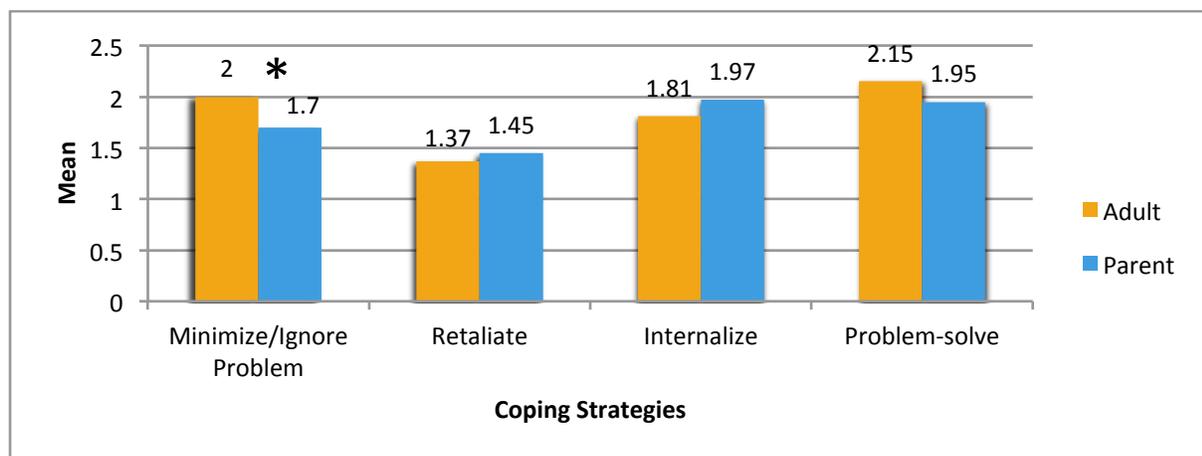
Adults with disabilities most commonly reported feeling sad and angry and having difficulty making friends and sleeping as problems resulting from being bullied (see Figure 9).

Figure 9. Effects of Bullying Victimization Reported by Adults with Disabilities



Adults with disabilities reported problem-solving and minimizing or ignoring the problem as the most common coping strategies (not retaliating or turning it inward). Parents reported that their child coped by problem solving and turning the problem inward (e.g., internalizing) most often. Adults with disabilities' reports of retaliating and internalizing coping strategies, as well as all coping strategy means reported by parents were between the "never" and "sometimes" range. Adults with disabilities' reported problem-solving and minimizing/ignoring coping strategies were coping strategies used "sometimes" or "usually." Adults with disabilities indicated that they minimize/ignore more than parents reporting about their child, as shown in Figure 10.

Figure 10. Coping Strategies to Deal with Bullying Victimization Reported by Parents of Children (Grades 3-12) and Adults with Disabilities



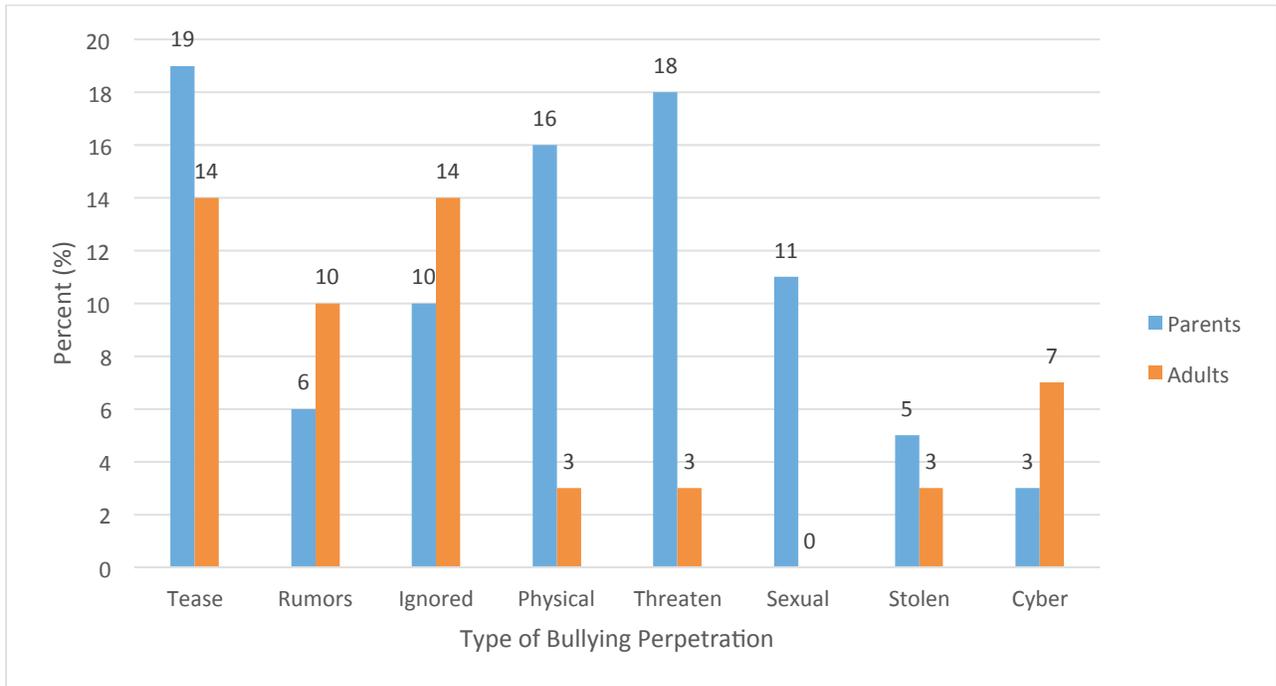
Note. Adults with disabilities' responses are on 3-point Likert-type scale ranging from 1 (*Never*) to 3 (*Always*). Parents' responses are on a 3-point Likert-type scale ranging from 1 (*Never*) to 3 (*Usually*). * is a significant difference between the two means reported by parents of children with disabilities and adults with disabilities.

Bullying Perpetration

Most parents indicated that their children with disabilities have not bullied in the past six months (between 81% and 97% of parents for each behavior). Consistent with parent report, the majority of adults with disabilities report that they never bully others (between 86% and 100% for each behavior). Service providers' perceptions were similar, but between 21% (verbal) to 57% (cyber-bullying) of service providers indicated that bullying behavior never occurred.

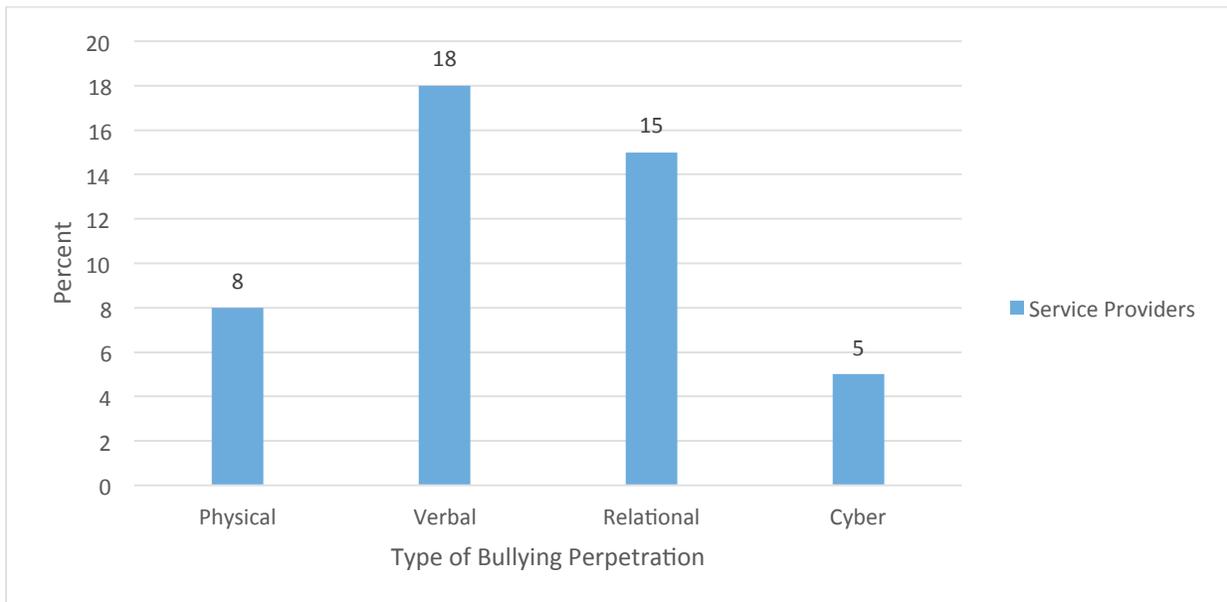
As shown in Figures 11 and 12, verbal bullying (e.g., teasing and name calling) was the most common bullying behaviors demonstrated by individuals with disabilities according to parents (19%), adults with disabilities (14%), and service providers (18%). Parents and service providers reported cyberbullying to be the least common bullying behavior of individuals with disabilities. For parents, verbal bullying was followed by making threats (18%), and hitting, pushing, or physically hurting another (16%). Adults with disabilities also indicated that they leave out/ignore others as often as they tease and call others names (14%), but they never make sexual comments or jokes (100%). For service providers, verbal bullying was followed by relational (15%), physical (8%), and cyberbullying (5%), as shown in Figure 12.

Figure 11. Bullying Perpetration Reported by Parents of Children (Grades 3-12) and Adults with Disabilities



Note. Percentages are reported for parents endorsing behaviors occurring 2 or more times in the past month or adults with disabilities endorsing behaviors occurring “a lot (once a week or more).”

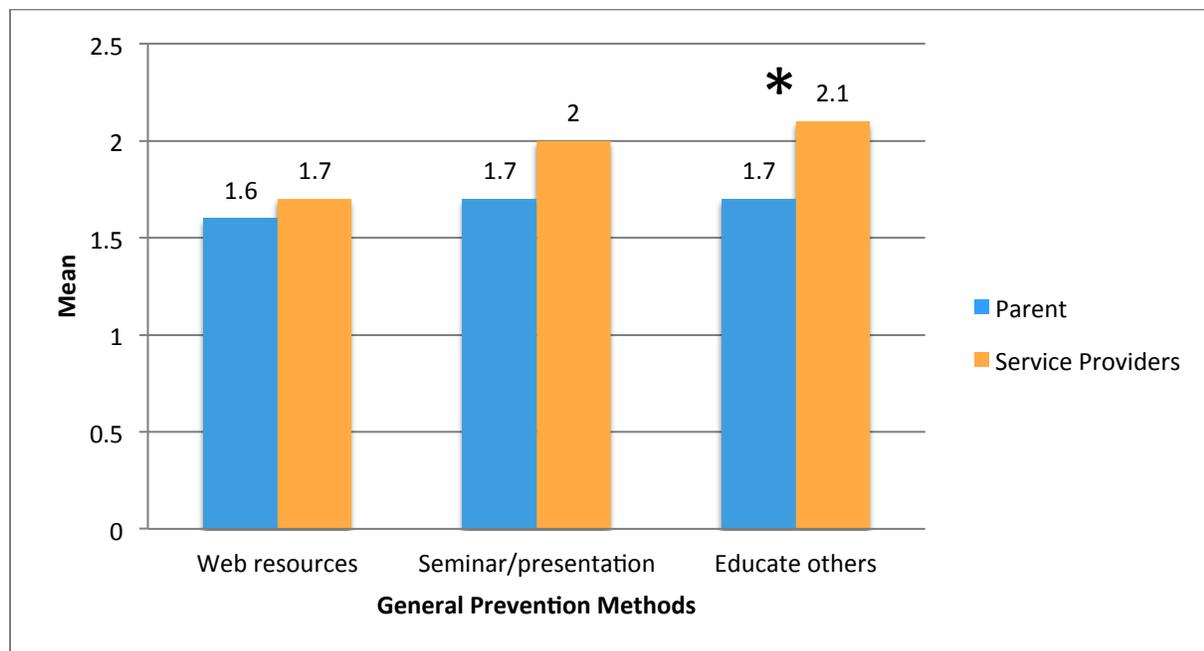
Figure 12. Bullying Perpetration Reported by Service Providers as Occurring “Often” or “Always”



Bullying Prevention Resources, Strategies, Programs, and Perceived Effectiveness

Respondents were asked about a variety of strategies they may have used to prevent bullying on a more general level. For those strategies that were used, they were asked to report on their effectiveness. Parents used web resources more and educating others on bullying less than service providers. Both parents and services providers attended seminars and presentations equally often. Service providers found educating others and attending seminars and presentations about bullying to be more effective (“somewhat effective” to “very effective”) than parents (“not at all effective” to “somewhat effective”). Parents and service providers found web resources to be “not at all effective” to “somewhat effective,” as shown in Figure 13.

Figure 13. Effectiveness of General Prevention Methods Reported by Parents of Children (Grades 3-12) with Disabilities and Service Providers



Note. Responses are on 3-point Likert-type scale from 1 (*Not at all effective*) to 3 (*Very effective*). * is a significant difference between the two means reported by parents of children with disabilities and service providers.

Parents who indicated that their child had been bullied were asked about the specific strategies they used. For the strategies they used, parents were also asked to indicate their effectiveness. As shown in Figure 14, the most common response for almost every strategy was “have not tried.” Strategies endorsed as being “somewhat effective” when the child was being bullied included avoiding contact between the bully and victim, suggesting things to say to the bully, telling the child to get help from a teacher, and seeing a counselor as “somewhat effective” strategies. Strategies such as restricting the child’s electronics and changing schools were perceived as even more effective, but it should be noted these were used less often. Most parents agreed that ignoring a child’s reports of bullying or telling the child to ignore it is not an effective strategy to deal with bullying.

Figure 14. Strategies Parents Have Tried When Their Child is Being Bullied and Effectiveness Reported by Parents of Children (Grades 3-12) with Disabilities

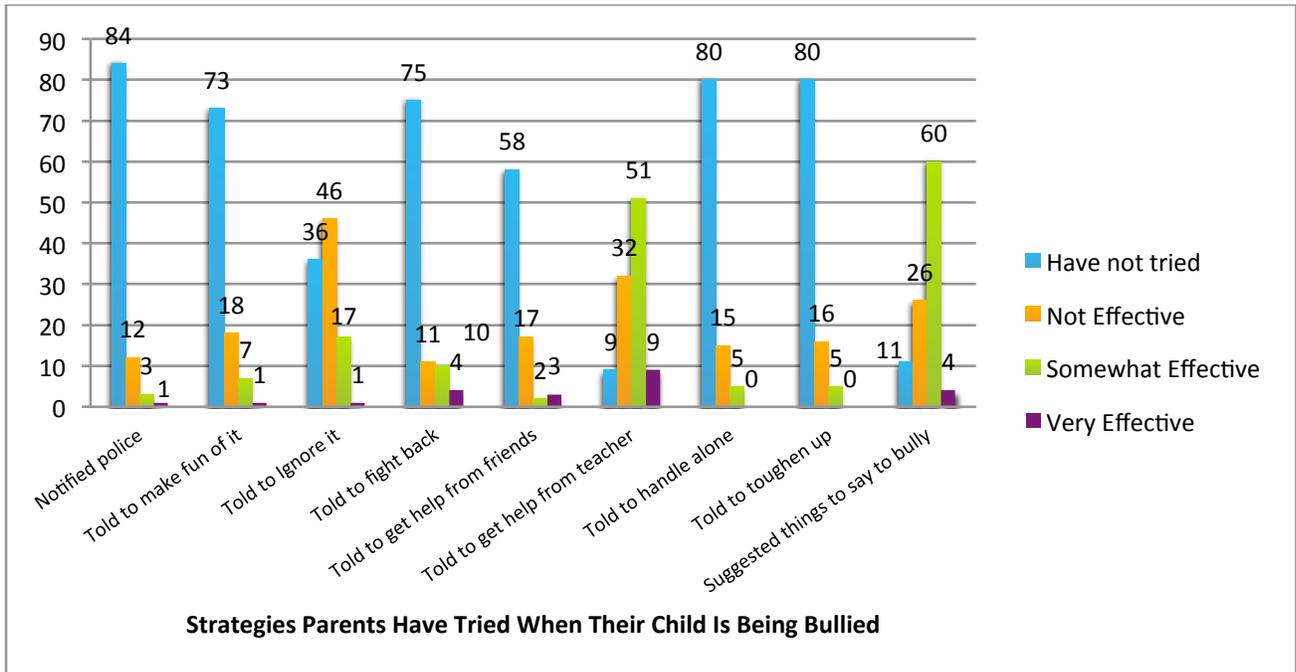
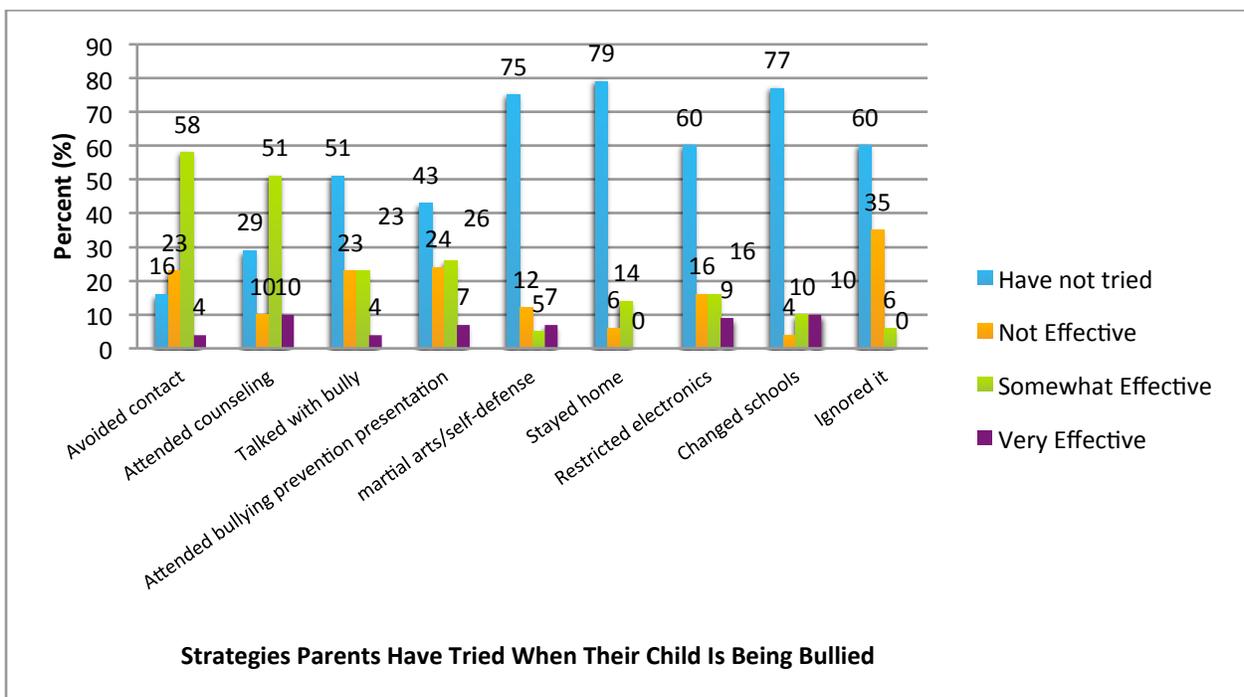
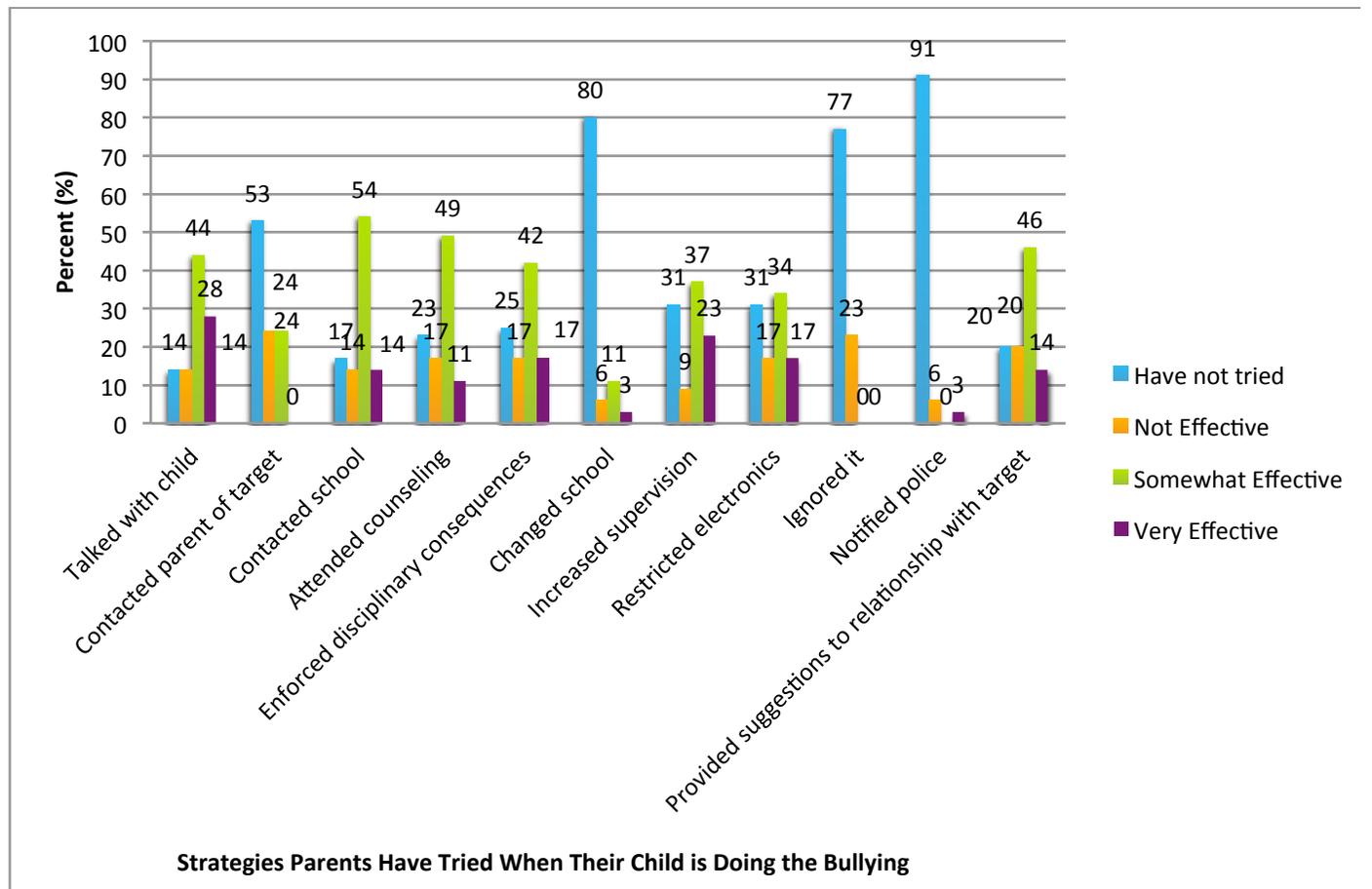


Figure 15. Additional Strategies Parents Have Tried When Their Child is Being Bullied and Effectiveness Reported by Parents of Children (Grades 3-12) with Disabilities



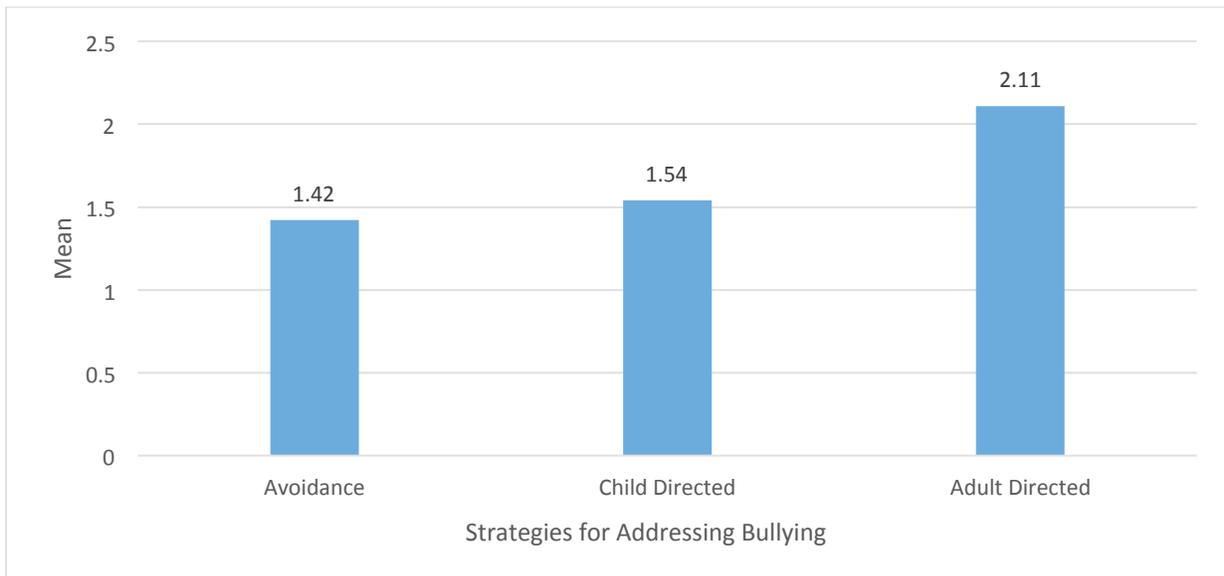
In contrast, when their child was doing the bullying, parents found that contacting the school, having the child attend counseling, talking with the child, enforcing disciplinary consequences, and providing suggestions to improve their relationship with the other child were “somewhat effective” (see Figure 16). Overall, parents found strategies to be more effective when their child was the bully than when their child was the target of bullying.

Figure 16. Strategies Parents Have Tried When Their Child is Doing the Bullying and Effectiveness Reported by Parents of Children (Grades 3-12) with Disabilities



Inconsistent with parent reports, service providers reported that avoidance strategies ($\alpha = .33$; 2 items), such as changing schools/work setting or staying home from school/work as less effective ($M = 1.42$, $SD = .41$; “not at all effective” to “somewhat effective”). Service providers also found child directed strategies (i.e., things the child can do to address bullying; $\alpha = .74$; 4 items) such as telling the child to try to make fun of it, ignore it, “toughen up,” and handle it on their own to be “not at all effective” to “somewhat effective” ($M = 1.54$, $SD = .47$). However, service providers found that adult-directed strategies (i.e., adult led strategies to address bullying; $\alpha = .77$; 6 items) were “somewhat effective” to “very effective” in addressing bullying ($M = 2.11$, $SD = .38$). These strategies included contacting the school, asking a teacher for help, and talking to the bully and/or target of bullying following an incident (see Figure 17).

Figure 17. Strategies Service Providers Have Tried and Their Effectiveness



Note. Responses are on 3-point Likert-type scale from 1 (*Not at all effective*) to 3 (*Very effective*).

Respondents agreed that all strategies on the survey (e.g., teaching people to be kind, avoiding contact between bullying and victim, counseling) would be helpful to treat each other better EXCEPT letting the people involved work it out alone. Service providers and parents disagree that letting the people involved work it out alone would be helpful, while adults with disabilities indicate equal responses that it would and would not be helpful. All respondents (parents, adults with disabilities, and service providers) perceived punishing people who treat others badly and separating the people from each other as less helpful strategies. Responses between service providers were also mixed about whether making more laws, teaching people how it feels to be treated badly so they know it's wrong (teaching reciprocity), and getting help from someone else would help people treat each other better. Parents of youth with disabilities provided mixed responses about whether teaching the child what it feels like to be bullied would help people treat each other better.

Summary of Quantitative Findings

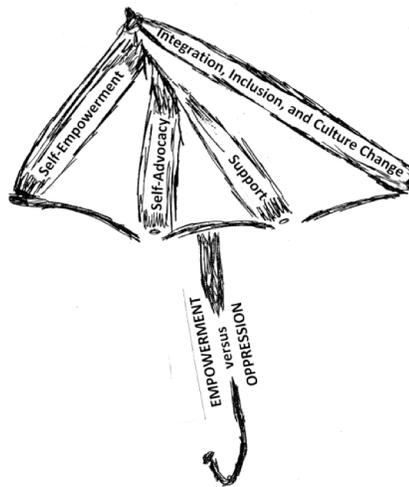
These results suggest that individuals with disabilities experience bullying victimization at rates comparable to or more than their peers without disabilities depending on the bullying behavior. Bullying perpetration by students with disabilities is less common than bullying victimization of students with disabilities, with the majority of respondents indicating that bullying perpetration had not occurred. Although parents and service providers use a variety of prevention and intervention strategies, bullying prevention and intervention for individuals with disabilities is complex without a one size fits all solution. Parents found strategies to be more effective when their child was the bully than when their child was the target of bullying. Most parents agreed that ignoring a child's reports of bullying or telling the child to ignore it is not an effective strategy to deal with bullying. Service providers suggest that child-directed strategies are not very effective, but adult-directed strategies may be more promising.

QUALITATIVE FINDINGS

Emergent Themes and a Core Category

The research team determined that the core idea or category for this data set was **Empowerment versus Oppression**, and that embedded within this core idea, there were four emergent themes:

- Self-Empowerment
- Self-Advocacy
- Support
- Integration, Inclusion, and Cultural Change



This figure is a graphic conceptualization of how the core idea/category anchors the four emergent themes.

The research team chose **Empowerment versus Oppression** as a core category because the comments, ideas, opinions, stories, and sentiments present in the dataset addressed the problem of bullying for people with disabilities as a form of oppression, which can be changed through empowerment. Even though there is a limited amount of research on bullying and individuals with developmental disabilities, the theme of oppression and powerlessness is clearly present in the general research that has been conducted on bullying. Bullying is an abuse of power that disempowers the target. It reduces a person's autonomy and produces oppression. As a result of oppression and powerlessness, targets experience negative emotions, diminished physical, emotional, and psychological health, and often, isolation.

Empowerment is key to addressing the problem of bullying and individuals with developmental disabilities. The comments, ideas, opinions, stories, and sentiments that participants shared with us spoke eloquently about the need for individuals with disabilities to have a voice, and to be integrated into the community as ways to reduce bullying. Empowerment is experienced on multiple levels, and as such, participants' comments, ideas, opinions, stories, and sentiments seemed to fall into four areas that all related to contexts that affect each other. These four areas became the emergent themes and allowed data to be grouped into one of these four areas. The four emergent themes were: (1) self-empowerment, (2) self-advocacy, (3) support, and (4) integration, inclusion, and cultural change. These themes overlap with each other, and are all connected to the idea of empowerment versus oppression.

The first emergent theme focuses on the **self-empowerment** of the individual. Being or becoming empowered is a unique experience for each person, and while no one becomes empowered alone, the experience itself is owned by the individual. Thus, self-empowerment of the individual is the first area of focus. Individuals, however, depend on relationships and connections within a like-minded community; thus, they are connected to others. The people in the **self-advocacy** movement are representative of this empowered community of individuals with disabilities who have claimed their voice and who seek to support their peers within the community of individuals with disabilities.

The work of self-advocates, however, does not stand on its own, as there are strong networks of **support** that come from family, staff, advocates, educators, service professionals, and others, as well as peers. These people are invested in promoting self-empowerment and self-advocacy within the community of individuals with disabilities.

Finally, all of these individuals, groups, and networks of support, are either promoted or constrained by conditions within the environment that represent a broader set of influences such as societal attitudes, political will, laws, and regulations. Thus, the final emergent theme was **integration, inclusion, and cultural change**.

Data Organization

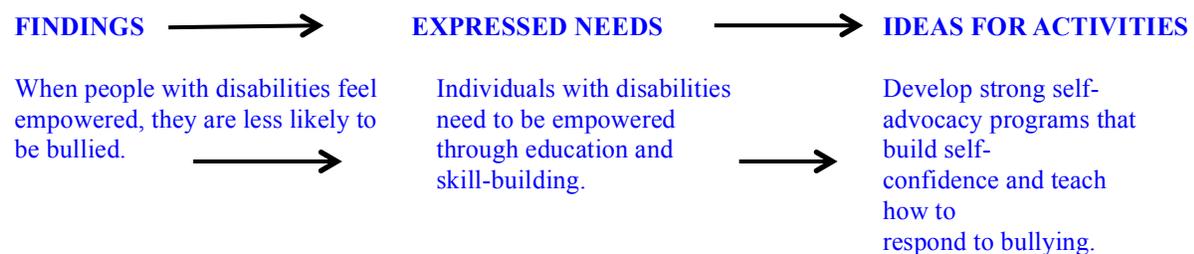
Under each theme, comments, ideas, opinions, stories, and sentiments were organized into three groups: (1) findings, (2) expressed needs, and (3) ideas for activities. For example, under the theme of self-empowerment, data are grouped by findings, expressed needs, and ideas for activities. These three groups capture the nature of the data.

Findings tend to be observations, statements of belief, or assertions. This does not mean that they are factually accurate. In fact, within some groups of findings there were conflicting ideas, yet they represent what was important to our participants with regards to the issue of bullying.

Expressed Needs reflect answers to questions about what is needed to deal with bullying and individuals with disabilities. Some of the needs are concrete and others are more abstract. **Expressed Needs** flow from the **Findings**.

The last section contains suggestions or **Ideas for Activities** that participants thought might be useful in addressing the problem of bullying for individuals with developmental disabilities. **Ideas for Activities** flow from **Expressed Needs**.

The following graphic illustrates the progression from **Findings** to **Expressed Needs** to **Ideas for Activities** (see Appendix C for a complete description).



Summary of Qualitative Findings

The focus group and interview findings coalesced around the idea of empowerment as opposed to oppression. Bullying is recognized as an oppressive experience that diminishes those who are bullied. Empowerment is seen as the primary vehicle for addressing the problem of bullying at the individual, family, community, and society levels. A major theme was the need for education, support, and social change with regard to bullying of and among individuals with developmental disabilities. Suggested activities for addressing bullying focused on promoting self-advocacy, creating or strengthening supports for individuals with disabilities and their families, improving educational opportunities for all involved, and publicizing and celebrating the contributions of people with disabilities.

Negative behavior cannot be "driven out," it can only be diluted and overwhelmed (gradually) by kindness and helping everyone feel his/her inherent worth (not conditioned on looks, skill-level, cronyism, etc.) We need to recognize that the basis of such environments is a plenitude of one-to-one and small group exchanges rooted in the belief that everyone belongs and we are all of equal worth. Schools for too long have embraced a culture of competition that has subjugated the very universal need to connect and belong. So while many schools can claim to have an "anti-bullying program," if at the same time they make a show of valuing some students more than others, some staff more than others, they are merely window-dressing.

-Comment from a General Survey Respondent

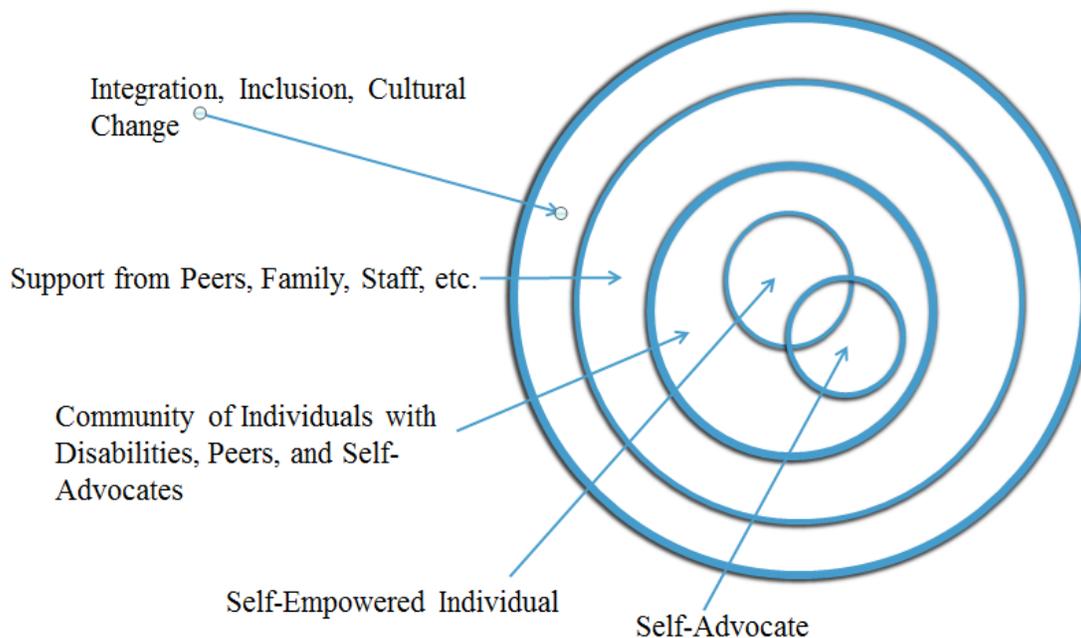
STRATEGIC PLANNING

Introduction

The process of developing a strategic plan was a collaborative effort between the Alberti Center research team and the NYS DDPC. On September 11, 2014, Amanda Nickerson and Katy Allen presented the findings to the NYS DDPC, at which members met in groups to discuss the findings and suggestions for future activities. The following goals and activities, integrating the feedback from the council, are the result.

The suggestions for the NYS DDPC strategic planning are organized in three groups, which reflect a social-ecological framework:

- Individuals with developmental disabilities that are part of a community of empowered individuals, peers, and self-advocates
- Families and advocates who support each other and individuals with developmental disabilities
- Systems-level, social, institutional, and cultural factors



Based on this framework, three goals were developed. They include:

- Increase the ability of people with developmental disabilities to prevent and respond to bullying in safe ways
- Increase supports for people with developmental disabilities and their families to deal with bullying
- Increase awareness of the problem of bullying of individuals with developmental disabilities through education, inclusion, and cultural change

Using input from stakeholders, suggestions for activities, projects, and initiatives were organized under the three goals. These suggestions are as follows:

Individuals with Developmental Disabilities, Peers, and Self-Advocates

GOAL 1: Increase the ability of people with developmental disabilities to prevent and respond to bullying in safe ways.

1. Create a program for and by individuals with developmental disabilities to develop awareness and skills around bullying prevention and intervention within the disability community. Implement the program within the self-advocacy community across the state.
2. Develop a formal educational program (or strengthen an existing program) for people with developmental disabilities (of all ages) to assume roles as self-advocates. Within the context of this program, develop and implement a formal support network for self-advocates which facilitates camaraderie and connection. [This project requires the need to identify the self-advocacy skills to be developed and how these are taught now].
3. Develop, implement, and evaluate a program that helps individuals with disabilities learn about their disabilities and be able to explain their disabilities to others. Measure the effectiveness of this skill with regards to bullying prevention and intervention.
4. Develop or adapt a prevention program on bullying specifically for school-age children with developmental disabilities that is appropriate for their developmental age. Include information on how to create and execute a “safety plan” for students. Support schools and other groups in the adoption and use of this program for individuals with disabilities.
5. Develop a bullying prevention program designed for individuals with developmental disabilities in the workplace. Disseminate this program through ARCs, self-advocacy groups, and Parent-to-Parent Networks across New York State.

Families and Advocates of Individuals with Developmental Disabilities

GOAL 2: Increase supports for people with developmental disabilities and their families to deal with bullying.

1. Using existing networks of support for parents and family members of people with developmental disabilities (e.g., Parent to Parent), develop an online and/or telephone support network to assist with problems around bullying of people with developmental disabilities.
2. Create and disseminate an educational program on bullying for families and advocates of people with developmental disabilities. Emphasize rights and resources, as well as information on bullying and how to help them help their children, both those who are being bullied and those who are bullying.
3. Within NYS, create a location and/or entity that collects, houses, and disseminates information for families, educators, service providers, organizations, and researchers on bullying and people with developmental disabilities.

Systems Level: Community, Educational Institutions, and Government

GOAL 3: Increase awareness of the problem of bullying of individuals with developmental disabilities through education, inclusion, and cultural change.

1. Develop an educational presentation about people with developmental disabilities by people with disabilities for leaders within communities and community organizations (e.g., faith communities,

Rotary/Lions Club, town boards, YMCA, youth development organizations, recreational programs, coaching organizations) to support the inclusion of people with disabilities within their communities.

2. Participate in the development of certification requirements (with OPWDD) for direct service providers that develop knowledge and skills to recognize and address bullying among and between the individuals with whom they work.
3. Strengthen and support peer relationships between youth with and without developmental disabilities through involvement in meaningful activities (recreation, sports, extra-curricular). Focus on natural supports, sustainability, and evaluation of these efforts (this may include adapted recreation, TIES - Together Including Every Student, Best Buddies, or other approaches).
4. Support the creation or expansion of programs that bring adults with and without disabilities together (such as Best Buddies Citizens). Evaluate the effectiveness of these programs.
5. Create, implement, and evaluate a course for pre-service or master's level teachers and educators where they work closely with an individual with developmental disabilities for a semester. Promote the course for those studying to be teachers but who are not getting certified in special education.
6. Convene a state level conference that includes national experts on bullying and national experts on individuals with developmental disabilities to discuss a variety of issues including the challenge of the CDC definition of bullying and its usefulness for this population. Produce a "white paper" or other type of conference document that could become a resource for scholars, agencies, organizations and individuals to guide research, policy, and programmatic efforts to address bullying of and among people with developmental disabilities.
7. Create a public relations/media campaign that promotes awareness of the contributions of people with developmental disabilities. Target the workplace and public transportation as being particularly needy regarding this message.

CONCLUSIONS

Participation in this project has been an enlightening and enriching experience for the Alberti Center research team. Our first “a-ha” was the realization that we have spent a great deal of time studying bullying but we have given little thought to this issue with respect to individuals with developmental disabilities across the lifespan. Our second epiphany was that there is an extensive and active developmental disabilities community that had been largely invisible to us that is concerned about the problem of bullying. Last, we were moved by the openness, generosity, and compassion of the study participants who spoke to us about this problem. These remarkable individuals and their advocates told stories, described challenges, and offered ideas that reflected a desire to be proactive instead of reactive, to problem-solve instead of blame and to become self-empowered instead of dependent.

In this work, we have recognized that the mainstream media has brought to the public’s attention the problem of bullying among youth, but individuals with disabilities have been largely excluded from this discussion. We have observed that people who study bullying often fail to include individuals with disabilities in their research programs, and that adults with disabilities are missing from the national discourse on bullying, as well as from the research agenda.

We now know that bullying is a serious problem for some, but not all people with developmental disabilities. For those who experience bullying, it is oppressive, exacerbates loneliness and isolation, and inhibits the ability to make and maintain friendships. We know that bullying reduces people’s quality of life, frustrates their need to belong, and impairs their healthy development.

We also know that individuals with emotional or behavioral disabilities, poor social skills, and communication challenges appear to be at greater risk for involvement in bullying than individuals with other types of disabilities. We understand that bullying has not been addressed adequately for individuals with disabilities in schools and communities, and that it is tied to their status in our society.

We know that bullying prevention and intervention efforts are rarely designed with individuals with disabilities in mind. We also recognize that the disability community is as diverse as the population in general, and efforts to develop programs and initiatives need to be sensitive to this diversity.

Our work has shown us that parents and advocates work tirelessly to ensure that the rights of people with disabilities are respected, that they receive the supports they need, and that they struggle against social attitudes and practices which often exclude people with disabilities. We are humbled by their passion, commitment, perseverance, and strength.

As a center that offers training, conducts research, and advocates for increased attention to the issue of bullying, we are encouraged by the NYS DDPC’s desire to address the problem of bullying as it affects individuals with intellectual and developmental disabilities. We realize that this is important work to do. It has been our pleasure to partner with the NYS DDPC on this project. This experience has reshaped our thinking and given us pause to reconsider our perspectives on the work that we do. We are grateful to have had this opportunity and we look forward to speaking out, with and on behalf of, individuals with disabilities with regard to the problem of bullying.

REFERENCES

Note: References corresponding to the Strategic Planning Goals, Activities, and Research Support are included in Appendix D

- Ali, S., & Frederickson, N. (2006). Investigating the evidence base of social stories. *Educational Psychology In Practice*, 22(4), 355-377.
- Andreou, E., Didaskalou, E., & Vlachou, A. (2013). Bully/victim problems among Greek pupils with special educational needs: Associations with loneliness and self-efficacy for peer interactions. *Journal of Research in Special Educational Needs*, epub, doi:10.1111/1471-38
- Arora, C. M. J. (1991). The use of victim support groups. In P. K. Smith, & D. Thomson (Eds.), *Practical approaches to bullying* (pp. 59-66). London: Fulton.
- Baladerian, N. J., Coleman, T. F., & Stream, J. (2012). *Abuse of people with disabilities: Victims and their families speak out: A report on the 2012 national survey on abuse of people with disabilities*. Los Angeles, CA: Spectrum Institute Disability Abuse Project. Retrieved from www.disabilityandabuse.org/survey
- Bienert, H., & Schneider, B. H. (1995). Deficit-specific social skills training with peer-nominated aggressive-disruptive and sensitive-isolated preadolescents. *Journal of Clinical Child Psychology*, 24, 287-299.
- Blake, J. J., Lund, E. M., Zhou, Q., Kwok, O., & Benz, M. R. (2012). National prevalence rates of bully victimization among students with disabilities in the United States. *School Psychology Quarterly*, 27(4), 210-222.
- Bohlander, A. J., Orlich, F., & Varley, C. K. (2012). Social skills training for children with autism. *Pediatric Clinics of North America*, 59(1), 165-174.
- Bourke, S., & Burgman, I. (2010). Coping with bullying in Australian schools: How children with disabilities experience support from friends, parents and teachers. *Disability & Society*, 25, 359-371.
- Branson, C. E., & Cornell, D. G. (2009). A comparison of self and peer reports in the assessment of middle school bullying. *Journal of Applied School Psychology*, 25(1), 5-27.
- Brock, S. E., Nickerson, A. B., O'Malley, M. & Chang, Y. (2006). Understanding children victimized by their peers. *Journal of School Violence*, 5, 3-18.
- Brown, W. H., Odom, S. L., & Conroy, M. A. (2001). An intervention hierarchy for promoting young children's peer interactions in natural environments. *Topics in Early Childhood Special Education*, 21, 162-175.
- Charmaz, K., (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.

- Coie, J. D., & Koeppl, G. K. (1990). Adapting intervention to the problems of aggressive and disruptive rejected children. In S. R. Asher & J. D. Coie (Eds.), *Peer rejection in childhood* (pp. 309-337). New York: Cambridge University Press.
- Cooper, L., & Nickerson, A. B. (2013). Parent retrospective recollections of bullying and current views, concerns, and strategies to cope with children's bullying. *Journal of Child and Family Studies, 22*, 526-540.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage.
- Cornell, D., Klein, J., Konold, T., & Huang, F. (2012). Effects of validity screening items on adolescent survey data. *Psychological Assessment, 24*(1), 21-35.
- Cornell, D., & Sheras, P. (2003). *School Climate Bullying Survey*. Charlottesville, VA: University of Virginia.
- Cowie, H. (1998). Perspectives of teachers and pupils on the experience of peer support against bullying. *Educational Research and Evaluation, 4*, 108-125.
- Cowie, H., & Sharp, S. (1994). Tackling bullying through the curriculum. In P. K. Smith & S. S. Sharp (Eds.), *School bullying: Insights and perspectives* (pp. 84-107). London: Routledge.
- Cowie, H., & Wallace, P. (2000). *Peer support in action: From bystanding to standing by*. London: Sage.
- Carter, B. B., & Spencer, V. G. (2006). The fear factor: Bullying and students with disabilities. *International Journal of Special Education, 21*(1), 11-23.
- Centers for Disease Control and Prevention. (2009). *Child maltreatment prevention*. Retrieved from <http://www.cdc.gov/violenceprevention/childmaltreatment/index.html>
- Davis, S., & Nixon, C. (2010). *Youth voice project*. Downloaded 10/28/2011. No longer available online.
- Dinkes, R., Kemp, J., & Baum, K. (2009). *Indicators of school crime and safety: 2009* (NCES 2010-012/NCJ 228478). Washington, DC: National Center for Education Statistics, Institute of Education Sciences, U.S. Department of Education, and Bureau of Justice Statistics, Office of Justice Programs, U.S. Department of Justice.
- Ervin, R. A., Miller, P. M., & Friman, P. C. (1996). Feed the hungry bee: Using positive peer reports to improve the social interactions and acceptance of a socially rejected girl in residential care. *Journal of Applied Behavior Analysis, 29*, 251-253.
- Espelage, D. L., Basile, K. C., & Hamburger, M. E. (2012). Bullying perpetration and subsequent sexual violence perpetration among middle school students. *Journal of Adolescent Health, 50*, 60-65.
- Estell, D. B., Farmer, T. W., Irvin, M. J., Crowther, A., Akos, P., & Boudah, D. J. (2009). Students with exceptionalities and the peer group context of bullying and victimization in late elementary school. *Journal of Child and Family Studies, 18*, 136-150

- Farmer, T. W., Hamm, J. V., Petrin, R. A., Robertson, D., Murray, R. A., Meece, J. L., & Brooks, D. S. (2010). Supporting early adolescent learning and social strengths: Promoting productive contexts for students at risk for EBD during the transition to middle school. *Exceptionality, 18*, 94-106.
- Farmer, T. W., Petrin, R., Brooks, D. S., Hamm, J. V., Lambert, K., & Gravelle, M. (2012). Bullying involvement and school adjustment of rural students with and without disabilities. *Journal of Emotional and Behavioral Disorders, 20*(1), 19-37.
- Favazza, P. C., & Odom, S. L. (1997). Promoting positive attitudes of kindergarten-age children toward people with disabilities. *Exceptional Children, 63*, 405-418.
- Felix, E. D., Sharkey, J. D., Green, J. G., Furlong, M. J., & Tanigawa, D. (2011). Getting precise and pragmatic about the assessment of bullying: The development of the California Bullying Victimization Scale. *Aggressive Behavior, 37*, 234-247.
- Gini, G. (2004). Bullying in Italian schools: An overview of intervention programmes. *School Psychology International, 25*, 106-116.
- 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 U.S. Department of Education.
- Good, C. P., McIntosh, K., & Gietz, C. (Sept/Oct 2001). Integrating bullying prevention into schoolwide positive behavior support. *Teaching Exceptional Children, 48-56*.
- Harrist, A. W., & Bradley, K. D. (2003). "You can't say you can't play": Intervening in the process of social exclusion in the kindergarten classroom. *Early Childhood Research Quarterly, 18*, 185-205.
- Hawkins, D., Pepler, D. J., & Craig, W. M. (2001). Naturalistic observations of peer interventions in bullying. *Social Development, 10*, 512-527.
- Hebron, J. & Humphrey, N. (2014). Mental health difficulties among young people on the autistic spectrum in mainstream secondary schools: A comparative study. *Journal of Research in Special Educational Needs, 14*, 22-32.
- Holzbauer, J. J. (2008). Disability harassment observed by teachers in special education. *Journal of Disability Policy Studies, 19*(3), 162-171.
- Holzbauer, J. J., & Conrad, C. F. (2010). A typology of disability harassment in secondary schools. *Career Development for Exceptional Individuals, 33*(3), 143-154.
- Hong, J. S., Espelage, D. L., Grogan-Kaylor, A., & Allen-Meares, P. (2012). Identifying potential mediators and moderators of the association between child maltreatment and bullying perpetration and victimization in school. *Educational Psychology Review, 24*, 167-186.

- Hoza, B., Mrug, S., Pelham, W. E. Jr., Greiner, A. R., & Gnagy, E. M. (2003). A friendship intervention for children with Attention-Deficit/Hyperactivity Disorder: Preliminary finding. *Journal of Attention Disorders, 6*, 87-98.
- Humphrey, N. & Symes, W. (2011). Responses to bullying and use of social support among pupils with autism spectrum disorders (ASDs) in mainstream schools: A qualitative study. *Journal of Research in Special Educational Needs, 10*(2), 82-90.
- IBM Corp (2011). *IBM SPSS Statistics for Windows, Version 20.0*. Armonk, NY: IBM Corp.
- Interactive Autism Network (2013). Bullying and school experiences of children with ASD survey (1.0.1). Retrieved from https://www.ianresearch.org/pdfs/Community/IAN_BullyingAndSchoolExperiencesOfChildrenWithASD01-28-2013.pdf
- Jacobson, M. R., Assam, T., & Baez, J. G. (2013). The nature and frequency of inclusion of people with disabilities in program evaluation. *American Journal of Evaluation, 34*(1), 23-44.
- Karkhaneh, M., Clark, B., Ospina, M. B., Seida, J. C., Smith, V., & Hartling, L. (2010). Social stories™ to improve social skills in children with autism spectrum disorder: A systematic review. *Autism, 14*(6), 641-662.
- Kazdin, A. E., Bass, D., Siegel, T., & Thomas, C. (1989). Cognitive-behavioral therapy and relationship therapy in the treatment of children referred for antisocial behavior. *Journal of Consulting and Clinical Psychology, 57*, 522-535.
- Kochenderfer-Ladd, B., & Pelletier, M. E. (2008). Teachers' views and beliefs about bullying: Influences on classroom management strategies and students' coping with peer victimization. *Journal of School Psychology, 46*, 431-453.
- Kokina, A., & Kern, L. (2010). Social story™ interventions for students with autism spectrum disorders: A meta-analysis. *Journal Of Autism And Developmental Disorders, 40*(7), 812-826.
- Ladd, G. W. (1981). Effectiveness of a social learning method for enhancing children's social interaction and peer acceptance. *Child Development, 52*, 171-178.
- Leaf, J. B., Oppenheim-Leaf, M. L., Call, N. A., Sheldon, J. B., Sherman, J. A., Taubman, M....Leaf, L. (2012). Comparing the teaching interaction procedure to social stories for people with autism. *Journal of Applied Behavior Analysis, 45*, 281-298.
- Livingston, J. *Peer victimization scale*. Unpublished raw data.
- Lochman, J. E., Burch, P. R., Curry, J. F., & Lampron, L. B. (1984). Treatment and generalization effects of cognitive-behavioral and goal-setting interventions with aggressive boys. *Journal of Consulting and Clinical Psychology, 52*, 915-916.
- Lochman, J. E., Coie, J. D., Underwood, M. K., & Terry, R. (1993). Effectiveness of a social relations intervention program for aggressive and nonaggressive, rejected children. *Journal of Consulting*

and *Clinical Psychology*, 61, 1053-1058.

- Lochman, J. E., & Lenhart, L. A. (1993). Anger coping intervention for aggressive children: Conceptual models and outcome effects. *Clinical Psychology Review*, 13, 785-805.
- Marini, Z., Fairbairn, L., & Zuber, R. (2001). Peer harassment in individuals with developmental disabilities: Towards the development of a multi-dimensional bullying identification model. *Developmental Disabilities Bulletin*, 29(2), 170-195.
- McDonald, K., & Patka, M. (2012). "There is no black and white": Scientific community views on ethics in intellectual and developmental disability research. *Journal of Policy and Practice in Intellectual Disabilities*, 9, 206-214
- McGrath, L., Jones, R. S. P., & Hastings, R. P. (2010). Outcomes of anti-bullying intervention for adults with intellectual disabilities. *Research in Developmental Disabilities*, 31, 376-380.
- Menesini, E., Codecasa, E., Benelli, B., & Cowie, H. (2003). Enhancing children's responsibility to take action against bullying: Evaluation of a befriending intervention in Italian middle schools. *Aggressive Behavior*, 29, 1-14.
- Merrell, K. W., Gueldner, B. A., Ross, S. W., & Isava, D. M. (2008). How effective are school bullying intervention programs? A meta-analysis of intervention research. *School Psychology Quarterly*, 23(1), 26-42.
- Nansel, T. R., Overpeck, M., Pilla, R. S., Ruan, W. J., Simons-Morton, B., & Scheidt, P. (2001). Bullying behaviors among US youth: Prevalence and association with psychosocial adjustment. *The Journal of the American Medical Association*, 285(16), 2094-2100.
- Naylor, P., & Cowie, H. (1999). The effectiveness of peer support systems in challenging school bullying: The perspectives and experiences of teachers and pupils. *Journal of Adolescence*, 22, 467-479.
- New York State Education Department. (2012). *The Dignity for All Students Act*. The Dignity Act. Retrieved from <http://www.p12.nysed.gov/dignityact/>
- New York State Office for People with Developmental Disabilities [OPWDD]. (2011). Part 624 Handbook. Retrieved from <http://www.opwdd.ny.gov/node/780>
- Nickerson, A. B., Brock, S. E., Chang, Y., & O'Malley, M. (2006). Responding to children victimized by their peers. *Journal of School Violence*, 5, 19-32.
- Norwich, B., & Kelly, N. (2004). Pupil's views on inclusion: Moderate learning disabilities and bullying in mainstream and special schools. *British Educational Research Journal*, 30(1), 43-65.
- O'Connell, P., Pepler, D., & Craig, W. (1999). Peer involvement in bullying: Insights and challenges for intervention. *Journal of Adolescence*, 22, 437-452.
- Oden, S., & Asher, S. R. (1977). Coaching in social skills for friendship making. *Child Development*, 48, 495-506.

- Odom, S. L., McConnell, S. R., McEvoy, M. A., Peterson, C., Ostrosky, M., Chandler, L. K., Spicuzza, R. J., Skellenger, A., Creighton, M., & Favazza, P. C. (1999). Relative effects of interventions for supporting the social competence of young children with disabilities. *Topics in Early Childhood Special Education, 19*, 75-91.
- Olweus, D. (1993). *Bullying at school*. Cambridge, MA: Blackwell.
- Raskauskas, J., & Modell, S. (2011). Modifying anti-bullying programs to include students with disabilities. *TEACHING: Exceptional Children, 44*(1), 60-67.
- Reichow, R., & Volkmar, F. R., (2010). Social skills interventions for individuals with Autism: Evaluation for evidenced-based practices within a best evidence synthesis framework. *Journal of Autism and Developmental Disorders, 40*, 149-166.
- 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*(3), 174-181.
- Reynhout, G., & Carter, M. (2011). Evaluation of the efficacy of Social Stories™ using three single subject metrics. *Research in Autism Spectrum Disorders, 5*, 885-900.
- Rigby, K. (1996). *Bullying in schools: And what to do about it*. Melbourne: The Australian Council for Educational Research Ltd.
- Rose, C. A., Espelage, D. L., & Monda-Amaya, L. E. (2009). Bullying and victimisation rates among students in general and special education: A comparative analysis. *Educational Psychology, 29*(7), 761-776.
- Rose, C. A., Forber-Pratt, A. J., Espelage, D. L., & Aragon, S. R. (2013). The influence of psychosocial factors on bullying involvement of students with disabilities. *Theory into Practice, 52*(4), 272-279.
- Rose, C. A., Monda-Amaya, L. E., & Espelage, D. L. (2011). Bully perpetration and victimization in special education: A review of the literature. *Remedial and Special Education, 32*(2), 14-130.
- Rose, C. A., Swearer, S. M., & Espelage, D. L. (October 2012). Bullying and students with disabilities: The untold narrative. *Focus on Exceptional Children, 45*(2), 1-10.
- Ross, S. W., & Horner, R. H. (2009). Bully prevention in positive behavior support. *Journal of Applied Behavior Analysis, 42*(4), 747-759.
- Sasso, G. M., & Rude, H. A. (1987). Unprogrammed effects of training high-status peers to interact with severely handicapped children. *Journal of Applied Behavior Analysis, 20*, 35-44.
- Sharp, S., & Smith, P. K. (1993). Tackling bullying: The Sheffield project. In D. Tattum (Ed.), *Understanding and managing bullying* (pp. 45-56). Oxford: Heinemann Educational.
- Sheard, C., Clegg, J., Standen, P., & Cromby, J. (2001). Bullying and people with severe intellectual disability. *Journal of Intellectual Disability Research, 45*(5), 407-415.

- Sherer, Y. C., & Nickerson, A. B. (2010). Anti-bullying practices in American schools: Perspectives of school psychologists. *Psychology in the Schools, 47*, 217-229.
- Smith, J. D., Schneider, B. H., Smith, P. K., & Ananiadou, K. (2004). The effectiveness of whole-school antibullying programs: a synthesis of evaluation research. *School Psychology Review, 33*, 547-560.
- Smith, P., & Sharp, S. (1994). *School bullying: Insights and perspectives*. New York: Routledge.
- Son, E., Parish, S. L., & Peterson, A. (2012). National prevalence of peer victimization among young children with disabilities in the United States. *Children and Youth Services Review, 34*, 1540-1545.
- Soronoff, K., Dark, E., & Stone, V. (2011). Social vulnerability and bullying in children with Asperger Syndrome. *Autism, 15*, 355-272.
- 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*(1), 1058-1064.
- Stevens, V., Van-Oost, P., & de-Bourdeaudhuij, I. (2000). The effects of an anti-bullying intervention programme on peers' attitudes and behavior. *Journal of Adolescence, 23*, 21-34.
- Sugai, G., Horner, R., & Algozzine, B. (2011). Reducing the effectiveness of bullying behavior in school. OSEP Center on Positive Behavioral Interventions and Supports. Retrieved from: www.pbis.org.
- Sullivan, P. M., & Knutson, J. F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect, 24*(10), 1257-1273.
- Swearer, S.M. (2001). *The Bully Survey*. Unpublished manuscript. Department of Educational Psychology, The University of Nebraska – Lincoln, Nebraska, United States.
- Swearer, S., Siebecker, A., Johnsen-Frerichs, L., & Wang, C. (2010). Assessment of bullying/victimization: The problem of comparability across studies and across methods. In S. Jimerson, S. Swearer, & D. Espelage (Eds.), *Handbook of bullying in schools: An international perspective* (pp. 305-327). New York, NY: Routledge.
- Swearer, S. M., Wang, C., Maag, J. W., Siebecker, A. B., & Frerichs, L. J. (2012). Understanding the bullying dynamic among students in special and general education. *Journal of School Psychology, 50*, 503-520.
- Test, D. W., Richter, S., Knight, V., & Spooner, F. (2011). A comprehensive review and meta-analysis of the Social Stories literature. *Focus on Autism and Other Developmental Disabilities, 26*(1), 49-62.
- Ttofi, M. M., & Farrington, D. P. (2009). What works in preventing bullying: Effective elements of anti-bullying programmes. *Journal of Aggression, Conflict, and Peace Research, 1*(1). 13-24.

- Ttofi, M. M., Farrington, D. P., & Baldry, A. C. (2008). *Effectiveness of programmes to reduce school bullying: A systematic review*. Stockholm: Swedish National Council for Crime Prevention. Retrieved from www.bra.se
- Turner, H. A., Vanderminden, J., Finkelhor, D., Hamby, S., & Shattuck, A. (2011). Disability and victimization in a national sample of children and youth. *Child Maltreatment, 16*(4), 275-286.
- Van Cleave, J., & Davis, M. M. (2006). Bullying and peer victimization among children with special health care needs. *Pediatrics, 118*(4), e1212-e1219.
- Vessey, J. A., & O'Neill, K. M. (2011). Helping students with disabilities better address teasing and bullying situations: A MASNRN study. *The Journal of School Nursing, 27*(2), 139-148.
- Visconti, K. J., Sechler, C. M., & Kochenderfer-Ladd, B. (2013). Coping with peer victimization: The role of children's attributions. *School Psychology Quarterly, 28*, 122-140.
- White, K. J., Sherman, M. D., & Jones, K. (1996). Children's perceptions of behavior problem peers: Effects of teacher feedback and peer-reputed status. *Journal of School Psychology, 34*, 53-72.
- Whitney, I., Smith, P. K., & Thompson, D. (1994). Bullying and children with special educational needs. In P. K. Smith & S. Sharp (Eds.), *School bullying: Insights and perspectives* (pp. 213-240). London: Routledge.
- Zablotsky, B., Bradshaw, C. P., Anderson, C. M., & Law, P. (2013). Risk factors for bullying among children with autism spectrum disorders. *Autism, 18*, 419-427.

APPENDIX A

SURVEYS

School-Aged Youth (Grades 5-12) Survey

We are trying to learn more about how people treat each other. We will be asking questions about how other people treat you and how you treat others. This is not a test and there is no grade or score.

We would like you to tell the truth when you answer the questions. We won't know which answers are yours because we don't know your name.

You don't need to rush; you can take your time. You are allowed to take a break if you get tired. You can ask someone to help you if you would like.

You do not need to answer any questions that make you feel uncomfortable. You are allowed to skip those questions. You will not get in trouble for any answers that you give.

Please answer the questions the best that you can. When you are answering the questions, you only need to pick ONE of the choices.

If you want to have a chance to win a \$25 gift card for helping, you can let us know on the last page.

Part 1: About You

1. I am a:

Boy

Girl

2. I am _____ years old.

3. I am: (you can check more than 1 if true for you)

Asian

Caucasian/White

Hispanic or Latino(a)

Black or African American

Other (please tell us) _____

4. What grade are you in?

- 5th 9th
 6th 10th
 7th 11th
 8th 12th
 not sure

Part 2: About Things That May Happen to You

5. Here are some things that can happen to people.

Please choose NEVER, A LITTLE (ONCE A MONTH) OR A LOT (ONCE A WEEK) to let us know how many times these things have happened to you:

How many times do you...	Never	A little (once a month)	A lot (once a week)
Get teased or called names in a mean way?			
Hear that people are saying mean things or telling lies about you when you're not around?			
Get left out of a group or ignored in a mean way?			
Get hit, pushed, or hurt in a mean way?			
Get threatened by someone in a mean way?			
Get something stolen or broken by someone in a mean way?			
Get teased or called names by someone on the computer or in a text message?			

If you answered NEVER to all questions above, move to

Part 3: About How You Treat Others (page 3)

6. Where did these things happen to you? (You can check more than 1)

- At school
- At home
- At an activity I am in (i.e. Scouts)
- In the community
- At the sport I play
- On the bus
- When I am at my friend's house
- Somewhere else (write in): _____

7. How much of a problem were these things for you?

	Never	A little	A lot
I felt sick			
I could not make friends			
I felt sad			
I felt angry			
I had problems eating			
I stayed home			
I had problems with my family			
I had problems sleeping			
It was hard to learn			
Other (please tell us):			

8. What did you do when these things happened to you? (you can check more than 1)

- I walked away
- I told a friend
- I told an adult or staff person
- I told the person to stop
- I yelled at the person
- I ignored it
- I started crying
- I laughed or made a joke
- I made plans to get back at them
- I hit or hurt the person
- Something else (write in): _____

9. Did any of these things make it better?

- Yes No

10. What made it better? (you can put a circle around the thing that made it better, or you can write it here):

Part 3. About How You Treat Others

11. Here are some ways you might treat other people.

Please choose NEVER, A LITTLE (ONCE A MONTH) OR A LOT (ONCE A WEEK) to let us know how many times you have done these things:

How many times do you?	Never	A little (once a month)	A lot (once a week)
Tease or call someone else names in a mean way?			
Say mean things, or tell lies, about someone when they are not around?			
Leave another person out of a group or ignore another person in a mean way?			
Hit, push, or hurt another person in a mean way?			
Scare another person in a mean way?			
Steal or break another person's things in a mean way?			
Tease or say mean things about someone on the computer or in a text message?			

Part 4. About What We Can Do

12. Have you been in any programs that help people treat each other better?

Yes No

13. What type of program helped?

14. What do you think will help people treat each other better?

(you can check more than 1):

- More rules
- Punish people who treat others badly
- Teach people to treat others kindly
- Let people work it out by themselves
- Show people how to stand up for themselves
- Show people how to help others that are being treated badly
- Talk about the problem
- Provide more opportunities for individuals with and without disabilities to interact
with each other
- Something else (write in): _____

15. Please share your ideas for how the New York State Developmental Disabilities Planning Council can best use resources to address bullying prevention for individuals with disabilities.

We may have information from your parent(s) or guardian(s). We would like to keep track of when parent(s) or guardian(s) and their child both fill out this survey. To do this we need your name. We will not share the information you provided with anyone, including your parent(s) or guardian(s).

16. What is your name (first and last)? _____

THANK YOU FOR TAKING THE TIME TO ANSWER OUR QUESTIONS.

Would you like to participate in an interview and talk more about bullying? If so, please check yes and a member of our team will contact you.

Yes, I would like to participate in an interview.

No, please do not contact me.

Would you like to have a chance to win a \$25 gift card?

Yes No

If you answered yes, please give us your name, phone number and address (we will NOT include this information with your responses to the questions)

Name: _____

Street Address: _____

City, State, Zip code: _____

Phone number (with area code): _____

E-mail address: _____

Parent/Guardian/Legal Advocate Survey (of Children in Grades 3-12)

This survey is being conducted by the Alberti Center for Bullying Abuse Prevention and the New York State Developmental Disabilities Planning Council. The purpose is to study the prevalence and impact of bullying for individuals with developmental disabilities, and to learn ways to prevent bullying.

This survey will take approximately 20 minutes to complete.

Please answer the following questions about your child with a disability to the best of your knowledge. Please provide ONE answer to each question unless the question indicates you may choose more than one.

If you want to have a chance to win a \$25 gift card for participating, you can let us know on the last page of the survey.

Part 1: About You and Your Child

1. I am a:

- Male Female

2. My age is _____

3. I am: (check all that are true for you)

- Asian
- Caucasian/ White
- Hispanic or Latino(a)
- Black or African-American
- Other (write in) ____

4. What is your relationship to this child?

- Biological mother Stepmother
- Biological father Stepfather
- Adoptive mother Grandparent
- Adoptive father Guardian/caregiver
- Other (please specify)

5. How old is your child? _____

6. What grade is your child in? (Circle one)

3rd 4th 5th 6th 7th 8th 9th 10th 11th 12th Ungraded Classroom

7. Please select the category of primary eligibility, as indicated on your child’s IEP:

- Blind/Visual Impairment
- Mild Intellectual Disability
- Moderate Intellectual Disability
- Severe Intellectual Disability
- Profound Intellectual Disability
- Autism
- Hearing Impairment
- Deaf & Blind
- Orthopedic Impairment
- N/A – my child does not have an IEP

8. How much time does your child spend in the general education setting?

- Inside the regular classroom most of the day.
- Inside the regular classroom about half of the day.
- Inside the regular classroom less than half of the day.
- In a separate school, residential facility, or homebound/hospital setting.

9. During the past year, has your child had a one-to-one or shared aide or assistant in the classroom?

- Yes, all day
- Yes, part of the day
- No

Part 2: About Things That May have Happened to Your Child

10. Please answer how often each of these things has happened to your child in the past 6 months...	Never	Rarely	Sometimes	Often	Always	I don't know
Tricked into telling secrets	Never	Rarely	Sometimes	Often	Always	I don't know
Tricked into taking the blame when not their fault	Never	Rarely	Sometimes	Often	Always	I don't know
Doing unreasonable favors with little chance of return	Never	Rarely	Sometimes	Often	Always	I don't know
Been taunted or insulted by	Never	Rarely	Sometimes	Often	Always	I don't know

other children to point of distress						know
Tricked through practical jokes by someone who has played practical jokes on them before	Never	Rarely	Sometimes	Often	Always	I don't know
Provoked by others and only one that gets into trouble	Never	Rarely	Sometimes	Often	Always	I don't know
Been taunted or insulted and retaliated physically	Never	Rarely	Sometimes	Often	Always	I don't know
Lent money or things to someone who is unlikely to repay	Never	Rarely	Sometimes	Often	Always	I don't know
Been deceived by someone who has already deceived your child before	Never	Rarely	Sometimes	Often	Always	I don't know
Done something that has got them into trouble at the suggestion of others	Never	Rarely	Sometimes	Often	Always	I don't know
Been a victim of physical bullying	Never	Rarely	Sometimes	Often	Always	I don't know
Says something because doesn't understand social rules and gets into trouble	Never	Rarely	Sometimes	Often	Always	I don't know
Treated unkindly by teacher because of difficulties	Never	Rarely	Sometimes	Often	Always	I don't know
Excluded from activity by a teacher because of difficulties	Never	Rarely	Sometimes	Often	Always	I don't know
Tricked into buying lunch/treats for another child	Never	Rarely	Sometimes	Often	Always	I don't know
Believe what s/he is told regardless of source reliability	Never	Rarely	Sometimes	Often	Always	I don't know
Believe what s/he is told regardless of prior deception by same person	Never	Rarely	Sometimes	Often	Always	I don't know
Tricked into giving up objects of value	Never	Rarely	Sometimes	Often	Always	I don't know
Believes things that other people would view as clearly untrue	Never	Rarely	Sometimes	Often	Always	I don't know
Gives in to suggestions to say something that he or she could get into trouble for	Never	Rarely	Sometimes	Often	Always	I don't know
Believes many things that sees/reads in advertisements/internet	Never	Rarely	Sometimes	Often	Always	I don't know
Believes someone when they have lied to them in the past	Never	Rarely	Sometimes	Often	Always	I don't know
Is easily fooled	Never	Rarely	Sometimes	Often	Always	I don't know
Believes rumors even when	Never	Rarely	Sometimes	Often	Always	I don't

come from unreliable source						know
-----------------------------	--	--	--	--	--	------

11. The following are some things that can happen at school. Please answer how often each of these things has happened to your child at school in the past 6 months.	Not in the past 6 months	Once in the past month	2 or 3 times in the past month	About once a week	Several times a week	I don't know
Been teased or called names in a mean or hurtful way						
Had rumors or gossip spread in a mean or hurtful way behind your child's back?						
Been left out of a group or ignored on purpose in a mean or hurtful way						
Been hit, pushed, or physically hurt in a mean or hurtful way						
Been threatened in a mean or hurtful way						
Had sexual comments, jokes, or gestures made to your child in a mean or hurtful way						
Had things stolen or damaged in a mean or hurtful way						
Been teased, had rumors spread, or threatened through the Internet (like MySpace, Facebook, or e-mail) or text messaging in a mean or hurtful way by a student at your child's school						

IF YOU RESPONDED "NOT IN THE PAST 6 MONTHS" FOR ALL OF THE OPTIONS UNDER QUESTION 10 (I – FF). PLEASE SKIP TO PART 3.

Please think about the **Main** person who did these things to your child in the past month.

11. Is this child in a position of power or authority over your child?

Yes No

Please explain _____

13. Why do you think someone did these things (like teasing, rumor spreading, hitting, tricking) to your child?

When someone picked on my child, it was because...	Never	Sometimes	Usually	Always
They don't get along with my child	Never	Sometimes	Usually	Always
They are jealous of my child	Never	Sometimes	Usually	Always
They want to be like my child	Never	Sometimes	Usually	Always
They have different friends than my child	Never	Sometimes	Usually	Always
They are not as popular as my child	Never	Sometimes	Usually	Always
They don't think my child is cool	Never	Sometimes	Usually	Always
My child did something mean to them	Never	Sometimes	Usually	Always
My child is different from them	Never	Sometimes	Usually	Always
My child is smaller or bigger than most people his/her age	Never	Sometimes	Usually	Always
My child did something bad or wrong	Never	Sometimes	Usually	Always
My child was bugging or annoying them	Never	Sometimes	Usually	Always
My child has difficulty communicating	Never	Sometimes	Usually	Always
My child made them mad	Never	Sometimes	Usually	Always
My child's race/color of my child's skin	Never	Sometimes	Usually	Always

14.. Where did these things (e.g., teasing, rumor spreading, hitting, tricking, etc.) happen to your child? (Check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Classrooms | <input type="checkbox"/> On the bus (school bus or public transportation) |
| <input type="checkbox"/> Hallways | <input type="checkbox"/> On the way to or from school |
| <input type="checkbox"/> Lunch or eating areas | <input type="checkbox"/> On the way to/from home |
| <input type="checkbox"/> On the playground or sports field | <input type="checkbox"/> At social or recreation program |
| <input type="checkbox"/> Bathrooms or locker rooms | <input type="checkbox"/> I don't know |

Somewhere else (write in): _____

15.. When do these things (e.g., teasing, rumor spreading, hitting, tricking, etc.) happen to your child?

- Before school
- During classes
- Between classes (passing periods)
- During breaks (e.g., like lunch)
- After school
- During recess
- At home
- When no one else is looking
- I don't know

Some other time (write in): _____

16. What does your child do when this (like teasing, rumor spreading, hitting, tricking) happens to him/her?

My child...	Never	Sometimes	Usually	I don't know
Tells himself/herself it doesn't matter	Never	Sometimes	Usually	I don't know
Tells the person to stop	Never	Sometimes	Usually	I don't know
Tells himself/herself it was no big deal	Never	Sometimes	Usually	I don't know
Tells the teacher about what happened	Never	Sometimes	Usually	I don't know
Talks to a friend about what happened	Never	Sometimes	Usually	I don't know
Has a friend do something about it	Never	Sometimes	Usually	I don't know
Talks to a parent about what happened	Never	Sometimes	Usually	I don't know
Asks a parent what he/she should do	Never	Sometimes	Usually	I don't know

				know
Asks his/her teacher what he/she should do	Never	Sometimes	Usually	I don't know
Asks a friend to help him/her get back at the person	Never	Sometimes	Usually	I don't know
Asks the teacher to do something about it	Never	Sometimes	Usually	I don't know
Asks a parent to do something about it	Never	Sometimes	Usually	I don't know
Thinks about getting even with the person	Never	Sometimes	Usually	I don't know
Makes something bad happen to the person who hurt them	Never	Sometimes	Usually	I don't know
Blames himself/herself for doing something to deserve it	Never	Sometimes	Usually	I don't know
Feels sorry for himself/herself	Never	Sometimes	Usually	I don't know
Ignores it	Never	Sometimes	Usually	I don't know
Just walks away	Never	Sometimes	Usually	I don't know
Yells at the person	Never	Sometimes	Usually	I don't know
Hurts the person	Never	Sometimes	Usually	I don't know
Hits something to let off steam	Never	Sometimes	Usually	I don't know
Tries to forget it ever happened	Never	Sometimes	Usually	I don't know
Tries to find out why the person picked on him/her	Never	Sometimes	Usually	I don't know
Tries to get along with the person who hurt him/her	Never	Sometimes	Usually	I don't know
Makes believe nothing happened	Never	Sometimes	Usually	I don't know

Part 3. About How Your Child Treats Others

17. Now, please answer some questions about how your child has treated others at school during the school day <u>in the past 6 months.</u> How often has YOUR CHILD...	Not in the past 6 months	Once in the past month	2 or 3 times in the past month	About once a week	Several times a week	I don't know
Left another student out of a group or ignored another student on purpose in a mean or hurtful way						
Hit, pushed, or physically hurt another student in a mean or hurtful way						
Threatened another student in a mean or hurtful way						
Made sexual comments, jokes, or gestures to another student in a mean or hurtful way						
Stole or damaged another student's things in a mean or hurtful way						
Teased, spread rumors, or threatened others through the internet (like MySpace, Facebook, or email) or text messaging in a mean or hurtful way						
Teased or called another student names in a mean or hurtful way						
Spread rumors or gossip behind another student's back in a mean or hurtful way						

Other – Please explain: _____

THE BEHAVIORS WE ASKED ABOUT DURING THIS SURVEY WERE REFERRING TO BULLYING, AND WE WILL USE THAT TERM IN THE NEXT QUESTIONS

Think about actual situations involving your child. Please indicate how effective the following strategies were for you in preventing and/or intervening with bullying.

18. General Prevention	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Read written or web-based anti-bullying resources	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Attended anti-bullying presentation or seminar	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Educated others about bullying prevention (e.g., discussed prevention at meetings)	Have not tried	Not at all Effective	Somewhat Effective	Very Effective

19. Check the box below if your child has never bullied another child and SKIP TO QUESTION 20.

My child has never bullied another child

If my child was DOING the bullying...	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Talked with my child following a bullying incident	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Contacted and/or met with the parents of the other child following an incident	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Contacted and/or met with school staff following an incident	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Took my child to see a counselor	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Enforced disciplinary consequences for bullying others	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Moved him/her to a different school	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Provided more supervision (e.g., bus stops, sports field)	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Restricted his or her access to electronic devices (e.g., cell phone, internet)	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Ignored it	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Notified the police	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Provided suggestions to improve their relationship with the other child	Have not tried	Not at all Effective	Somewhat Effective	Very Effective

20. Check the box below if your child has never been bullied by another child and SKIP TO SECTION 4.

My child has never been bullied by another child

If my child was BEING bullied...	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Developed ways to avoid contact between the bully and my child	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Took my child to see a counselor	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Talked with the bully following an incident	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Attended bullying prevention presentation or	Have not	Not at all	Somewhat	Very

seminar	tried	Effective	Effective	Effective
Enrolled my child in martial arts or self-defense	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Let him/her stay home from school because he or she was afraid	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Restricted his or her access to electronic devices (e.g., cell phone, internet)	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Moved him/her to another school	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Ignored it	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Notified the police	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Told him/her to try to make fun of it	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Told him/her to try to ignore it	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Told him/her to fight back	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Told him/her to get help from friends	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Told him/her to get help from a teacher	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Told him/her to try to handle it alone	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Told him/her to try to “toughen up”	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Suggested things that he or she could say to the bully	Have not tried	Not at all Effective	Somewhat Effective	Very Effective

Section 4: About What We Can Do

21. Do you agree that the following are effective in helping people treat each other better?

	Agree	Not sure	Disagree
More laws to protect people with disabilities	Agree	Not sure	Disagree
Educate people in the community about the problem	Agree	Not sure	Disagree
Punish people who treat others badly	Agree	Not sure	Disagree
Teach people to treat others kindly	Agree	Not sure	Disagree
Teach people how it feels to be treated badly so they know it is wrong	Agree	Not sure	Disagree
Let the people involved work it out themselves	Agree	Not sure	Disagree

Make rules about not treating others badly at day programs and job sites	Agree	Not sure	Disagree
Show people how to stand up for themselves	Agree	Not sure	Disagree
Teach the person being unkind better ways to treat people	Agree	Not sure	Disagree
Separate the people from each other	Agree	Not sure	Disagree
Provide more opportunities for individuals with and without disabilities to interact with each other	Agree	Not sure	Disagree
Get help from someone else	Agree	Not sure	Disagree
Parents need to teach their kids not to treat others unkindly	Agree	Not sure	Disagree
Teach coping skills	Agree	Not sure	Disagree
Provide counseling	Agree	Not sure	Disagree

22. What bullying prevention programs are you aware of?

23. Of the bullying prevention programs you listed above which were helpful? Why?

24. Please share your ideas for how the New York State Developmental Disabilities Planning Council can best use resources to address bullying prevention for individuals with disabilities.

We may have information from your child. We would like to keep track of when parent(s) or guardian(s) and their child both fill out this survey. To do this we need your child's name. We will not share your child's name with anyone.

25.) What is your child's name (first and last)? _____

THANK YOU FOR TAKING THE TIME TO ANSWER OUR QUESTIONS.

Would you like your child to fill out a similar survey?

Yes No

If yes, what format would you like your child to fill it out?

Online Printed/Paper and Pencil

Would you or your child like to participate in an interview where you speak further about bullying? If so, please check yes and a member of the research team will contact you.

- Yes, **I** would like to participate in an interview.
- Yes, I would like only **my child** to participate in an interview.
- Yes, I would like both **my child and I** to participate in interviews.
- No

Would you like to have a chance to win a \$25 gift card (only email needed below)?

- Yes No

Would you like to receive a summary of the study results when the study is complete (only email needed below)?

- Yes No

If you answered yes to ANY of these questions, please give us your name, phone number and address (we will NOT include this information with your responses to the questions).

Your Name: _____

Street Address: _____

City, State, Zip code: _____

Phone number (with area code): _____

E-mail address: _____

Your Child's Name: _____

Adult Survey (18 and older)

We are trying to learn more about how people treat each other. We will be asking questions about how other people treat you and how you treat others. This is not a test and there is no grade or score.

We would like you to tell the truth when you answer the questions. We won't know which answers are yours because we don't know your name.

You don't need to rush; you can take your time. You are allowed to take a break if you get tired of answering too many questions, but please remember to come back to finish. You can ask someone to help if you would like.

You do not need to answer any questions that make you feel uncomfortable. You are allowed to skip those questions. You will not get in trouble for any answers that you give.

Please answer the questions the best that you can. When you are answering the questions, you only need to pick ONE of the choices unless the question says you may choose more than one.

If you want to have a chance to win a \$25 gift card for participating, you can let us know on the last page.

Part 1: About You

1. I am:

- Male Female

2. I am _____ years old.

3. I am: (you can check more than 1 if true for you)

- Asian
- Caucasian/ White
- Hispanic or Latino(a)
- Black or African-American
- Other (write in) ____

4. Has a doctor, or someone else, ever told you that you have a disability?

- Yes No I don't know

5. If you answered yes to the last question, do you know the name of the disability you were told that you have? (you can check more than 1 if true for you)

- Cerebral Palsy
- Intellectual Disability
- Physical Disability
- Autism / Asperger’s Syndrome
- I don’t know
- Other: _____
- Down Syndrome
- Learning Disability
- Vision and/or Hearing Impairment
- Traumatic Brain Injury (TBI)
- I’m not comfortable saying

6. Does having a disability ever stop you from going to community events or going to work?

- Yes
- No

Part 2: About Things That May Happen to You

7. Here are some things that can happen to people.

Please choose NEVER, A LITTLE (ONCE A MONTH) OR A LOT (ONCE A WEEK) to let us know how many times these things have happened to you:

How many times do you...	Never	A little (once a month)	A lot (once a week)
Get teased or called names in a mean way	Never	A little	A lot
Hear that people are saying mean things or telling lies about you when you’re not around	Never	A little	A lot
Get left out of a group or ignored in a mean way	Never	A little	A lot
Get hit, pushed, or hurt in a mean way	Never	A little	A lot
Get threatened by someone in a mean way	Never	A little	A lot
Get sexual comments or jokes said to you in a mean way	Never	A little	A lot
Get something stolen or broken by someone in a mean way	Never	A little	A lot

If you answered NEVER to all questions above, move to

Part 3: About How You Treat Others

8. Where did these things (being teased, left out, threatened) happen to you? (You can check more than 1)

- | | |
|--|---|
| <input type="checkbox"/> At home | <input type="checkbox"/> At work or where you volunteer |
| <input type="checkbox"/> At day program | <input type="checkbox"/> On the way to or from work |
| <input type="checkbox"/> On the bus | <input type="checkbox"/> During lunch |
| <input type="checkbox"/> Out in the community | <input type="checkbox"/> On my computer |
| <input type="checkbox"/> On my phone | <input type="checkbox"/> At my friend's house |
| <input type="checkbox"/> At a sport that I play | <input type="checkbox"/> At a group that I am part of |
| <input type="checkbox"/> At my doctor or therapy appointment | <input type="checkbox"/> Other: _____ |

9. When someone does these things to me, it is because....

	Never	Sometimes	Always
They want the things I have	Never	Sometimes	Always
We don't get along	Never	Sometimes	Always
I am not as cool as them	Never	Sometimes	Always
I did something mean to them	Never	Sometimes	Always
We don't like each other	Never	Sometimes	Always

The color of my skin	Never	Sometimes	Always
I am different from them	Never	Sometimes	Always
I am smaller or bigger than most people	Never	Sometimes	Always
I did something bad or wrong	Never	Sometimes	Always
I have more friends than they do	Never	Sometimes	Always
They want to be like me	Never	Sometimes	Always
I was bugging or annoying them	Never	Sometimes	Always
I don't dress the same as them	Never	Sometimes	Always
They have a hard time understanding me when I talk	Never	Sometimes	Always
We have different friends	Never	Sometimes	Always
They don't like my friends	Never	Sometimes	Always

10. How much of a problem were these things (being teased, left out, threatened) for you?

I felt sick	Not at all	A little	A lot
I could not make friends	Not at all	A little	A lot
I felt sad	Not at all	A little	A lot
I felt angry	Not at all	A little	A lot
I had problems eating	Not at all	A little	A lot
I stayed home	Not at all	A little	A lot
I had problems with my family	Not at all	A little	A lot
I had problems sleeping	Not at all	A little	A lot
It was hard to work	Not at all	A little	A lot
Other (please tell us):	Not at all	A little	A lot

11. What do you do when people treat you badly?

	Never	Sometimes	Always
Tell yourself it is not a big deal	Never	Sometimes	Always
Tell a family member about what happened	Never	Sometimes	Always
Talk to a friend about how it made you feel	Never	Sometimes	Always
Tell a staff person about what happened	Never	Sometimes	Always
Think about getting back at the person	Never	Sometimes	Always
Tell the person to stop	Never	Sometimes	Always
Pretend nothing happened	Never	Sometimes	Always
Tell someone else that you trust about what happened	Never	Sometimes	Always

Ask a family member to help you	Never	Sometimes	Always
Make something bad happen to the person who was mean	Never	Sometimes	Always
Try to forget about it.	Never	Sometimes	Always
Ask a staff person to help you	Never	Sometimes	Always
Ask a friend to help you	Never	Sometimes	Always
Ask the person why they were mean to you	Never	Sometimes	Always
Blame yourself for letting it happen	Never	Sometimes	Always
Ask someone else that you trust to help you	Never	Sometimes	Always
Get away from the person	Never	Sometimes	Always
Yell at the person	Never	Sometimes	Always
Hurt the person	Never	Sometimes	Always
Try to get along or be nice to the person who hurt you	Never	Sometimes	Always
Hit something to let off steam	Never	Sometimes	Always
Write about your feelings	Never	Sometimes	Always
Feel sorry for yourself	Never	Sometimes	Always
Ignore the person who is being mean	Never	Sometimes	Always
Do something to make you feel better (watch tv, eat, walk)	Never	Sometimes	Always

12. Now think about what other people you spend time would do in the following situations.

People you spend time with would help out if:	Never	Sometimes	Most of the Time
A person is making fun of or teasing another person	Never	Sometimes	Most of the Time
A person is spreading rumors or lies about another person when they are not around	Never	Sometimes	Most of the Time
A person was being mean to someone else on the computer or on the phone	Never	Sometimes	Most of the Time
A person or group of people is pushing, shoving, or trying to fight with another person.	Never	Sometimes	Most of the Time

Part 3. About How You Treat Others

13. Here are some ways you might treat other people.

Please choose **NEVER, A LITTLE (ONCE A MONTH) OR A LOT (ONCE A WEEK)** to let us know how many times you have done these things:

How many times do you:	Never	A little (once a month)	A lot (once a week or more)
Tease or call another person names in a mean way	Never	A little	A lot
Spread rumors, lies, or say mean things about someone when they are not around	Never	A little	A lot
Leave another person out or ignore another person in a mean way	Never	A little	A lot
Hit, push, or hurt another person in a mean way	Never	A little	A lot
Threaten or scare another person in a mean way	Never	A little	A lot
Make sexual comments or jokes to another person in a mean way	Never	A little	A lot
Steal, damage, or break another person's things in a mean way	Never	A little	A lot
Tease or say mean things about someone on the computer or on the phone	Never	A little	A lot

Part 4. About What We Can Do

14. Have you been in any programs that help people treat each other better?

Yes No

15. What type of program helped?

16. Do you agree that the following are effective in helping people treat each other better?

	Agree	Not sure	Disagree
More laws to protect people with disabilities	Agree	Not sure	Disagree
Educate people in the community about the problem	Agree	Not sure	Disagree
Punish people who treat others badly	Agree	Not sure	Disagree

Teach people to treat others kindly	Agree	Not sure	Disagree
Teach people how it feels to be treated badly so they know it is wrong	Agree	Not sure	Disagree
Let the people involved work it out themselves.	Agree	Not sure	Disagree
Make rules about not treating others badly at day programs and job sites	Agree	Not sure	Disagree
Show people how to stand up for themselves	Agree	Not sure	Disagree
Teach the person being unkind better ways to treat people	Agree	Not sure	Disagree
Separate the people from each other	Agree	Not sure	Disagree
Get help from someone else	Agree	Not sure	Disagree
Parents need to teach their kids not to treat others unkindly	Agree	Not sure	Disagree
Teach coping skills	Agree	Not sure	Disagree
Provide more opportunities for individuals with and without disabilities to interact with each other.	Agree	Not sure	Disagree
Provide counseling	Agree	Not sure	Disagree

17. Please share your ideas for how the New York State Developmental Disabilities Planning Council can best use resources to address bullying prevention for individuals with disabilities.

THANK YOU FOR TAKING THE TIME TO ANSWER OUR QUESTIONS.

Would you like to participate in an interview where you speak further about bullying? If so, please check yes and a member of the research team will contact you.

Yes, I would like to participate in an interview.

No, please do not contact me.

Would you like to have a chance to win a \$25 gift card (only email needed below)?

Yes No

Would you like to receive a summary of the study results when the study is complete (only email needed below)?

Yes No

If you answered yes, please give us your name, phone number and address (we will NOT include this information with your responses to the questions)

Name: _____

Street Address: _____

City, State, Zip code: _____

Phone number (with area code): _____

E-mail address: _____

General Survey (Educators, Service Providers, Employers, and Others who Interact with People with Disabilities)

This is an anonymous survey conducted by the Alberti Center for Bullying Abuse Prevention and the New York State Developmental Disabilities Planning Council. The project's mission is to measure the impact of bullying for individuals with developmental disabilities across all ages and settings, identify existing resources, supports, and programming on bullying prevention, and community capacity to address bullying prevention.

This survey will take approximately 20 minutes to complete. At the end of this survey you may wish to give us your contact information (email address and/or phone number) so we can send you a link that allows you to schedule participation in an individual interview or focus group

Please answer the following questions about your experiences with people with disabilities to the best of your ability. Please provide ONE answer to each question unless the question indicates you may choose more than one.

If you want to have a chance to win a \$25 gift card for participating, you can let us know on the last page.

Part 1: About You

1. Which of the following best describes your relationship with people with disabilities?

- Administrator/manager of organization serving people with disabilities
- Educator (pre-K -12)
- Direct care worker
- Social worker in the field of disabilities
- Mental health professional
- Court official (attorney, parole or probation worker, judge)
- Policymaker (legislator or work for one)
- Employer of person with disabilities
- Concerned citizen
- Other (write in)* _____

*Note: If you are a person with a disability, please complete the School Age or Adult Survey

If you are a parent of a child with a disability (in grades 5-12), please complete the Parent Survey

2. How much time per week do you spend with individuals with intellectual or developmental disabilities?

- 1-10 hours
- 11-20 hours
- 21-30 hours
- 31-40 hours
- more than 40 hours
- I do not spend any time interacting DIRECTLY with people with intellectual or developmental disabilities [IF YOU CHECK THIS OPTION, SKIP TO PART 2]

3. What are the ages of the individuals with disabilities you typically interact with (Check all that apply)?

- Infants/Preschools
- High School Adolescents
- Elementary Children
- Adults (Over 18)
- Middle School Adolescents

4. How many people with intellectual and developmental disabilities do you interact with on a daily basis?

- 1-5 people
- 6-10 people
- 11-15 people
- 16-20 people
- more than 20 people

5. In what setting do you DIRECTLY interact with people with intellectual and developmental disabilities? (Check all that apply)

- General education school setting
- Special education school setting
- Individual's apartment or home
- Residential placement (e.g., group home, residential treatment)
- Day program or volunteer site
- Community-based setting (e.g., recreation department, religious)
- Employment site of individual with a disability
- Other (please explain): _____

Part 2: Experiences with Bullying

Bullying is any **unwanted aggressive behavior(s)** by another individual or group of individuals who are not siblings or current dating partners that involves **an observed or perceived power imbalance**. **It is repeated multiple times or is highly likely to be repeated**. Bullying may inflict harm or distress on the targeted individual including physical, psychological, social, or educational **harm**.

This also may include **cyberbullying**, which happens using electronic devices such as a cell phone, a computer, or an iPad. People sometimes use these devices to text, email, do electronic chat, post on Facebook, send photos, or tweet. Cyberbullying is when someone uses these devices to repeatedly tease, harass, or socially isolate someone on purpose.

6. Using this definition, and thinking about the past 6 months, please answer to the best of your knowledge how often the following incidents have happened to someone with a disability that you know/interact with.

How often has someone with a disability that you know...	Never	Rarely	Sometimes	Often	Always
Been physically bullied (repeatedly hit, kicked, or shoved by someone on purpose)	Never	Rarely	Sometimes	Often	Always
Been verbally bullied (repeatedly teased, put down, or insulted by someone on purpose)	Never	Rarely	Sometimes	Often	Always
Been relationally bullied (repeatedly ignored, left out on purpose, or gossiped about)	Never	Rarely	Sometimes	Often	Always
Been cyberbullied (repeatedly teased, harassed, or socially isolated through electronics like cell phone, internet, on purpose)	Never	Rarely	Sometimes	Often	Always

7. Who do you believe is the most likely person to bully people with disabilities?

- A stranger who a person with a disability encounters alone in a private or public place
- Someone with whom he/she is acquainted
- Someone who works closely with the person
- Other _____

8. Using the same definition of bullying, and thinking about the past 6 months, please answer to the best of your knowledge, how often someone with a disability that you know/interact has done these things to someone else (with or without a disability).

How often has someone with a disability that you know...	Never	Rarely	Sometimes	Often	Always
Physically bullied others (repeatedly hitting, kicking, or shoving others on purpose)	Never	Rarely	Sometimes	Often	Always

Verbally bullied others (repeatedly teasing, putting down, or insulting others on purpose)	Never	Rarely	Sometimes	Often	Always
Relationally bullied others (repeatedly ignoring, leaving out on purpose, or gossiping about others)	Never	Rarely	Sometimes	Often	Always
Cyberbullied others (repeatedly teasing harassing, or socially isolating others through electronics like cell phone, internet, on purpose?)	Never	Rarely	Sometimes	Often	Always

9. Based on your observations or experiences, how much more prevalent is bullying against people with disabilities compared to people without disabilities?

- Much less common for individuals with disabilities to be bullied
- Slightly less common for individuals with disabilities to be bullied
- Individuals with disabilities and individuals without disabilities are bullied about the same
- Slightly more common for individuals with disabilities to be bullied
- Much more common for individuals with disabilities to be bullied
- I don't know

10. These are some reasons why people might be bullied. Please indicate how often you think each one is a reason for bullying individuals with disabilities.

When people bully individuals with disabilities it is because...	Never	Sometimes	Usually	Always
They are just jealous of the person with the disability	Never	Sometimes	Usually	Always
They don't get along with the person with the disability	Never	Sometimes	Usually	Always
They want to be like the person with the disability	Never	Sometimes	Usually	Always
They have different friends than the person with the disability	Never	Sometimes	Usually	Always
They are not as popular as the person with the disability	Never	Sometimes	Usually	Always
They (and the person with the disability) like different kinds of people	Never	Sometimes	Usually	Always
They don't think the person with the disability is cool	Never	Sometimes	Usually	Always

They are bugged or annoyed by the person with the disability	Never	Sometimes	Usually	Always
The person with the disability did something mean to them	Never	Sometimes	Usually	Always
The person with the disability is different from them	Never	Sometimes	Usually	Always
The person with the disability is smaller or bigger than most people his/her age	Never	Sometimes	Usually	Always
The person with the disability did something bad or wrong	Never	Sometimes	Usually	Always
The person with the disability was bugging or annoying them	Never	Sometimes	Usually	Always
The person with the disability is difficult to understand	Never	Sometimes	Usually	Always
The person with the disability is not as good looking as other people	Never	Sometimes	Usually	Always
The person with the disability did something they didn't like	Never	Sometimes	Usually	Always
The person with the disability made them mad	Never	Sometimes	Usually	Always
The person with the disability would not leave them alone	Never	Sometimes	Usually	Always
The person with the disability is a different race or has a different color of skin	Never	Sometimes	Usually	Always

Part 3: Resources and Strategies

11. Think about actual bullying situations involving individuals with disabilities with whom you interact. Please indicate how effective the following strategies were in preventing and/or intervening with bullying.

	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Developed ways to avoid contact between the bully and victim	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Obtained written or web-based anti-bullying resources	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Attended anti-bullying presentation or seminar	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Talked with the person being bullied following a bullying incident	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Talked with the bully following an incident	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Contacted and/or met with the parents/family member of a bully or victim following an incident	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Contacted and/or met with official (school staff, employer) following a bullying incident	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Enforced disciplinary consequences for bullying others	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Educated others about bullying (e.g., discussed at meetings)	Have not tried	Not at all Effective	Somewhat Effective	Very Effective

Provided more supervision (e.g., bus stops, sports field)	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Tried to comfort person being bullied.	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Referred person being bullied to a counselor	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Referred person being bullied to martial arts or self-defense	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Let person being bullied stay home from school or work because he or she was afraid	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Restricted person being bullied's access to electronic devices (e.g., cell phone, internet)	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Moved person being bullied to another school or work setting	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Ignored it	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Notified the police	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Told person being bullied to try to make fun of it	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Told person being bullied to try to ignore it	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Told person being bullied to fight back	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Told person being bullied to get help from friends	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Told person being bullied to get help from a teacher or employer	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Told person being bullied to try to handle it alone	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Told person being bullied to try to "toughen up"	Have not tried	Not at all Effective	Somewhat Effective	Very Effective
Suggested things that person being bullied could say to the bully	Have not tried	Not at all Effective	Somewhat Effective	Very Effective

12. Do you agree that the following are effective in helping people treat each other better?

	Agree	Not sure	Disagree
More laws to protect people with disabilities	Agree	Not sure	Disagree
Educate people in the community about the problem	Agree	Not sure	Disagree
Punish people who treat others badly	Agree	Not sure	Disagree
Teach people to treat others kindly	Agree	Not sure	Disagree
Teach people how it feels to be treated badly so they know it is wrong	Agree	Not sure	Disagree
Let the people involved work it out themselves	Agree	Not sure	Disagree

Make rules about not treating others badly at day programs and job sites	Agree	Not sure	Disagree
Show people how to stand up for themselves	Agree	Not sure	Disagree
Teach the person being unkind better ways to treat people	Agree	Not sure	Disagree
Separate the people from each other	Agree	Not sure	Disagree
Provide more opportunities for individuals with and without disabilities to interact with each other	Agree	Not sure	Disagree
Get help from someone else	Agree	Not sure	Disagree
Parents need to teach their kids not to treat others unkindly	Agree	Not sure	Disagree
Teach coping skills	Agree	Not sure	Disagree
Provide counseling	Agree	Not sure	Disagree

13. What bullying prevention programs are you aware of?

14. Of the bullying prevention programs you listed above which were helpful? Why?

15. Please share your ideas for how the New York State Developmental Disabilities Planning Council can best use resources to address bullying prevention for individuals with disabilities.

THANK YOU FOR TAKING THE TIME TO ANSWER OUR QUESTIONS.

Would you like to participate in an interview where you speak further about bullying? If so, please check yes and a member of the research team will contact you.

Yes No

Would you like to have a chance to win a \$25 gift card?

Yes No

Would you like to receive a summary of the study results when the study is complete?

Yes No

If you answered yes to ANY of these questions, please give us your name, phone number and address (we will NOT include this information with your responses to the questions).

Your Name: _____

Street Address: _____

City, State, Zip code: _____

Phone number (with area code): _____

E-mail address: _____

APPENDIX B

FOCUS GROUP AND INTERVIEW PROTOCOLS

Focus Group/Interview¹ Protocol For Individuals with Intellectual or Developmental Disabilities

(Italicized text is spoken. Bullets are probes. Non italicized text is directive or informational.)

Introduction and Purpose

Hi. My name is _____. I will be conducting the interview/focus group today. I am from the Alberti Center at the University of Buffalo. I want to thank you for participating today.

(Introduce others in the room [e.g., note-taker, videographer, etc.] and explain why they are there and what they will be doing.)

Since the two types of data collection (interview and focus group) are very similar, it will be up to the interviewer to find out from the interviewee what it is that has prompted him or her to ask to be interviewed beyond participation in the focus group. If he or she has participated in a focus group the footnote suggests how the opening to the conversation might go. For example, it may be that the person said nothing in the focus group. If that is the case, the protocol questions are relevant. However, it might be that the person has a very personal story to tell and didn't want to tell it in the group setting. In this case, an opening question such as, "You indicated that you had more information to share. Would you like to begin there?" should be enough to prompt the person, with the protocol supplying guidance to what follows in the interview. If the person hasn't participated in a focus group, then the focus group protocol would become the protocol for the interview.

The purpose of this interview/focus group is to talk to you about what you know about bullying and experiences that you may have had with bullying. I am part of a group of people who are interested in finding out what you know about bullying. We don't know enough about this topic. We are hoping that you can help us.

Interview: The length of this interview will depend on how much you have to share. It might be as short as 20 minutes, or as long as 60 minutes.

Thank you for your willingness to participate.

(If the person is a child or has a legal guardian)

Your legal guardian has given permission for you to speak with us. It is also important for us to know that you want to do this. We don't want anyone to make you feel that you have to do this.

¹ If the person being interviewed has already participated in a focus group, the protocol will be modified to reflect this previous experience. The interviewer will still begin by reviewing the participant's rights as a research subject. However, when introducing each topic (i.e., victimization or bullying) the interviewer will ask what, if anything in particular, prompted the person to want to participate in an interview. The interviewer will ask questions such as, "Did you want to talk more about that? If so, what would you like to add?" Following that, the questions for the interview will be guided by this protocol.

(If the person is an adult)

Please know that during the interview/focus group, if there is a question or topic that you don't want to talk about, you don't have to. Also, if at any time you don't want to participate any more, you can leave, and it is OK.

If you decide not to answer a question, nothing bad will happen to you. If you decide to leave during the focus group (or end the interview), nothing bad will happen to you.

The information that you tell us is for the New York State Developmental Disabilities Planning Council and for the University of Buffalo. We will share your comments with other people, but we will not tell them your name(s) or where you live.

Also, you won't get in trouble for talking to us about bullying. We want you to feel comfortable sharing your thoughts and experiences with us. We want you to feel safe. If you are uncomfortable or need assistance at any time, please tell us. If you don't understand something, please ask us to explain it again. We want this to be a good experience for you. So please tell us if you have a need or a concern at any time.

Along those lines, you may want to talk about specific people. If you do, it would be best if you did not share their names with us. However, if you do, we will not use their real names when we talk or write about what you tell us. If you want to make up a fake name for the person, that would be O.K.

Focus Group: Because this is a conversation with several people, we would like to ask everyone here to keep the information they hear today to themselves and not share it with other people, especially the names of people in this group who shared information and the people they talked about. Also if someone talks about a specific person and uses that person's name, we need to keep that information to ourselves. We call this confidentiality. We are not able to guarantee that everyone will keep this information private, but we will try. So, to begin, can everyone agree that what they hear said in this focus group will be kept confidential? That means that you will keep it to yourself and not tell anyone else, nor will you tell the names of the people from this group.

(Look for nods from all participants.)

Focus Group: This focus group is being videotaped so that we can remember exactly what you say and write down your comments in your own exact words. We will keep these tapes and copies of your comments as a part of our research, but we will not tell anyone whose voice is on the tape or who made the comments in our written record or reports. This focus group will take 1½ to 2½ hours. We will take a break after about one hour and fifteen minutes. Do you have any questions?

Interview: This interview is being tape recorded so that we can remember exactly what you say, and write down your comments in your own exact words. We will keep these tapes and copies of your comments as a part of our research, but we will not tell anyone whose voice is on the tape or who made the comments in our written record or reports. Do you have any questions?

You are volunteering to speak with us. That means that you don't have to do this if you don't want to. Are you willing to participate?

(Focus groups: Ask for either a nod of the head or a verbal “yes.” For minors or legal dependents, this qualifies as assent.)
(For interviews: Get a verbal assent.)

So before we begin to talk about bullying, I want to make sure that you are comfortable.

- *If you don't want to answer a question or talk about something, do you have to?*
- *If you don't answer a question or talk about something, will anything bad happen to you?*
- *If you want to leave during the focus group (or end the interview), can you?*
- *If you leave the focus group (or end the interview), will anything bad happen to you?*
- *What will you do if you don't understand a question?*
- *What will you do if you have a concern?*

Focus Group: A focus group is a conversation among several people. It is an activity where people are asked to talk about certain topics or answer questions. In a focus group, you are free to talk to each other, as well as to me about the topics or questions. You can ask the people in the group what they mean by a comment or you can ask them questions that you think will help us understand their experiences and ideas better. If you want to make a comment or ask a question, just raise your hand and you can talk when the speaker is finished. When people are done speaking, I'll ask another question. That way, the conversation will keep going. Do you have any question about how a focus group works? Let's begin by going around and introducing ourselves to each other.... Just say your first name.

Thank you.

Victimization

I'd like to begin by asking a general question: Can you tell me what you know about bullying? Can you talk about being bullied?

This could be something you experienced yourself, or it could be something that you know about that happened to someone else.

- *What happened?*
- *When did it happen?*
- *Where did it happen?*
- *Who did it?*
- *What did the person or persons do?*
- *What did the person bully about? (topic)*
 - *What did the person say or do that was hurtful?*
- *What do you think caused the person to bully?*
 - *Do you have any thoughts as to why the person bullied?*
- *Did the person mean to cause hurt by the bullying or was it on accident?*
- *How many times did it happen?*
- *Did the bullying involve a cell phone, an electronic tablet, or a computer?*
 - *If so, what can you tell me about that?*
 - *Who? What? When? Where? How many times? Your (the bully's) feelings? Your response? Others' responses? Was someone told about it? What media platform (i.e., text, Twitter, Facebook, etc.)*
- *How did it make you (or the target) feel?*
- *Did the bullied person do or say anything to the person or persons to try to get them to stop?*
 - *If so, what did you (or the targeted person) do?*
 - *Did it get the person to stop?*

- *Did you (the person targeted) tell anyone? Why or why not? Did that person help you (them)?*
- *How did the person or persons help?*
- *When the bullying happened were there any bystanders? Bystanders are people who watch or see something happen.*
 - *If so, who were they and what did they do?*
- *Has being bullied affected your (the targeted person's) health? In other words, has it made you (the targeted person) feel sick? Has it caused you (the targeted person) to feel stressed? Has it caused you (the targeted person) to worry? If so, how?*
- *How has being bullied changed you (the targeted person)?*
- *Has anyone ever taught you (the targeted person) how to respond to bullying?*
 - *If so, what did you (they) learn?*
 - *Have you (they) used that information?*
 - *If so, when, where, and how did it work?*
- *Do you know how to get help if you can't make the person stop hurting you?*
 - *Where can you go to get help?*
- *Do you know who to get help from if you can't make the person stop hurting you?*
 - *Who can you go to get help?*
- *Before we move on to a different conversation, is there anything anyone/you want(s) to say about the problem of bullying or about being bullied?*

Bullying

I'm curious to know what you know about people who bully others. Maybe some of you know people who bully. Maybe some of you have bullied others yourself.

Would you be willing to talk about that?

I understand if you don't want to talk about your own experience, but it will help us to understand bullying better if we can understand how and why some people bully others.

What can you tell us about bullying others?

- *What happened?*
- *When did it happen?*
- *Where did it happen?*
- *Did the bullying involve a cell phone, an electronic tablet, or a computer?*
 - *If so, can you tell me about that?*
 - *Who? What? When? Where? How many times? Your (the bully's) feelings? Your response? Others' responses? Was someone told about it? What media platform (i.e., text, Twitter, Facebook, etc.)*
 - *Did anyone help you? What did they do? What were the effects on you?*
- *What did you (the bully) bully the person about?*
- *What was it about the situation or the person that caused you (the bully) to bully the person?*
- *How many times did it happen?*
- *How did it make you (the bully) feel?*
- *Did anyone tell you (or the bully) to stop doing it? If so, who and when? Did you (the bully) stop bullying the person after that?*
- *When the bullying happened were there any bystanders?*

- *If so, who were they and what did they do?*
- *Had the person you bullied ever bullied you? OR Did the person who bullied ever been bullied by the person he/she bullied?*
- *What effect did being a bully have on you (the bully)?*
- *Before we end our interview/focus group, is there anything anyone /you want(s) to say about the problem of bullying or about bullying other people?*

Conclusion

I would like to thank you for all of your time and your effort in helping us out. Before we finish, is there anything that I didn't ask you about that you would like to talk about? Are there any concerns or issues that you would like to mention? Is there anything else you want to share about something having to do with bullying?

(Probe as necessary.)

Also, if you would like to speak to a researcher alone to share more information, we invite you to participate in an interview.... but only if you have more to say than what you said in this group. If you would like to participate in an interview and you did not indicate this on the sheet you filled out at the beginning, please let us know. We will give the sheet back to you and you can fill it out. These interviews will be held at another time. We will contact you to set up a time and a place for the interview. It might be held over the phone or using Skype on a computer. If you do want to participate in an interview, please make sure that you sign another consent form before you go today.

If you are feeling upset or uncomfortable about our conversation today and you would like some support, we have a list of resources here that can help you. If you have an immediate problem with bullying, there are also resources that you can contact to get help with your situation. Please feel free to contact someone if you are feeling upset, worried, or sad about our conversation today.

**Focus Group/Interview² Protocol for
Family Members/Advocates/Friends/Acquaintances/Classmates/Coworkers
of Individuals with Intellectual or Developmental Disabilities**

(Italicized text is spoken. Bullets are probes. Non italicized text is directive or informational.)

Introduction and Purpose

Hi. My name is _____. I will be conducting the interview/focus group today. I am from the Alberti Center at the University of Buffalo. I want to thank you for participating today.

(Introduce others in the room [e.g., note-taker, videographer, etc.] and explain why they are there and what they will be doing.)

Since the two types of data collection (interview and focus group) are very similar, it will be up to the interviewer to find out from the interviewee what it is that has prompted him or her to ask to be interviewed beyond participation in the focus group. If he or she has participated in a focus group the footnote suggests how the opening to the conversation might go. For example, it may be that the person said nothing in the focus group. If that is the case, the protocol questions are relevant. However, it might be that the person has a very personal story to tell and didn't want to tell it in the group setting. In this case, an opening question such as, "You indicated that you had more information to share. Would you like to begin there?" should be enough to prompt the person, with the protocol supplying guidance to what follows in the interview. If the person hasn't participated in a focus group, then the focus group protocol would become the protocol for the interview.

I am part of a group of people from the New York State Developmental Disabilities Planning Council and the University of Buffalo who are interested in learning about the experiences of individuals with intellectual or developmental disabilities and the problems they have with bullying because we don't know enough about this topic.

We are hoping that you can help us. We appreciate your willingness to talk to us. Please know that if there is a question you don't want to answer or a topic you don't wish to discuss, you don't have to. Also, if at any time you don't want to participate any more, you can leave or end the interview, and it is OK. There will be no consequences for you or your dependent.

We will share your comments with other people, but we will not tell them who you are or who your son/daughter/sibling/legal dependent, etc., is. When we share this information we will not use anyone's real name. In our reports we will identify you as a family member, guardian, legal advocate, friend, associate, etc. of an individual with disabilities, and we will give your age, gender, and race/ethnicity. It is important that we share what we learn so that we

² If the person being interviewed has already participated in a focus group, the protocol will be modified to reflect this previous experience. The interviewer will still begin by reviewing the participant's rights as a research subject. However, when introducing each topic (i.e., victimization or bullying) the interviewer will ask what, if anything in particular, prompted the person to want to participate in an interview. The interviewer will ask questions such as, "Did you want to talk more about that? If so, what would you like to add?" Following that, the questions for the interview will be guided by this protocol.

can determine the scope and nature of the problem of bullying for individuals with intellectual and developmental disabilities, and devise some ways to address this problem.

This focus group is being videotaped (or this interview is being tape-recorded) so that we can remember exactly what you say, and write down your comments in your own exact words. We will not disclose your identity to anyone. The recordings will be kept in a secure location at the Alberti Center and only members of the research team will have access to them.

Focus Group: Because this is a conversation with several people, we would like to ask everyone here to keep the information they hear today to themselves and not share it with other people, especially the names of people in this group who shared information and the people they talked about. We call this confidentiality. Can everyone agree that what they hear here will be kept confidential?

Focus Group: Likewise, we ask that you try not to use someone's real name, other than your family member's name, when telling us about his or her experiences. We will not use his or her name in any of our reports or documents. We wish to protect the anonymity of your child or legal dependent, as well as those you speak of, but if you do mention anyone's name, we will not include it in any of our documents or reports.

Thank you!

Do you have any questions?

Focus Group: In a focus group, you are free to talk to each other, as well as to me about the topics. You can ask the people in the group what they mean by a comment or you can ask them questions that you think will help us understand their experiences and ideas better. This focus group will take 1½ to 2½ hours. We will take a break after about one hour and fifteen minutes.

At the end of this if you would like to give more input on this subject, please sign up to participate in an interview. If you would like to participate in an interview, we'll return your Demographic Information Sheet to you so that you can add the necessary information.

If you do wish to be interviewed, please sign an additional consent form before you leave. If you are under the age of 18, and you want to be interviewed, please take a consent form home with you and have your parent/guardian sign it. We will contact you about the logistics for an interview in the next few weeks. Most interviews will be conducted over the telephone or Skype, and these interviews will be audiotaped. Even if you sign up for an interview and provide us with a consent form, you can change your mind later if you don't want to participate. There will be no consequences if you change your mind.

Interview: The length of this interview will depend on how much you have to share. It might be as short as 20 minutes, or as long as 60 minutes.

Introduction

Focus Group:

Let's begin by going around and introducing ourselves to each other. What is your first name?

Focus Group and Interview:

Who among your family members is an individual with intellectual or developmental disabilities?

- *In what capacity are you involved with your child, legal dependent, and his or her peers?*
 - *Do you get to observe your child or legal dependent with peers? (first hand info)*

- *Do you only hear about your child's/legal dependent's interactions with peers from him or her?... or from his or her caregivers? (second hand info)*

Can you tell me about him or her?

- *What is the nature of his/her disability?*
- *Where does he/she work or go to school?*
- *Where and with whom does he/she live?*
- *What is your involvement with him/her?*
 - *To what extent do you advocate for him/her?*
 - *To what extent are you responsible for him/her?*

Victimization

Do you know if _____ has ever experienced bullying by peers?

Can you tell me what you know about it?

- *What happened?*
- *When did it happen?*
- *Where did it happen?*
- *Who did it?*
- *What did the person or persons do?*
 - *Did it involve the use of cell phones, electronic tablets, or computers? If so, can you tell me about it?*
- *What did the person bully _____ about?*
- *Do you have any thoughts about why the person bullied _____?*
- *How many times did it happen?*
- *How did it make _____ feel?*
- *How did it make you feel?*
- *Do you know if _____ did anything to the person or persons to try to get them to stop? If so, what did _____ do? Did it get the person to stop?*
- *Were there any bystanders around when this happened?*
 - *If so, who were they and what did they do?*
- *How did you learn about this situation?*
- *Did _____ tell anyone? Why or why not? Did that person help _____?*
- *How did the person or persons help _____?*
- *Has being bullied affected _____'s health? If so, how?*
- *How has being bullied changed _____?*
- *How has this affected you and/or your family?*
- *Has anyone ever taught _____ how to respond to bullying?*
 - *If so, what did _____ learn?*
 - *Has _____ used that information?*
 - *If so, when, where, and how did it work?*
- *Do you know of any other experiences that _____ had with being bullied?*
 - *Repeat questions above regarding each instance of bullying.*

Bullying

I'm curious to know if _____ has ever bullied anyone.

Are you aware of any instances?

Can you tell me about _____ bullying others?

- *What happened?*
- *When did it happen?*
- *Where did it happen?*
- *What did _____ bully the person about?*
 - *Did the bullying involve the use of cell phones, electronic tablets, or computers? If so, can you tell me about it?*
- *What did the target or targets do in response?*
- *Were there any bystanders there when this happened?*
 - *If so, who was there and what did they do?*
- *Do you have any thoughts about why _____ bullied the person?*
- *How many times did it happen?*
- *Are you aware of what _____ was feeling when he/she bullied the person?*
- *Do you know if the person did anything to _____ to get him/her to stop?*
 - *If so, what did the person do?*
 - *Did it get _____ to stop?*
- *Did an adult or supervisor get involved with _____ as a result of the bullying?*
 - *What did the person do to stop the bullying and prevent it from happening again?*
 - *Did it work? In other words, was it effective?*
- *How did you learn about this situation?*
- *What effect has this had on you/your family?*
- *Do you know if and what kind of education or training _____ has had regarding bullying and why it is not acceptable?*
 - *If so, what was included in the training?*
 - *Do you think _____ understood the information?*
- *Have you had access to information to help you with this problem?*
 - *If so, what information did you have?*
 - *Where did you get it?*
 - *Did it help you?*
- *Do you know of any other instances where _____ was involved in bullying others?*
 - *Repeat questions above regarding each instance of bullying.*

Prevention/Intervention

What types of prevention education would be helpful for individuals with intellectual and developmental disabilities and their families?

Where do you think this information and/or training should come from?

- *Who do you think should do it?*

What could or should be done when it comes to intervening in bullying problems with individuals with intellectual and developmental disabilities?

Definition of Bullying

Before we finish up, could you give me a definition of bullying, or explain what makes a particular situation bullying, and not something else?

Use of Resources

Research on bullying and individuals with intellectual and developmental disabilities is an understudied concern. If funds and resources were available to study this problem, what do you think we should specifically look at?

If resources were available to spend on initiatives that might address the problem of bullying and individuals with intellectual and developmental disabilities:

- *What types of things do you think should be done?*
- *What should we consider... educational programs, public campaigns to promote inclusion/integration and acceptance, work to help individuals with intellectual and developmental disabilities have better communication skills and coping strategies, etc....?*
- *Who should we target for these initiatives... the individuals with intellectual and developmental disabilities themselves, families, caregivers, support staff, managers... etc.?*

Conclusion

I would like to thank you for all of your time and your effort in helping us out. Before we finish, is there anything that I didn't ask you about that you would like to talk about? Any concerns? Any issues?

(Probe as necessary.)

Also, if you would like to speak to a researcher alone to share more information, we invite you to participate in an interview.... but only if you have more to say than what you said in this group. If you would like to participate in an interview and you did not indicate this on the sheet you filled out at the beginning, please let us know. We will give the sheet back to you and you can fill it out. These interviews will be held at another time. We will contact you to set up a time and a place for the interview. It might be held over the phone or using Skype on a computer. If you do want to participate in an interview, please make sure that you sign another consent form before you go today.

If you are feeling upset or uncomfortable about our conversation today and you would like to talk to a counselor or support person, we have a list of resources here that can help you. If you have an immediate problem with bullying, there are also resources that you can contact to get help with your situation. Please feel free to contact someone if you are feeling upset, worried, or sad about our conversation today.

Focus Group/Interview³ Protocol for Direct Service Providers, Organization Managers, Professional Providers, and Agency Personnel who Support and Interact Directly or Indirectly with Individuals who Have Intellectual or Developmental Disabilities

(Italicized text is spoken. Bullets are probes. Non italicized text is directive or informational.)

Introduction and Purpose

Hi. My name is _____. I will be conducting the interview/focus group today. I am from the Alberti Center at the University of Buffalo. I want to thank you for participating today.

(Introduce others in the room [e.g., note-taker, videographer, etc.] and explain why they are there and what they will be doing.)

Since the two types of data collection (interview and focus group) are very similar, it will be up to the interviewer to find out from the interviewee what it is that has prompted him or her to ask to be interviewed beyond participation in the focus group. If he or she has participated in a focus group the footnote suggests how the opening to the conversation might go. For example, it may be that the person said nothing in the focus group. If that is the case, the protocol questions are relevant. However, it might be that the person has a very personal story to tell and didn't want to tell it in the group setting. In this case, an opening question such as, "You indicated that you had more information to share. Would you like to begin there?" should be enough to prompt the person, with the protocol supplying guidance to what follows in the interview. If the person hasn't participated in a focus group, then the focus group protocol would become the protocol for the interview.

I am part of a group of people from the Developmental Disabilities Planning Council and the University of Buffalo who are interested in learning about the experiences of individuals with intellectual or developmental disabilities and the problems they have with bullying because we don't know enough about this topic.

We are hoping that you can help us. We are particularly interested in speaking with you because you observe students/individuals with disabilities in environments where they interact with their peers. Researchers seldom have direct access to these situations, so we appreciate your willingness to talk to us.

Please know that if there is a question you don't want to answer or a topic you don't wish to discuss, you don't have to. Also, if at any time you don't want to participate any more, you can leave or end the interview, and it is OK.

We will share your comments with other people, but we will not tell them who you are or how you are connected to individuals with disabilities is. When we share this information we will not use anyone's real name. It is important that we share what we learn so that we can determine the scope and nature of the problem of bullying for individuals with intellectual and developmental disabilities, and devise some ways to address this problem.

³ If the person being interviewed has already participated in a focus group, the protocol will be modified to reflect this previous experience. The interviewer will still begin by reviewing the participant's rights as a research subject. However, when introducing each topic (i.e., victimization or bullying) the interviewer will ask what, if anything in particular, prompted the person to want to participate in an interview. The interviewer will ask questions such as, "Did you want to talk more about that? If so, what would you like to add?" Following that, the questions for the interview will be guided by this protocol.

This interview is being tape recorded or (This focus group is being videotaped) so that we can remember exactly what you say, and write down your comments in your own exact words. We will not disclose your identity to anyone. The recordings will be locked in a secure location at the Alberti Center and only members of the research team will have access to them.

Focus Group: Because this is a conversation with several people, we would like to ask everyone here to keep the information they hear today to themselves and not share it with other people, especially the names of people in this group who shared information and the people they talked about. We call this confidentiality. Can everyone agree that what they hear here will be kept confidential?

Focus Group: Likewise, we ask that you try not to use anyone's real name when telling us about the experiences of employees with developmental disability. We wish to protect the identity of those you speak of, but if you do mention anyone's name, we will not include it in any of our presentations or reports.

Thank you!

Do you have any questions?

Focus Group: In a focus group, you are free to talk to each other, as well as to me about the topics. You can ask the people in the group what they mean by a comment or you can ask them questions that you think will help us understand their experiences and ideas better. This focus group will take 1½ to 2½ hours. We will take a break after about one hour and fifteen minutes.

At the end of this if you would like to give more input on this subject, please sign up to participate in an interview. If you would like to participate in an interview, we'll return your Demographic Information Sheet to you so that you can add the necessary information.

If you do wish to be interviewed, please sign an additional consent form before you leave. We will contact you about the logistics for an interview in the next few weeks. Most interviews will be conducted over the telephone or Skype, and these interviews will be audiotaped. Even if you sign up for an interview and provide us with a consent form, you can change your mind later if you don't want to participate. There will be no consequences if you change your mind.

Interview: The length of this interview will depend on how much you have to share. It might be as short as 20 minutes, or as long as 60 minutes.

Introduction

Focus Group:

Let's begin by going around and introducing ourselves to each other. What is your first name?

Focus Group and Interview:

Can you tell me a little bit about yourself?

- *What is your first name? (Omit if redundant.)*
- *In what capacities do you work with individuals with intellectual or developmental disabilities?*
- *Do you get to observe individuals with disabilities directly?*
- *Do individuals with disabilities tell you about their experiences with peer bullying?*
- *Or both?*

Can you tell me about these individuals?

- *What is the nature of their disabilities?*

- *What is your involvement with these students/individuals with disabilities?*
 - *What activities do you do with students/individuals with disabilities?*
 - *What are your overall responsibilities for students/individuals with disabilities?*
 - *In what ways do you get to observe students/individuals with disabilities with peers?*

Victimization

Do you know if any of the students/individuals with disabilities ever experienced bullying by peers?

Can you tell me what you know about it?

- *What happened?*
- *When did it happen?*
- *Where did it happen?*
- *Who did it?*
- *What did the person or persons do?*
- *What did the person bully the individual with disabilities about?*
 - *Did the bullying involve the use of cell phones, electronic tablets, or computers? If so, can you tell me about it?*
- *Do you have any thoughts about why the person bullied the student/individual with disabilities?*
- *How did it make the student/individual with disabilities feel?*
- *Do you know if the student/individual with disabilities did anything to the person or persons to try to get them to stop?*
 - *If so, what did the student/individual with disabilities do?*
 - *Did it get the person to stop?*
- *Were there any bystanders there when this happened?*
 - *If so, who were they and what did they do?*
- *How did you learn about this situation?*
- *Did the student/individual with disabilities tell anyone?*
 - *Why or why not?*
 - *Did that person help the student/individual with disabilities?*
- *How did the person or persons help the student/individual with disabilities?*
- *Has being bullied affected the student's/individual with disabilities' health? If so, how?*
- *How has being bullied changed the student/individual with disabilities?*
- *Has anyone ever taught the student/individual with disabilities how to respond to bullying?*
 - *If so, what did the student/individual with disabilities learn?*
 - *Has the student/individual with disabilities used that information?*
 - *If so, when, where, and how did it work?*
- *Do you know of any other experiences that the student/individual with disabilities had with being bullied?*
 - *Repeat questions above regarding each instance of bullying.*

Bullying

I'm curious to know if the students/individuals with disabilities have ever bullied anyone.

Are you aware of any instances?

Can you tell me about the students/individuals with disabilities bullying others?

- *What happened?*

- *When did it happen?*
- *Where did it happen?*
- *What did the target or targets do in response?*
 - *Did the bullying involve the use of cell phones, electronic tablets, or computers? If so, can you tell me about it?*
- *What did the student/individual with disabilities bully the person about?*
- *Do you have any thoughts about why the student/individual with disabilities bullied the person?*
- *How many times did it happen?*
- *Are you aware of what the student/individual with disabilities was feeling when he/she bullied the person?*
- *Do you know if the person did anything to the student/individual with disabilities to get him/her to stop?*
 - *If so, what did the person do?*
 - *Did it get the student/individual with disabilities to stop?*
- *Did an adult or supervisor get involved with the student/individual with disabilities as a result of the bullying?*
 - *What did the person do to stop the bullying and prevent it from happening again?*
 - *Did it work? In other words, was it effective?*
- *How did you learn about this situation?*
- *Do you know if and what kinds of education or training your student/individual with disabilities have had regarding bullying and why it is not acceptable?*
 - *If so, what was included in the training?*
 - *Do you think your student/individual with disabilities understood the information?*
- *Do you know of any other instances where the student/individual with disabilities was involved in bullying others?*

Repeat questions above regarding each instance of bullying.

Prevention/Intervention

What types of prevention education would be helpful for individuals with intellectual and developmental disabilities and their teachers and care givers?

Where do you think this information and/or training should come from?

- *Who do you think should do it?*

What could or should be done when it comes to intervening in bullying problems with individuals with intellectual and developmental disabilities? (i.e., What actions should be taken and by whom?)

Is there anything that your administrators/managers could do to help you in dealing with bullying and your students/individuals with disabilities?

Definition of Bullying

Before we finish up, could you give me a definition of bullying, or explain what makes a particular situation bullying, and not something else?

Use of Resources

Research on bullying and individuals with intellectual and developmental disabilities is an understudied concern. If funds and resources were available to study this problem, what do you think we should specifically look at?

If resources were available to spend on initiatives that might address the problem of bullying and individuals with intellectual and developmental disabilities:

- *What types of things do you think should be done?*
- *What should we consider... educational programs, public campaigns to promote inclusion/integration and acceptance, work to help individuals with intellectual and developmental disabilities have better communication skills and coping strategies, etc....?*
- *Who should we target for these initiatives... the individuals with intellectual and developmental disabilities themselves, families, caregivers, support staff, managers... etc.?*

Conclusion

I would like to thank you for all of your time and your effort in helping us out. Before we finish, is there anything that I didn't ask you about that you would like to talk about? Any concerns? Any issues?

(Probe as necessary.)

Also, if you would like to speak to a researcher alone to share more information, we invite you to participate in an interview.... but only if you have more to say than what you said in this group. If you would like to participate in an interview and you did not indicate this on the sheet you filled out at the beginning, please let us know. We will give the sheet back to you and you can fill it out. These interviews will be held at another time. We will contact you to set up a time and a place for the interview. It might be held over the phone or using Skype on a computer. If you do want to participate in an interview, please make sure that you sign another consent form before you go today.

If you are feeling upset or uncomfortable about our conversation today and you would like some support, we have a list of resources here that can help you. If you have an immediate problem with bullying, there are also resources that you can contact to get help with your situation. Please feel free to contact someone if you are feeling upset, worried, or sad about our conversation today.

APPENDIX C

EMERGENT THEMES: FINDINGS, EXPRESSED NEEDS, AND IDEAS FOR ACTIVITIES

I. Self-Empowerment

Definition of Empowerment

Empowerment is a helping process whereby groups or individuals are enabled to change a situation, and given skills, resources, opportunities, and authority to do so. It is a partnership that respects and values self and others – aiming to develop a positive belief in self and future. Enablement is about changing the nature and distribution of power that recognizes that power originates from self-esteem. The individual has the power and freedom to make choices and to accept responsibility for actions should he or she wish to do so. Empowerment involves a partnership and mutual decision-making (Rodwell, 1996).

Findings: Self-Empowerment

Related to *Coping*

- There is a need and a desire for people with disabilities to talk about bullying.
- For people with disabilities, bullying back is a way of protecting oneself from the bullying.
- People with disabilities get punished for fighting back and trying to protect themselves.
- Lashing out in frustration can be interpreted as bullying.
- People with disabilities may have more tolerance for bullying because they don't have the capacity to fight back (i.e., they are resigned to it, or just accept it.)

Related to *Knowledge*

- If people with disabilities don't understand bullying, they don't know the effect their actions can have on people.

Related to *Autonomy*

- Autonomy is an essential human need.
- In this world, the more independent you are, the greater your chances for increasing your social capital.
- People gravitate towards power and dominance.
- People use power to achieve status and a sense of belonging.
- When people with disabilities feel empowered, they are less likely to be bullied.
- Loneliness, isolation, and vulnerability are risk factors for bullying and can also be the effects of bullying.
- Human nature is very competitive (can be positive/make people better; can be negative and turn into bullying).

Expressed Needs: Self-Empowerment

Related to *Education/Training*

- Self-defense training.
- Teach people how to say, "No. Stop it."
- Of all kids, the kids with special needs are the ones that need to learn the language of conflict resolution, mediation, and problem solving. Teach them the language and the skills.
- Social media provides a needed connection for people with disabilities, but at the same time they need training in how to be in those forums and use them successfully and safely.

- Teach people with disabilities to tell administrators early, instead of waiting until the bullying is very serious.
- Perhaps it should be required that a person go through training or a class regarding bullying if they are reportedly involved in an incident. For example, if a report is filed within an agency between two consumers, the consumer who was guilty of bullying the other should have to have a special discussion or counseling session focusing on the event and why their actions were inappropriate and should not be allowed to reoccur.
- We need training (not counseling, real training) for the kid being bullied -- how to stand up for yourself in a safe way, how to understand and strategize around power (what are your social tools and strategies; not the pie in the sky can't we all get along approach, but how do you face someone down and flip the script on them so the shame runs the other way?

Related to *Protection*

- People with disabilities need safe people to go to get help from bullying.
- We have to teach the people we are trying to protect to protect themselves. A lot of people don't know what they can do.
- Staff needs to be able to let people with developmental disabilities solve problems themselves.

Related to *Connection*

- Social media provides a needed connection for people with disabilities, but at the same time they need training in how to be in those forums and use them successfully and safely.
- Help people to understand and learn to explain their disability to others; it empowers them.

Ideas for Activities: Self-Empowerment

Related to *Social Skills*

- Promote the development, implementation, and evaluation of social skills programs for youth with disabilities so that they have the skills of conflict resolution, mediation, and problem solving.
- Skill building would be good. Teach people with disabilities how to treat peers in relationships. People with disabilities want to date. Create structures where more groups of people with disabilities can socialize. Teach them appropriate social skills for interpersonal interactions.
- Teach adults with disabilities what their rights are so that they can use the legal system. Maybe get law students involved.
- Stress training has helped. Learning how to manage the stress has helped. Stress balls to squeeze when you're getting bullied.

Related to *Bullying Education and "Telling"*

- Teach people how to tell that they are being bullied (e.g., by calling 911 before it becomes too violent; by telling kids who are being bullied that it's OK to tell and to not be afraid to tell).
- If we had a video, slide show, or a book that had very easy concepts, that would be helpful to our individuals (who have pretty severe disabilities) to understand bullying. It would have to be very basic, and make it relevant to our day hab environment. We could play it over and over.
- Teach people how to cope with bullying and have a voice. Teach people who've been bullied how not to turn into bullies.
- Have a bullying prevention specialist in the schools for mainstream and special education students to use.

Related to *Self-Advocacy*

- Start self-advocacy programs when people with disabilities are young. Self-empowerment should be a lifelong goal for all people with disabilities.

- It's amazing how many people don't know anything about their disability. Help people to understand and learn to explain their disability to others. This makes them less vulnerable to bullying. Being able to explain to others why you act the way you do can be very helpful. People accept people when they do that.
- Train people with disabilities how to use social media appropriately.
- Provide kids who are bullied with opportunities outside of the school environment to be involved in projects or groups that do community service and leadership development... promote self-empowerment.
- Teach people with developmental disabilities how to protect themselves instead of staff doing it for them; support independence.

II. Self-Advocacy

Definition of Self-Advocacy

Self-advocacy is defined as people with developmental disabilities, individually or in groups (preferably both) speaking or acting on behalf of themselves, or on behalf of issues affecting people with disabilities (SANYS).

Findings: Self-Advocacy

Related to *Identity*

- Self-advocates don't relate to each other on the basis of their disabilities. They relate based on interests and commonalities.
- Self-advocacy gives people responsibility.
- Self-advocacy creates strong identities.
- Peer leadership and self-advocacy need to be modeled.

Related to *Support*

- Self-advocacy is healthy, productive, and necessary; peer support is a key part of self-advocacy.
- The improved self-esteem, self-confidence, connectedness, and empowerment that come with self-advocacy become a protective factor against bullying.
- In this world, the more independent you are, the greater your chances for increasing your social capital.

Related to *Bullying and Power*

- When people with disabilities feel empowered, they are less likely to be bullied.
- High functioning people bully low functioning people among those with developmental disabilities.
- People use power to achieve status and a sense of belonging.

Expressed Needs: Self-Advocacy

Related to *Education/Training*

- Children and adults need training to becoming a self-advocate.
- Bullying prevention should be developed and provided to all individuals with developmental disabilities.
- Individuals with disabilities need training in how to respond to bullying.
- People with disabilities need to learn how to resolve conflicts peacefully.
- People with disabilities need to learn problem solving and communication skills.
- People with disabilities need to learn how to behave in a dating relationship.

Related to *Support*

- Promote conversations about bullying within the self-advocacy community at large.

- Encourage the formation of support networks among self-advocates to learn from each other how to address the problem of bullying.

Related to *Leadership*

- Provide opportunities for self-advocates to develop and use leadership skills both within and without the community of people with disabilities.

Ideas for Activities: Self-Advocacy

Related to *Relationships*

- Develop programs that promote social support and friend networks among people with disabilities.
- People who live in houses together often have conflict. Is there a way for them to advocate for themselves to move to another house? Are there methods for doing conflict resolution among people with disabilities in their houses or workplaces? (e.g., Restorative Practices; Conflict Resolution).

Related to *Education/Training*

- Develop programs for people without disabilities on bullying of people with disabilities
- Develop bullying prevention programs by, for, and with people with disabilities; focus on “don’t become a bully” and “become allies of each other to end bullying.”
 - Teach people not to be afraid to tell; teach people that it’s OK to tell.
 - Teach people who to tell and how to tell.
- Develop programs that are created and implemented by self-advocates to teach children and adults how to be self-advocates.
- Develop programs by self-advocates for direct care providers on bullying among people with disabilities. Have self-advocates go into group homes or structured work settings to present their program.
- Engage self-advocates in doing education with the general public on disabilities; teach people not to want to hurt people with special needs.
- Engage self-advocates in educating the public on the value of having group homes in your neighborhood.
- Support parents in teaching their children the value of self-advocacy and how to help their children learn self-advocacy attitudes and skills.
- Teach adults with disabilities what their rights are so that they can use the legal system. Seek the involvement of law students.
- Because the community of people with disabilities is SO spread out, it would be great if there was a group that traveled (like SANYS) to different locations and did classes with individuals with disabilities and staff to give them additional anti-bullying tools they can use on their own. It could even be an interactive webinar that everyone could participate in.

Related to *Policy*

- Support the creation of policies and practices so that people who live in group homes can participate in the hiring of people who work in the group homes.
- Try to get people with disabilities or their parents on boards of education, especially in rural communities that are resistant to change.

Other

- Within the self-advocacy movement, promote volunteering as a way to improve one’s self-worth, self-esteem, and dignity.

III. Support

Definitions of Support

Social support “is an individual's general support or specific support behaviors (available or enacted upon) from people in the social network, which enhances their functioning and/or may buffer them from adverse outcomes” (& Demaray, 2002, p. 2). Types of social support (Tardy, 1985) include *Emotional support* - feeling taken care of or valued; *Instrumental support* - receiving time and resources; *Appraisal support* - receiving instructive feedback; and *Informational support* - providing needed information.

Findings: Support

Related to *Peers and Friends of Peers*

- Peer support is part of self-advocacy.
- Friends can make a difference when it comes to being protected from bullying.
- Bullying exists among individuals with disabilities. As within many groups, a pecking order is developed which establishes dominance of higher functioning people over lower functioning people.
- Kids want friends badly; they want to fit in and to be accepted. This may contribute to their vulnerability with regards to bullying.
- Not everyone has to be your friend; the solution to bullying is not necessarily that everyone has to be friends.

Related to *Families*

- Abusive or unsupportive families make it more difficult; home should be a safe haven.
- Sibling abuse is a problem for individuals with developmental disabilities.
- Attitudes and behaviors come from the home. The school isn't to blame everything.
- Bullying of a person with a disability affects the family, not just the person with the disability.
- How the family thinks about the individual is critical to how people treat a family member with a disability. Language (e.g., “My son is retarded.”) shapes how people think and act.
- People who live with their families are generally not as self-sufficient as people who live in group homes. Self-sufficiency may be a protective factor against bullying.
- There are inequities in who has or gets access to resources. Kids with disabilities whose parents don't advocate for them get less and parents who have more money and education get more for their children.
- Some parents see themselves as always “fighting” for their child's needs (even adult child's needs) (e.g., fighting like a ‘lioness’). It is exhausting and never ending.

Related to *Staff, Educators, and Service Providers*

Staff

- Staff do exceptionally hard work for little pay.
- Staff are doing civil rights work on behalf of people with developmental disabilities. They need to be recognized for this.
- Some people are not suited to work in the disabilities field.
- Bullying is when people with expertise use their jargon to keep parents ignorant.
- Staff can push people's buttons and provoke aggression, and then staff says they're the victims.
- Some staff are overprotective of people with disabilities.
- Staff may think it is funny when some situations take place. For example, they might think it was “cute” to see people fighting. They see people with disabilities for their entertainment value, as opposed to understanding their disability and recognizing that their behavior was due to their disability.

Educators

- Some educators are ignorant and even hostile about people with disabilities.
- Teachers bully, too.
- When educators get complaints, “hearing” the complaints means more work, so it’s easier to tune it out.
- Educators use parents’ lack of information to avoid dealing with bullying problems.
- Schools that say they don’t have bullying are in denial; schools wear blinders.
- Teachers can act like they don’t see what is happening. Adults don’t pay attention to bullying and individuals with developmental disabilities. Educators, “Look the other way.”

Service Providers

- Supervisors can turn into bullies and not know it.
- Favoritism towards some people within the developmental disability population is viewed as unfair by some people with disabilities.
- There is preferential treatment for some who get away with behaviors that aren’t accepted from everyone – Is a person’s disability viewed as an “excuse” for bullying?

Expressed Needs: Support

Related to *Peers and Friends of Peers*

- There is a need to develop ways for peers to support each other with regard to bullying.
- Need to develop ways for students to see their peers with disabilities as part of their school community.
- We need a training component that frames abuse as bullying when it’s peer to peer or with similarly aged people, for people with disabilities.
- Trust – people with disabilities need to know whom to trust to not bully them.

Related to *Families*

- Parents need to be taught how to talk about their children so that they are using language that promotes their children’s dignity. “You act how you speak.”
- Families need support so that they can find out their rights (and their children’s rights), and gain access to resources.
- Families need support in working with schools to insure that their children’s needs and rights are met.

Related to *Staff, Educators, and Service Providers*

Staff

- Staff needs to be able to let people with developmental disabilities solve problems themselves.
- Staff needs to think differently about people with disabilities. They need to think more in terms of “Main Street” smarts, and less protection from staff; support independence for people with disabilities.
- When dealing with problems of bullying among people with disabilities, staff needs ways to have consequences for those who bully, but these consequences have to be ones that do not take a person’s services away or impinge on their rights.

Educators

- Teachers need training on temperament, disabilities such as ADHD and Asperger's, and how to make meaningful connections with children with disabilities.
- All teachers need to be special education teachers.

Service Providers

- Managers who oversee direct care providers need to create ways for their staff to “let off steam” after a difficult day with individuals with developmental disabilities. Staff needs to be able to acknowledge that they have worked hard under stressful conditions.

Related to All Constituents

- The definitions of bullying used by researchers are problematic for people with developmental disabilities. There needs to be a collaborative conversation among researchers and experts in the field of disability to reconcile some of the challenges of the traditional definition of bullying.

Ideas for Activities: Support

Related to Peers and Friends of Peers

- Friendships are a protective factor against bullying. Develop a program for people with disabilities (self-advocates) to learn how to be friends with each other. Foster opportunities for people with disabilities to come together to nurture friendships.
- Start “Be a Friend” clubs in schools where students without disabilities get to know students with disabilities in a social context. This creates natural bonds that reduce the likelihood of bullying.
- Put a buddy with a child who might get bullied in school, to accompany the child throughout the day.
- Provide more opportunities for interactions between special needs and typical children. Provide school programs to teach children about various disabilities. Create reward programs that encourage respect and interaction with children with disabilities.
- Promote the integration of students with disabilities into sports. Sports shape the dynamics of how kids interact with each other.
- Create a hotline for children who are bullied at school so that if the school isn’t responsive to their problems with bullying, then there is an outside entity that has some authority over the school that can intervene.
- Develop bullying prevention programs for adults as a part of their job skills preparation before they enter the workplace.
- Individuals with disabilities need to have an advocate available to them that they can talk to when they are or feel they are being bullied, especially in schools, but also in other contexts.

Related to Families

- Put together a fact sheet for parents to help them recognize the signs of their child [with a disability] being bullied.
- Create programs for families of people with developmental disabilities that help them understand their child’s potential. Include education on language and empowerment. Include individuals with disabilities in the development and dissemination of the program.
- Teach parents how to let go. Teach them how to be there for their child, but at the same time to take care of themselves and to be able to deal with their life by themselves. Help parents teach their children what’s going on in the world.
- Offer workshops for parents on coping mechanisms and awareness, and their rights and due process.
- Set up a phone number to a hotline to report bullying anonymously and to counsel people with disabilities and/or their families on bullying.
- Prepare more people to be educational advocates for parents of children with disabilities who can go into the schools and support parents whose children are being bullied, but the school doesn’t see the bullying.

Related to *Staff, Educators, and Service Providers*

Staff

- Training for support staff so that they are sensitive to people with disabilities.
- It might be helpful to use restorative justice to solve problems in group homes. It would help residents to be more responsible for their actions and it could be used to address problems of bullying.
- Thank staff people for the hard work that they do. We need to let them know that we appreciate them. Create ways for staff to manage the stress of their work.

Educators

- Develop a script of how to talk about a student with a disability in an integrated classroom in a way that is respectful, helpful and not stigmatizing – maybe with concrete examples of what behavior might look like and ways that students can respond best.
- Teach non-disabled children to be friends with children who have disabilities so that they “don’t add to another child’s suffering.”
- There needs to be a bullying prevention curriculum that is designed for people with disabilities because in schools they may not be understanding the prevention curriculum that the general education students are getting. Parents need to be included in that training.
- Promote the training of social skills to “higher functioning” students within the context in which the skills are needed, not in a decontextualized way. These kids don’t transfer the skills, so they need to be taught in the contexts where they are needed.
- Make signs in schools. The word bully with a slash through it. And by each sign put a picture of a person crying. In the hallways. Put them in colleges or in day programs.
- Make informational sessions on bullying and people with disabilities as widely available as possible through meetings, webinars, school systems (including widespread education of teachers!), etc.
- Educate the students without disabilities. Identify the popular kids and have them involved in a demonstration of how it can impact you since they don't usually experience this instead of having the students with special needs lead a presentation.

Service Providers

- Put cameras in the day hab so there’s a record of people’s behaviors.
- Have more staff in the day hab so that they can see what’s happening.
- Develop a system for residents of group homes to report bullying by staff to someone outside of the group home.
- Develop a program to train direct care providers to recognize bullying. Provide staff with training to deal with a situation where a person with a disability is bullying staff and how to resolve it without causing a problem. Educate staff about the early warning signs of bullying and how to intervene before it gets out of hand. Teach staff how to recognize if a fellow employee is bullying you, and what to do about it.

Others

- Teach people how to be supportive bystanders. Use skits.
- Create a hotline for people who are being bullied, or if you see something, you can call that number and report it.
- There needs to be a place for resources that are gathered and monitored so that any person can get connected to it. It needs to include the bullying resources for the general population with materials developed for and reflecting the needs of people with disabilities.
- Manual for modification of bullying prevention program for individuals with developmental disabilities.

- Start a program modeled after Big Brothers-Big Sisters that brings people in communities together with people with developmental disabilities.

IV. Integration, Inclusion, and Cultural Change

Findings: Integration, Inclusion, and Cultural Change

Related to *Cultural Norms*

- Meanness is everywhere: on TV, in movies, in society.
- Reality TV teaches people to bully.
- Bullying is cultural. The media contributes to it.
- Having a disability is stigmatizing. Separating and segregating people with developmental disabilities creates stigma. We need to remove the stigma of having a developmental disability.
- We are not all the same and kids know it.
- Universities contribute to elitism by making it seem imperative that everyone has to go to college. This creates a hierarchy of who and what is valued. A degree puts you above someone else.
- Schools for too long have embraced a culture of competition that has subjugated the very universal need to connect and belong.
- Bridge the gap between general education kids and kids with special needs. There's too much distinction and division between the groups.
- Exclusion (at all levels) is a form of bullying.

Related to *Values*

- People with developmental disabilities have different ways of communicating. We need a broader understanding of "communication."
- In this world, the more independent you are, the greater your chances for increasing your social capital.
- Enabling has allowed some people with disabilities to get away with bullying behaviors.
- The state says everyone has to work, so that is what is valued.
- Blaming is a common response to the frustration of bullying and individuals with developmental disabilities... blaming includes society, families, parents, schools, communities, systems, politicians, and policymakers.

Related to *Systemic Inequality*

- Bullying is systemic.
- Bullying happens at many levels.
- There are inequities in who has or gets access to resources. Kids whose parents don't advocate for them get less.
- Resources are not distributed equally. People who are advantaged are able to get more than people who have less to start out with.
- Bullying keeps people in their place.
- Bullying of individuals with developmental disabilities promotes discrimination.
- The more protected our people are (individuals with disabilities), the less exposure they have to situations where they could learn life skills.
- "Red tape" is a barrier to getting needs met and things done. Red tape can contribute to situations that put individuals with developmental disabilities at risk of bullying.
- The majority of the population is ignorant about people with developmental disabilities.
- The excessive use of the term "bullying" is diluting the situation.
- People with disabilities have been left out of the national/public discourse on bullying.

Expressed Needs: Integration, Inclusion, and Cultural Change

Related to the *Public Environment*

- “Don’t put people with disabilities in a slummy neighborhood.”
- “Landlords that aren’t a jerk.”
- “Treat people as adults, not like little children. Treat everyone equal.”
- There needs to be better treatment of people with disabilities on public transportation.
- Outings for people with disabilities should be more creative. They should involve exposure to the community. We need to do better connecting people to places that are available to everyone... rather than bringing people into services that are designed just for them. We need to use outings to bridge people to the community.
- We need to spread the word by putting the higher functioning, more verbal people in programs that are presented in the public forums.
- People have preconceived ideas and stereotypes and we need to help them see that it’s not always this way.
- Every person needs to have both disability awareness training and bullying prevention training.
- We need to acknowledge that the community of individuals with developmental disabilities is itself a diverse community and that people with disabilities create identities that are not solely about their disabilities, but reflect a much broader complexity (i.e., identity includes gender, race, sexual orientation, gender expression, ethnicity, etc.).
- We have to teach people not to want to hurt people with special needs.

Related to *OPWD, Education, and Policy*

- Policy has to be changed so that people who work with people with disabilities get training and are taught how to and are required to respond to problems of bullying.
- The big elephant in the room is the low wages for staff. The other thing is the interviewing process. Wages need to go up for people who work with people with disabilities. We need to bring in people with greater skill sets. We take the wrong people. We need to make sure that the people we hire are sensitive and caring.
- The “front door” policy in placement in residential settings is creating a situation that creates risk for bullying. The state owns a bed when someone leaves. They have to go through OPWDD’s front door. The only people going into homes are people who are at risk. The state tries to force you to take people who won’t be a good fit in a home...speaks to the issue of bullying that can develop in that situation. It creates an at-risk situation for bullying to develop. It leads to peer-to-peer bullying because if people are put in less than optimal settings, they are at risk.
- The Justice Center is a great idea but it is understaffed. The fact that it takes so long to get new hires through the system puts tremendous stress on staff who have to work extra hours to fill in for the spots that are unfilled. When people are stressed they are more likely to bully residents.
- We need more protection for people with developmental disabilities in school districts. OPWDD should be involved in helping schools understand safety and protection (with regards to bullying) for people with disabilities. There is a disconnect between regulations regarding people with disabilities between the boards of education and OPWDD. Our folks experience culture shock when they go from being in the educational system and enter the state system.
- There’s a disconnect between the school and the service providers. We need to be talking to each other if we are servicing the same individuals. If two people are together all day long, and then are with us in the after school hours, we need to know if they are having problems during the day. We need better lines of communication.
- There is a need for transition services from home to school, school to day program to consider the risk of bullying during these times. Transition services need to be guided by the principles of inclusion, integration, and

acceptance. This includes the people providing transportation, anyone else on the bus, and the people on the receiving end who assist the person with a disability.

- Bullying needs to be viewed from a long lens. Some policies actually increase the risk of bullying for some people with developmental disabilities. The context in which people live, which may be mandated by the state, may contribute to their vulnerability, and hence put them at risk for peer bullying because their needs are not being met.

Related to *Education and Social Change*

- There needs to be a “don’t become a bully” focus.
- Education should begin with the staff. They need to be vetted to make sure that they have the ability and desire to connect emotionally.
- Teachers have been educated but they don’t have any emotional connection to this issue.
- We need more training to teach schools about the laws against discrimination.
- We need better training for mental health professionals on bullying: counselors, therapists, psychiatrists, social workers, and teachers. We need to be able to detect bullying sooner. We need to be able to deal with it better.
- We need to educate the community. We are trying to help people be as independent as possible. We need policy change around what communities can and can’t do to prohibit group homes for people with disabilities.
- We need to go into municipalities and educate them, because they are the people that will actually make those determinations about where people with disabilities will live and how they are treated. The police force, the mayor, any elected official. Any of those people. I don’t think they realize that they are part of the problem, and somehow or another, we need to get to them. They have the ultimate say.
- We need a simple brochure for agencies to use with bullet points of positive strategies to reduce/eliminate bullying.
- Provide bullying seminars for individuals with disabilities to share stories and improve their skills in effectively dealing with bullying.
- As much as possible, embrace the concept of "differently-abled" and allow that message/belief to gradually supersede the stereotypic baggage associated with "dis-abled".
- What is bullying? We need a concrete operational definition so that we can label these behaviors. In this world, labeling behaviors is critical, especially in the disability world. The research definition of bullying is challenging to apply in cases of people with disabilities. There needs to be work done on this problem that includes researchers, people with disabilities and people in the disabilities field.

Related to *Needs in Schools*

It is clear that there are serious needs within some educational settings regarding youth with disabilities. These include:

- Bullying of students with disabilities by adults in the school
- Tacit approval from adults of students who bully students with disabilities
- Failure of adults to understand when a person who is aggressive is the target and not the bully
- Failure of school adults to understand when aggressive behavior is a form of communication and is part of an individual’s disability
- Failure to see when the school adults are being manipulated by the bullies who know that they can frame victims to look like bullies
- Codes of conduct that are written to put power into the hands of the bullies (by requiring equal punishment of those who fight and those who fight back to defend themselves)
- Dismissal or disregard (and sometimes blaming) of parents who seek help for their children with disabilities and are within their rights to do so

These problems reflect systemic issues within our communities, institutions, and society as a whole, but may be particularly acute within educational settings.

Ideas for Activities: Integration, Inclusion and Cultural Change

Related to *Media* and *Public Discourse*

- Media stories that tell people about people with disabilities.
- “I’d like to see something on TV... public service announcements. Tell true stories, show commercials on what disabilities are that could reach everyone. Have a media campaign.”
- Involve people in a public discussion.
- Model what we want people to do.
- Have a national discourse about how everyone is valuable. Instead of having “measurable outcomes,” have people tell their stories.
- Find natural events to integrate persons with disabilities and persons without disabilities. Social events. Ask for volunteers in events that showcase persons with disabilities (i.e., Special Olympics, Voices Unlimited).
- Have disabled people who were bullied participate in a national campaign in the media and in schools, community centers, day hab program etc., to talk of their experiences.
- Create more opportunities for people with and without disabilities to work together.

Related to *Programming* and *Support*

- Start a buddying program.
- Have a scavenger hunt. Get people talking to one another... a mentoring program. Interact with people that they have common ground with.
- It would be helpful for people to understand the different types of disabilities. Awareness education.
- Spread the Word to End the Word (replace the R word with respect). It’s called Project Respect, a campaign.
- Schools.... Sensitivity training for students has to start in Kindergarten. The earlier it is taught and discussed, the better.
- Start programs like TIES, Together Including Every Student in all schools.
- I feel that our teachers and schools need to have a social program in place where students without a disability should be assigned to become a buddy for those with disabilities within the school, learn about each other and learn to become compassionate individuals.
- I grew up in a family with an aunt who has a disability and now have a daughter with one. I never saw my aunt as "different" because I grew up with her. I think this is something teachers should also be taught and it should not be an elective to be a special ed teacher. This is learning compassion, and accepting that we are all different and we all want to be loved and treated with kindness.
- Educate employers about what they may encounter, how to make accommodations, and how to make the individual feel welcomed and accepted when there are employees with disabilities.

Related to *Programming* and *Education*

- Plays, skits and role plays... presentations, videos that you can watch, have someone follow someone around who is getting bullied and make a video, so they can see what’s going on so that it will stop.
- We need sensitivity training for other people in the classroom (inclusion classroom). Teach the rest of the class about the person with the disability. You must talk about this before the class assembles. There’s a person waiting in the class who can be a bully. We need to educate about the inclusion person. The message and the modeling needs to be: We want to see you befriend that person. Not just tolerate, but engage. And have an incentive to promote and reward this behavior.
- People with disabilities who are self-advocates can go to schools where kids bully each other and tell kids not to bully.
- We should provide real life training of young adults with disabilities to come and speak to 3rd - 5th grade levels

so that they do not fear what they do not know - that is the main cause, fear and ignorance - if they could see how typical most people are, disability or not, they would see there is nothing to make fun of.

- Bring back “Kids on the Block.”
- One thing I wish for would be to have access to a person for a short program to be presented. I have attempted many avenues and agencies to have a short presentation on bullying of children with special needs but to no avail.
- Consider having a recognized person ("a name" if you will) present how bullying affected them to schools through a video presentation that can be shown in a variety of locations.
- EDUCATION for those without disabilities about disabilities.

Related to *Laws and Policy*

- Better laws against bullying to keep people safe.
- There needs to be a certification process for direct support personnel. It would save on employment costs, turnover, and lawsuits, and it would reduce bullying.
- Lobby for changes to OPWDD’s “front door” policy.
- Lobby for more funding for and improvements at the Justice Center.
- We are trying to help people be as independent as possible. We try to reduce their need for supervision. We can reduce some of that supervision if society is a kind society. Train the citizens of NY... to be kind to people with disabilities.... Get OPWDD to put out messages about being kind to people with disabilities.
- Lobby for policy changes so that it is easier to set up group homes for people with disabilities and to deal with the problem of NIMBY (Not in My Backyard).
- Help to enact workplace bullying laws in New York State to protect all people in the work place.
- Teach the police how to treat people with disabilities.
- Teach people in psych units and emergency rooms about people with disabilities. Not all aggressive or violent behaviors are due to mental illness. Some are due to a person’s disability.
- A hotline where parents can call in abuse incidents by staff working with their child without retaliation!!!!
- Cameras on all school buses!!!!

Others

- People need guidance on how to start a not-for-profit to address the problems of bullying for people with and without disabilities, so that they don’t have to spend all of their own money advocating for their children.
- Maybe get some entrepreneurs in to help us think differently. Get some of these brilliant billionaires to share their knowledge with us so that we can figure this all out... wages and spending are connected to bullying.
- Grade kids on manners and how they get along with others, just like they used to do when we were kids.
- Do a research study on how much time students with disabilities miss school or class because of being bullied.

References

Malecki, C. K. & Demaray, M. K. (2002). Measuring perceived social support: Development of the Child and Adolescent Social Support Scale. *Psychology in the Schools, 39*, 1–18.

Rodwell, C. M. (1996). An analysis of the concept of empowerment. *Journal of Advanced Nursing, 23*, 305-313.

SANYS (2014). *Workforce and talent management: Training curriculum series: Self-advocacy/self-determination: Participant's manual*. New York State: OPWDD. Retrieved from http://www3.opwdd.ny.gov/wp/images/sa-sd_participant_manual.pdf

Tardy, C. H. (1985). Social support measurement. *American Journal of Community Psychology*, 13, 187–202.

APPENDIX D

LONG RANGE STRATEGIC PLAN: GOALS AND ACTIVITIES

Individuals, Peers, and Self-Advocates

GOAL 1: Increase the ability of people with developmental disabilities to prevent and respond to bullying in safe ways.

1. Create a program for and by individuals with developmental disabilities to develop awareness and skills around bullying prevention and intervention within the disability community.

Needs Assessment Findings

Service providers support helping individuals with developmental disabilities improve their social skills, enhance coping strategies, and develop adaptive responses. Additionally, if skills around bullying prevention and intervention include coping skills, all stakeholders surveyed support teaching coping skills to individuals with intellectual and developmental disabilities.

Additionally, participants in focus groups and interviews suggested that the emphasis on self-empowerment within the self-advocacy movement would be a good context for the development of awareness and skills around bullying. This approach is strength-based, and supports individuals with disabilities with regards to autonomy, self-determination, and independence.

Bullying Prevention Interventions

While the research on the effectiveness of bullying prevention programming for students within the general education population is beginning to proliferate, there are few published studies evaluating the effectiveness of bullying prevention and intervention programs specific to individuals with disabilities.

Northway and colleagues (2013) asked adults with intellectual disabilities about strategies and support related to abuse. One of the most popular responses for how individuals with disabilities can keep themselves safe was, “Learn to speak up.” Other results by Northway et al. (2013) indicated that feeling heard and having someone they trust believe them was also important in cases of abuse. Although this study did not address bullying, the results highlight the need for individuals with disabilities to be able to advocate, and to have support systems in place to hear reports of violence and concerns.

McGrath, Jones, and Hastings (2010) conducted a 10-session anti-bullying intervention for adults with intellectual disabilities at their workplaces. There were two interventions evaluated: one designed to provide information and strategies related to bullying, and another intervention providing the same information with participation from community stakeholders such as local police. The researchers found that incidents of bullying significantly decreased for individuals in either intervention group compared to a wait list control group. Topics addressed in the intervention are listed below (from McGrath et al., 2013, p. 378, Table 1):

- Introduction: What is bullying
- Session 2: How does bullying make us feel
- Session 3: Why do people bully
- Session 4: Why people get bullied
- Session 5: What to do if we are bullied

- Session 6: What to do if we are bullied (continued)
- Session 7: Who to tell
- Session 8: What to do if you are a bully
- Session 9: The role of the bystander
- Session 10: Summary of previous sessions

Other Programs

In the Minnesota Governor's Council on Developmental Disabilities program, self-advocates called "Ambassadors for Respect" conducted training sessions for an anti-bullying program, PeaceMaker Minnesota, for 4th grade students across their state. Self-advocates received training on implementing the program. The program has not been evaluated.

In the Kentucky Youth Advocacy Project, self-advocacy skills are taught to children with intellectual and developmental disabilities (ages 7-18) with the goal of increased self-determination (Kleinert, Harrison, Fisher, & Kleinert, 2010). The program utilized the Self-Determined Learning Model of Instruction, which has been shown to be an effective instructional approach for individuals with disabilities. The current project lasts an entire academic year, including multiple steps beginning at the start of the school year. The aim of the program was for students to work on their own age appropriate goals throughout the school year. There is minimal adult supervision required, so it is a program that may be easy to implement. No evaluation data were available for this program to date.

A program was developed in Alaska called the Friendships and Dating Program for adults with developmental disabilities. The goal of the program was to support adults with developmental disabilities in developing the social skills needed to engage in mutually supportive, healthy, and appropriate dating practices. An additional objective was to reduce interpersonal violence in close relationships. A formative assessment found that all of the participants increased their social networks and reduced the number of interpersonal violence incidents (Ward, Atkinson, Smith, & Windsor, 2013).

References

- Kleinert, J., Harrison, E. M., Fisher, T. L., & Kleinert, H. L. (2010). "I can" and "I did"- Self-advocacy for young students with developmental disabilities. *Teaching Exceptional Children*, 43(2), 16-26.
- McGrath, L., Jones, R. P., & Hastings, R. P. (2010). Outcomes of anti-bullying intervention for adults with intellectual disabilities. *Research in Developmental Disabilities*, 31(2), 376-380.
- The Minnesota Governor's Council on Developmental Disabilities (2014). *Council-Sponsored Grant Activities: Self Advocacy – Anti-Bullying Campaign*. Retrieved from <http://mn.gov/mnddc/council/grant-activities-respect.html>
- Northway, R., Bennett, D., Melsome, M., Flood, S., Howarth, J., & Jones, R. (2013). Keeping safe and providing support: A participatory survey about abuse and people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 10(3), 236-244. doi:10.1111/jppi.12049
- Ward, K. M., Atkinson, J. P., Smith, C. A., & Windsor, R. (2013). A friendships and dating program for adults with intellectual and developmental disabilities: A formative evaluation. *Intellectual and Developmental Disabilities*, 51(1), 22-32.

Individuals, Peers, and Self-Advocates

GOAL 1: Increase the ability of people with developmental disabilities to prevent and respond to bullying in safe ways.

2. Develop a formal educational program (or strengthen an existing program) for people with developmental disabilities (of all ages) to assume roles as self-advocates. Within the context of this program, develop and implement a formal support network for self-advocates which facilitates camaraderie and connection. [This project requires the need to identify the self-advocacy skills to be developed and how these are taught now.]

Needs Assessment Findings

Assertiveness, Friendship, Self-Advocacy, and Support

Throughout the data, there were strong indications that educating people about how to stand up for themselves in assertive and prosocial ways was something that all individuals with developmental disabilities could benefit from. Assertiveness is sometimes challenging for individuals who are dependent on those around them for assistance. Only 50% of adults with disabilities reported that people around them would help “most of the time” if someone else was making fun or teasing another person, spreading rumors or lies, being mean on the computer or phone, and/or pushing/shoving/trying to fight with another person items

Research on bullying among those without disabilities suggests that friendship is a buffer and a protective factor with regards to bullying. Thirty percent of adults reported that an effect of being bullied is having trouble making friends. This seems to indicate a reciprocal relationship, in that making friends is difficult, but that having friends protects people from bullying.

There were also indications that seeking support from others may be helpful in dealing with bullying. A number of self-advocates indicated that participation in focus groups on bullying victimization was a positive experience. The research team observed that self-advocates were caring, thoughtful, and respectful of peers’ recounting of bullying experiences and the pain they experienced because of it. It appeared that participation in a focus group that was open, non-judgmental, and caring, was similar to a support group experience and afforded some of the benefits of participating in a support group.

Following these observations, the research team concluded that when self-advocates are offered an opportunity to discuss their experiences with peers, the result is an increase in connection and an improvement in overall well-being. Thus, the research team suggests that a network of self-advocates be created to offer camaraderie and connection as a way to strengthen self-advocacy skills, develop supportive friendships, and learn how to take care of one’s self in an assertive and positive way.

Self-Determination

Self-determination means that individuals have a right to make their own major life decisions. Decisions for individuals with intellectual and developmental disabilities are often made for them, without their input or support. Nonnemacher (2011) explored this by interviewing self-advocates who identified elements of self-determination and ways in which it is stifled. Self-advocates defined self-determination as “speaking out” and “being in charge” (p. 331). The authors identified five themes related to actions by support staff to promote self-determination: (1) expanding options and experiences to encourage choice, (2) supporting access to people of authority, (3) being approachable and accessible, (4) listening without judgment, and (4) providing support for follow through.

Self-Advocacy Framework

A comprehensive literature review yielded four components to effective self-advocacy (Test et al., 2005): (1) knowledge of self, (2) knowledge of rights, (3) communication, and (4) leadership.

Researchers have posited that self-advocacy develops in the context of relationships (Caldwell, 2010). In his study of self-advocacy leadership, Caldwell (2010) suggests that opportunities to function in leadership roles builds the skills necessary to bring others into the self-advocacy movement, and that one of the effects is the ability of self-advocates to support each other's personal growth and development.

Self-advocacy and learning to be a leader within the self-advocacy movement counter the oppression that individuals with developmental disabilities often experience through teasing and bullying (Caldwell, 2010). Leaders within the self-advocacy movement describe how they find others who have shared similar life experiences, and that this contributes to an increase in a sense of belongingness within a community (Caldwell, 2011).

Programs on Self-Advocacy

Schools are required to develop Transition Plans for all individuals with disabilities upon moving from a community school setting to placements outside of the community. The National Secondary Transition Technical Assistance Center (NSTTAC) conducted a literature review to identify transition curricula that have empirical support for effectiveness. These programs are free to low cost.

One of the categories identified was self-determination, which was integrated into curriculum and was intended to promote independence through decision-making in major life domains, such as education, employment, and independent living (National Secondary Transition Technical Assistance Center, 2012). These programs focus on encouraging individuals to participate in their educational and occupational decisions. Common elements include: (1) identifying personal interests, (2) building decision making skills, (3) setting goals, and (4) communication skills.

This table provides information about six programs with evidence-based support for promoting self-determination:

Name of Program	Website	Cost
ChoiceMaker Self-Determination Transition Curriculum Components	http://store.cambiumlearning.com/safe-schools-pbis/	>\$100 per Component
Whose Future Is It Anyway?	http://www.ou.edu/content/dam/Education/documents/wfc-guide-final.pdf	Free
The Self-Advocacy Strategy	http://www.edgeenterprisesinc.com/product_detail.php?product_id=87	\$45 for Manual and CD-Rom
Next S.T.E.P.: Student Transition and Educational Planning	http://www.proedinc.com/customer/productView.aspx?ID=3485	\$215 for Complete Program
Steps to Self-Determination: A Curriculum to Help Adolescents Learn to Achieve Their Goals	http://www.proedinc.com/customer/productView.aspx?ID=3601	\$139 for Complete Program
The Transitions Curriculum	http://www.stanfield.com/products/school-to-work-skills/transitions-curriculum/	\$499 for 3 Modules

In addition to formal school curricula, leadership training programs have been another avenue for individuals with intellectual and developmental disabilities to learn to self-advocate. Grenwelge and Zhang (2012) found that a summer leadership forum designed for high school students with disabilities significantly increased the students' self-reported self-advocacy behaviors. The intervention involved utilizing the Texas Statewide Youth Leadership Forum curriculum as implemented by individuals with disabilities with the support of the research team. This included the following topics addressed through a variety of activities such as lecture, discussion, in-vivo activities, and field trips:

- Disability history
- Team building and leadership
- Self-advocacy
- Legislative advocacy
- Postsecondary education
- Employment
- Volunteerism

The Autistic Self Advocacy Network is a member-based organization designed and managed by self-advocates with Autism. Chapters provide support for self-advocates, mentoring of adolescents, skill development, and information on legal rights.

Online Resources to Promote Self-Advocacy

The Arc is a community based national organization promoting self-advocacy for individuals with intellectual and developmental disabilities and their families. The Arc's website provides resources created by self-advocates to inform and promote advocacy behavior. The website includes factsheets related to "Abuse of Children with Intellectual Disabilities." Additionally, in collaboration with the Research and Training Center on Community Living (RTC), the Arc created Self-Advocacy Online. This resource includes videos created by self-advocates promoting wellness (i.e., physical health). This organization also offers paid positions for individuals with disabilities to facilitate outreach and increase their voice beyond the disability community. Also included are topics related to building healthy relationships, speaking up for one's self. These videos may be more powerful as they are created by self-advocates themselves.

Self-Advocates Becoming Empowered

Since 1990, Self-Advocates Becoming Empowered has been a national organization that focuses on empowering individuals and promoting inclusion within the community. There are national chapters and a national convention.

Self-Advocacy Training in Other Domains

Feldman and colleagues (2012) found that following a comprehensive self-advocacy training related to health behaviors, individuals were more likely to report engaging in such behaviors at follow up. The curriculum, "3-Rs (Rights, Respect and Responsibility) health self-advocacy" included training on health knowledge as well as issues related to violations of individuals' rights, respect, and responsibility. Self-advocates were a part of the development of the curriculum and protocols. The curriculum included information about the human body and common ailments through the use of multimedia approaches (i.e., PowerPoint). The health rights curriculum utilizes numerous video scenarios as well as in-person training. At the conclusion of the study, local agencies were given the curriculum to implement with others. The success of this investigation demonstrates that self-advocacy training can be done with a specific topic, utilizing uniform procedures such as videos and multimedia displays.

Finally, the ability to use the Internet may be a valuable source of connection and camaraderie for individuals with developmental disabilities. Within the context of the self-advocacy movement, successful use of the Internet may be considered a necessity for some individuals (Moisey, & van de Keere, 2007).

References

- Autistic Self Advocacy Network. (2014). Autistic Self Advocacy Network. Retrieved from <http://autisticadvocacy.org/chapters/>
- Caldwell, J. (2010). Leadership development of individuals with developmental disabilities in the self-advocacy movement. *Journal of Intellectual Disability Research, 54*(2), 1004-1014. doi: 10.1111/j.1365-2788.2010.01326.x
- Caldwell, J. (2011). Disability identity in leaders of the self-advocacy movement. *Intellectual and Developmental Disabilities, 49*(5), 315-326.
- Feldman, M. A., Owen, F. F., Andrews, A. A., Hamelin, J. J., Barber, R. R., & Griffiths, D. D. (2012). Health self-advocacy training for persons with intellectual disabilities. *Journal of Intellectual Disability Research, 56*(11), 1110-1121. doi:10.1111/j.1365-2788.2012.01626.x
- Grenwelge, C., & Zhang, D. (2013). The effects of the Texas Youth Leadership Forum summer training on the self-advocacy abilities of high school students with disabilities. *Journal of Disability Policy Studies, 24*(3), 158-169. doi:10.1177/1044207312457415
- Moisey, S., & van de Keere, R. (2007). Inclusion and the Internet: Teaching adults with developmental disabilities to use information and communication technology. *Developmental Disabilities Bulletin, 35*(1 & 2), 72-102.
- National Secondary Transition Technical Assistance Center (2012). Comprehensive Transition Curricula Annotated Bibliography, Retrieved from <http://www.nsttac.org/content/transition-curricula>
- Nonnemacher, S. L., & Bambara, L. M. (2011). "I'm supposed to be in charge": Self-advocates' perspectives on their self-determination support needs. *Intellectual and Developmental Disabilities, 49*(5), 327-340.
- Research and Training Center on Community Living. *Self Advocacy Online*. Retrieved from <http://www.selfadvocacyonline.org/>
- Self-Advocates Becoming Empowered. (2014). Retrieved from <http://www.sabeusa.org/>
- Test, D. W., Fowler, C. H., Wood, W. M., Brewer, D. M., & Eddy, S. (2005). A conceptual framework of self-advocacy for students with disabilities. *Remedial and Special Education, 26*(1), 43-54. doi:10.1177/07419325050260010601
- The Arc. (2014). *The Arc for Individuals with Disabilities*. Retrieved from <http://www.thearc.org/>

Individuals with Developmental Disabilities, Peers, and Self-Advocates

GOAL 1: Increase the ability of people with developmental disabilities to prevent and respond to bullying in safe ways.

3. Develop, implement, and evaluate a program that helps individuals with disabilities learn about their disabilities and be able to explain their disabilities to others. Measure the effectiveness of this skill with regards to bullying prevention and intervention.

Needs Assessment Findings

Participants in focus groups suggested that when individuals with developmental disabilities can explain their disabilities to others, they are less likely to be bullied for behaviors or conditions over which they have no control. Thus, understanding one's disability and being able to talk about it may enhance an individual's self-confidence and reduce the likelihood of being victimized by bullying.

Background Research and Theory

Self-determination theory has supported the involvement of individuals with developmental disabilities in participating in decisions that affect them (Abernathy & Taylor, 2009; Jones, 2006; Palmer et al., 2013; Wehmeyer & Abery, 2013; Zhang, Katsiyannis, Singleton, Williams-Diehm, & Childes, 2006). One aspect of being self-determining is self-knowledge (Abernathy & Taylor, 2009; Jones, 2006). Research on self-determination and individuals with disabilities is linked to self-advocacy, suggesting that understanding one's disability and being able to explain it to others is evidence of being a self-advocate (Ancil, Ishikawa, & Scott, 2008).

Additionally, attribution research has found that when those who observe inappropriate behavior attribute it to a factor beyond the individual's control, they are more likely to offer help as opposed to responding with hostility or aggression (Weiner, 1980, 1993). This suggests that when individuals with developmental disabilities are able to explain their disability and include information about what they are unable to exert control over, peers will be less likely to respond to challenging or difficult behaviors with bullying.

One argument in favor of teaching individuals with disabilities about their disabilities is that over-protection seems to be a risk factor for lower self-esteem and lower self-cognition (Dunn, Fuqua, & McCartan, 1988; Nosek, Hughes, Swedlund, Taylor, & Swank, 2003). In other words, when families, educators, or caregivers do not support individuals with disabilities in learning about their disability, they may be acting in an over-protective way. Such conditions seem to undermine the ability of individuals to be self-determining.

Program Development and Evaluation

Roffman, Herzog, and Wershba-Gershon (1994) piloted a program for college students with learning disabilities to see if learning about the disability while in college had any future effects. The participants were taught about their disabilities and supported in learning how to use this knowledge to improve their social interactions with others. The findings from this experimental study indicated that those who had participated in the program had better work adjustment one year later than the control group.

Future Efforts

Aside from this one program for college students, it appears that no formal programs have been evaluated with regards to learning about one's disability and its connection to an increase in self-determination. Additionally, no programs seem to exist which teach individuals with disabilities about their disability in an effort to enhance their ability to avoid bullying victimization.

Although limited, existing theory and research suggest that helping individuals to understand and be able to talk about their disability may enhance self-esteem, self-determination, and self-advocacy. If this is the case, then it is also likely that efforts such as this can reduce the risk of bullying victimization, although this hypothesis has not been tested.

References

- Abernathy, T. V., & Taylor, S. S. (2009). Teacher perceptions of students' understanding of their own disability. *Teacher Education and Special Education, 32*(2), 121-136.
- Ancil, T. M., Ishikawa, M. E., & Scott, A. T. (2008). Academic identity development through self-determination. *Career Development for Exceptional Individuals, 31*(3), 164-174.
- Dunn, N. L., Fuqua, R. W., & McDartan, K. W. (1988). Young children with orthopedic handicaps: Self-knowledge about their disability. *Exceptional Children, 55*(3), 249.
- Jones, M. (2006). Teaching self-determination: Empowered teachers, empowered students. *Teaching Exceptional Children, 39*(1), 12-17.
- Nosek, M. A., Hughes, R. B., Swedlund, N., Taylor, H. B., & Swank, P. (2003). Self-esteem and women with disabilities. *Social Science & Medicine, 56*, 1737-1747.
- Palmer, S. B., Summers, J. A., Brotherson, M. J., Erwin, E. J., Maude, S. P., Stroup-Rentier, V., Wu, H-Y., Peck, N. F., Zheng, Y., Weigel, C. J., Chu, S-Y., Mcgrath, G. S., & Haines, S. J. (2013). Foundations for self-determination in early childhood: An inclusive model for children with disabilities. *Topics in Early Childhood Special Education, 33*(1), 38-47.
- Roffman, A. J., Herzog, J. E., & Wershba-Gershon, P. M. (1994). Helping young adults understand their learning disabilities. *Journal of Learning Disabilities, 27*(7), 413-419.
- Wehmeyer, M. L., & Abery, B. H. (2013). Self-determination and choice. *Intellectual and Developmental Disabilities, 51*(5), 399-411.
- Weiner, B. (1980). A cognitive (attribution)-emotion-action model of helping behavior: An analysis of judgments of help giving. *Journal of Personality and Social Psychology, 39*, 1142-1162.
- Weiner, B. (1993). On sin versus sickness: A theory of perceived responsibility and social motivation. *American Psychologist, 48*, 957-965.
- Zhang, D., Katsiyannis, A., Singleton, S. H., Williams-Diehm, K., & Childes, K. (2006). Self-determination: How students learn to live. *Principal Leadership, 6*(9), 28-34.

Individuals with Developmental Disabilities, Peers, and Self-Advocates

GOAL 1: Increase the ability of people with developmental disabilities to prevent and respond to bullying in safe ways.

4. Develop or adapt a prevention program on bullying specifically for school-age children with developmental disabilities which is appropriate for their developmental age. Include information on how to create and execute a “safety plan” for students. Support schools and other groups in the adoption and use of this program for individuals with disabilities.

Needs Assessment Findings

Findings from surveys, focus groups, and interviews point to the need to educate youth in schools about bullying because it is often a serious problem for students with disabilities. It is noteworthy that seventy-five percent of service providers think bullying is slightly or much more common for individuals with disabilities, supporting the idea that individuals with disabilities need support on the topic of bullying.

Although stakeholders in the survey indicated that existing programs could serve as a starting point, there was concern that individuals with disabilities were not involved in the creation of these programs. Many participants made the point that programming on bullying prevention for general education student may not be understandable or appropriate for students with disabilities. Additionally, concern was expressed that what might work as a response to bullying for students without a disability, might not be appropriate for students with a disability. Participants suggested that students with a disability might need specifically designed plans to insure safety with regards to bullying. Therefore, it would be important to act in collaboration with individuals with disabilities, as well as experts in special education, to develop appropriate program materials on bullying for students with disabilities.

Results from the survey support activities that improve education on bullying for students with disabilities that promotes inclusion and respect:

- Parents of children with disabilities and adults with disabilities report that being teased, ignored, and having rumors spread were the most common (occurring 2-3 times/month or more) types of bullying behaviors experienced.
- Approximately two thirds of parents surveyed reported that their child was left out of a group or ignored, as well as teased and called names. Parents reported that the least common bullying behavior their child experienced was having things stolen or damaged (22%).
- All survey respondents agreed that teaching better ways to treat people would help.

Bullying Prevention Programs (for General School-aged Population)

Mandates for schools to address bullying problems have led to the creation of many bullying prevention programs marketed to schools. Studies of bullying prevention programs have shown that they can increase awareness, knowledge, and teacher reports of increased ability to intervene, but they do not necessarily produce substantial reductions in bullying behaviors and victimization (Merrell, Gueldner, Ross, & Isava, 2008; Smith, Schneider, Smith, & Ananiadou, 2004).

Ttofi and Farrington’s (2011) meta-analysis of international bullying prevention programs has revealed more promising results:

- Comprehensive, multicomponent programs demonstrate the largest effect sizes.
- Programs that made more intensive efforts (e.g., intensive training for teachers, more education for students) had greater impact on both bullying and victimization than briefer programs.
- The most important program elements in reducing bullying were meetings/ training efforts for parents and close playground supervision.
- Firm disciplinary sanctions for students engaged in bullying (e.g., serious talks, referrals to the principal), and loss of privileges were also associated with reduced bullying.

Ttofi, Farrington, and Baldry (2008) identified several elements of bullying prevention programs, some of which contribute to reduced bullying perpetration, reduced victimization, or both:

Element of Program	Reduced Bullying?	Reduced Victimization?
Parent Training	✓	✓
Improved playground supervision	✓	✓
Disciplinary measures	✓	✓
Videos	✓	✓
School conferences	✓	
Information for parents	✓	
Classroom rules	✓	
Classroom management	✓	
Work with peers		✓
Cooperative group work		✓

Note. The duration of the program for children and teachers, and the intensity of the program for teachers were significantly associated with reducing victimization (Ttofi et al., 2008)

The University at Buffalo’s Alberti Center for Bullying Abuse Prevention created a guide that describes 10 school-wide bullying prevention programs that have evidence of their effectiveness in the United States. These programs include:

- Al’s Pals: Kids Making Healthy Choices
- Bully Busters
- Bullying Prevention in Positive Behavioral Interventions and Support
- Bully-Proofing Your School
- Creating a Safe School
- Get Real about Violence
- Olweus Bullying Prevention Program
- Second Step: A Violence Prevention program
- Steps to Respect: A Bullying Prevention Program

Note. For more information about the age groups, costs, availability, and research concerning these programs, please see the full guide at

http://gse.buffalo.edu/gsefiles/documents/alberti/Bullying%20Prevention%20Program%20Guide%20-%20FINAL%203.16.12_0.pdf

What Schools are Doing

The Alberti Center’s surveys of New York State educators from 2012 and 2013, respectively, reveal that the following programs are being used most commonly:

- Positive Behavioral Interventions and Supports (44%)
- Rachel’s Challenge (42%, 39%) – Please note that to our knowledge there is no research support for this program
- Second Step (20%, 22%)
- Olweus Bullying Prevention Program (14%, 22%)
- Steps to Respect (5%, 6%)

Unfortunately, these programs do not systematically address students with disabilities, raising the question of whether or not programs designed for the general education population are suitable for students with disabilities. As with any program, new, existing, or revised, evaluation to determine effectiveness is essential.

Sustainability of Bullying Prevention Programs

Although evidence of effectiveness is very important, schools and community agencies are often not prepared to implement and sustain programs due to issues such as limited capacity, insufficient preparation, or lack of readiness (Elliott & Mihalic, 2004). Important elements for sustaining school-based programs include (Elliott & Mihalic, 2004; Han & Weiss, 2005; Safe Schools Healthy Students, 2010):

- Strong administrative support
- Acceptance by teachers and administrators (including having a respected local “champion” of the program)
- Feasibility in terms of implementing programs with available resources
- Basing program selection on a needs assessment
- Including a selection committee of representative stakeholders (teachers, parents, students, and administrators) to judge the potential success and acceptability of possible interventions

Guidance and Resources for Bullying Prevention and Individuals with Disabilities

As with other bullying prevention efforts, working with students with disabilities requires comprehensive efforts at multiple levels of intervention. The figure below depicts a multi-tiered framework for bullying prevention and intervention developed by Rose & Monda-Amaya (2012):

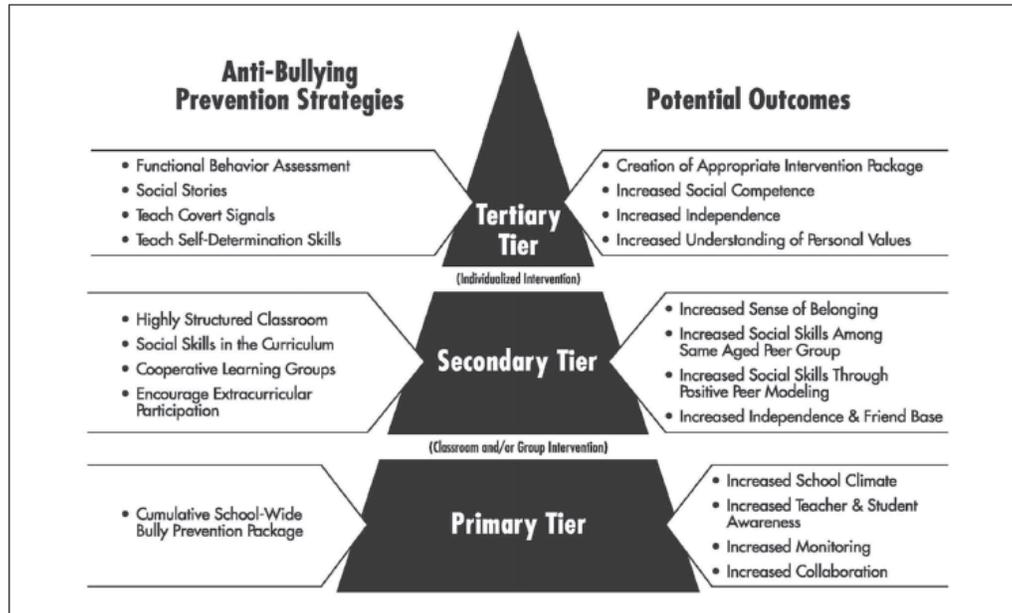


Figure 1. Intervention strategies and potential outcomes for bully prevention within a multitiered framework

In one of the few studies looking at students with disabilities with regard to a universal bullying prevention program (Sheffield Project in UK), students with disabilities reported a decrease in victimization and bullying perpetration following the implementation of the intervention. The students with disabilities also reported that they had more friends after the intervention (Whitney, Smith, & Thompson, 1994).

In another study, eleven school nurses conducted a 12-session, bi-weekly support/discussion group intervention for 65 students with disabilities, aged 8-14, using materials from the *Stop Bullying Now* campaign (see <http://www.stopbullying.gov/kids/index.html>). After the program, students reported being significantly less bothered by teasing and bullying, and possessed significantly improved self-concepts (Vessey & O'Neill, 2011).

Raskauskas and Modell (2011) provide several recommendations for how bullying prevention programs can be modified to better meet the needs of students with disabilities:

- Needs assessment/surveys on prevalence of bullying – make sure definition is understandable; provide alternate methods of response (paper and pencil, electronic, verbal)
- Program content – train staff working with students with disabilities on how to recognize and respond to problem behaviors; assess policies to ensure that they are effective for a wide spectrum of disabilities; take into account language and communication difficulties and provide several ways to report bullying (hand signal, anonymous report); match bullying content and training with positive behavior support; educate students about tolerance, empathy, respect, and responding to bullying
- Delivery – integrate additional examples into content; provide concrete examples; allow more repetition of concepts; give opportunities to practice identifying, responding to, and reporting bullying; make materials available in accessible ways (large print, audio recording, Braille).

Life's WORC, a private organization that supports individuals with developmental disabilities and families in Queens, Nassau and Suffolk counties, has a Life's WORC bullying committee that aims to provide education, strategies, and empowerment to individuals with developmental disabilities to eliminate bullying. The Life's WORC bullying committee

has developed presentations and a pamphlet and may serve as a valuable model or template for adapting bullying prevention programs for school-age children with developmental disabilities. For more information see <http://lifework.org/contact-lifes-work>.

As detailed in the section on Bullying Prevention Programs (for General School-aged Population), there are several considerations that need to be taken into account in order to implement programs effectively. Therefore, an initiative to adapt an existing bullying prevention program for individuals with disabilities would need to involve multiple stakeholders, administrative support, resources and time to implement it feasibly, and careful program evaluation of the effort.

References

- Elliott, D. S., & Mihalic, S. (2004). Issues in disseminating and replicating effective prevention programs. *Prevention Science, 5*, 47-52.
- Han, S. S., & Weiss, B. (2005). Sustainability of teacher implementation of school-based mental health programs. *Journal of Abnormal Child Psychology, 33*, 665-679.
- Merrell, K. W., Gueldner, B. A., Ross, S. W., & Isava, D. M. (2008). How effective are school bullying intervention programs? A meta-analysis of intervention research. *School Psychology Quarterly, 23*, 26–42. doi:10.1037/1045-3830.23.1.26
- Raskauskas, J., & Modell, S. (2011). Modifying anti-bullying programs to include students with disabilities. *TEACHING: Exceptional Children, 44*(1), 60-67.
- Rose, C. A., & Monda-Amaya, L. E. (2012). Bullying and victimization among students with disabilities: Effective strategies for classroom teachers. *Intervention in School and Clinic, 48*(2), 99-107.
- Safe Schools Healthy Students (2010). *Evidenced-based program home*. Retrieved from <http://sshs.promoteprevent.org/node/4789>
- Serwacki, M., & Nickerson, A. (2012). *Guide to schoolwide bullying prevention programs*. Retrieved from http://gse.buffalo.edu/gsefiles/documents/alberti/Bullying%20Prevention%20Program%20Guide%20-%20FINAL%203.16.12_0.pdf
- Smith, J. D., Schneider, B. H., Smith, P. K., & Ananiadou, K. (2004). The effectiveness of whole-school anti-bullying programs: A synthesis of evaluation research. *School Psychology Review, 33*, 547–560.
- Ttofi, M. M., & Farrington, D. P. (2011). Effectiveness of school-based programs to reduce bullying: A systematic and meta-analytic review. *Journal of Experimental Criminology, 7*, 27–56. doi:10.1007/s11292-101-9109-1
- Ttofi, M. M., Farrington, D. P., & Baldry, A. C. (2008). *Effectiveness of programmes to reduce school bullying: A systematic review*. Stockholm: Swedish National Council for Crime Prevention.
- Vessey, J. A., & O'Neill, K. M. (2011). Helping students with disabilities better address teasing and bullying situations: A MASNRN study. *The Journal of School Nursing, 27*(2), 139-148.
- Whitney, I., Smith, P. K., & Thompson, D. (1994). Bullying and children with special educational needs. In P. K. Smith & S. Sharp (Eds.), *School bullying: Insights and perspectives* (pp. 213-240). London: Routledge.

Individuals with Developmental Disabilities, Peers, and Self-Advocates

GOAL 1: Increase the ability of people with developmental disabilities to prevent and respond to bullying in safe ways.

5. Develop a bullying prevention program designed for individuals with developmental disabilities in the workplace. Disseminate this program through ARCS, self-advocacy groups, and Parent-to-Parent Networks across New York State.

Needs Assessment Findings

According to adults with developmental disabilities, 12% reported that they had experienced bullying in the workplace or in locations where they volunteer. Additionally, study participants suggested that one of the reasons that people with developmental disabilities “may have more tolerance for bullying” is because they don’t have the capacity to fight back. This suggests that learning how to address bullying in the workplace would be a valuable skill for adults with disabilities.

Research on Bullying in the Workplace and Individuals with Developmental Disabilities

Information on bullying of individuals with developmental disabilities within the workplace is virtually non-existent (see Vickers, 2009 for one exception). More research is available on the topic of disability harassment. However, there is rather substantial literature on workplace bullying in general. Thus, information that would assist in the development of a workplace bullying prevention education program for individuals with disabilities is drawn primarily from the literature on bullying in the workplace in general.

It is important to note that harassment that creates a hostile working environment is more likely to be litigated than bullying in the workplace. This is because there are legal definitions of harassment and prohibitions against it, whereas there are none for bullying in the workplace. Thus, without a clear and consistent understanding of what bullying in the workplace actually is, and without laws that prohibit it, it is difficult to address this problem. Those who are able to establish that harassment produces a hostile work environment are able to avail themselves of anti-discrimination laws. However, if bullying in a workplace setting cannot be framed as harassment, then efforts to address the bullying will rely on the individual’s ability to confront the aggressor or seek support to cope with the aggression.

Harassment, Bullying, and Disability Harassment

Harassment is generally defined as:

Harassment is governed by state laws, which vary by state, but is generally defined as a course of conduct which annoys, threatens, intimidates, alarms, or puts a person in fear of their [sic] safety. Harassment is unwanted, unwelcomed and uninvited behavior that demeans, threatens or offends the victim and results in a hostile environment for the victim. Harassing behavior may include, but is not limited to, epithets, derogatory comments or slurs and lewd propositions, assault, impeding or blocking movement, offensive touching or any physical interference with normal work or movement, and visual insults, such as derogatory posters or cartoons.⁴

⁴ <http://definitions.uslegal.com/h/harassment/>

Bullying is an aggressive behavior, intended to cause harm that is usually repeated and that exploits an imbalance of power (Gladden, Vivolo-Kantor, Hamburger, & Lumpkin, 2014). It is generally accepted that harassment does not have to be repeated or directed towards an individual person in order to create a hostile environment. For example, the presence of a calendar of nude women hanging in the break room constitutes sexual harassment even though it may not be directed at any one person.

Holzbauer (2004) has stated that disability harassment is “work-related harassment on the basis of disability.” In the first years after the passage of the Americans with Disability Acts, disability harassment was cited in 7.7% of complaints received by the Equal Employment Opportunity Commission (Holzbauer & Berven, 1996). A decade ago, Robert (2003) found that adults with disabilities experienced the following forms of harassment in the workplace: “jokes, needling, name-calling, mimicry, innuendo, rumors, rudeness, sabotage, inappropriate questioning, and insensitive remarks” (Robert, 2005, p. 148; Robert & Harlan, 2006). If these behaviors were intentionally harmful and repeated (or likely to be repeated), then they would fit the definition of bullying, as well as qualifying as harassment. Robert and Harlan (2006) conclude that “harassment operates as an interpersonal mechanism of discrimination,” (p. 614), just as bullying does.

In addition to bullying and harassment, Vickers (2009) provides evidence suggesting that it is difficult for many people with disabilities to find employment. She suggests this is due to a variety of reasons including stigmatization and flawed stereotypes around disabilities. By extension, it is likely that bullying is related to stereotypes and stigmatization with regards to disability, and that even when people with disabilities do find employment, they are likely to experience bullying and harassment, which is the result of stigmatization because of their disability.

Thus, it seems that the issue of bullying of individuals with disabilities in the workplace is closely linked to harassment of individuals with disabilities in the workplace, and because of this any program that addresses bullying should also include information on the multiple forms of harassment, as well as specific information on disability harassment.

Bullying Prevention and Adults with Intellectual and Developmental Disabilities

McGrath, Jones, and Hastings (2010) evaluated a program designed to reduce bullying and bullying victimization of adults with developmental disabilities. The program components includes those which drew “on other aspects of other anti-bullying programs” (p. 377) (e.g., rules against bullying, procedures for reporting bullying), plus anger management and relaxation strategies, and was “cognitive behavioral in orientation” (p. 377).

While this study offers limited information about what to include in a bullying prevention program for individuals with developmental disabilities in the workplace, it suggests several areas to consider:

- Information on what bullying is with clear examples that include racial, sexual, gender, ethnic, and disability bullying.
- Ways to recognize and cope with strong feelings.
- Demonstration of strategies for responding to and telling about bullying, including ways to stay safe from hostile or frightening situations and people (i.e., have a “safety plan;” use the “cognitive rehearsal⁵” strategy [Griffin, 2004; Smith, 2011]).
- A focus on positive social behaviors that promote inclusion and friendship, and reduce the likelihood of being accused of or engaging in bullying behaviors.

⁵ Cognitive rehearsal involves practicing what a person can say and do when confronted with bullying or harassing behaviors.

- Social skills development, which includes problem solving and conflict resolution strategies.

It should be noted that literature on bullying suggests that education for targets or perpetrators of bullying, by itself does not make significant changes in prevalence. Bullying is a complex phenomenon and is seldom solely the result of a person's individual behavior. The cultures and climates of workplace environments have an impact on how people behave. Thus, while education and skill development for the individual is beneficial, by itself it is not likely to make major changes for individuals with developmental disabilities (Langan-Fox & Sankey, 2007; Lutgen-Sandvik, Namie, & Namie, 2009; McKay, Ciocirlan, & Chung, 2010; Vega & Comer, 2005). Workplaces that are supportive of people with disabilities will have understandable and accessible reporting procedures for those who experience bullying and/or harassment. Such policies and procedures contribute to safe, inclusive environments in which people with disabilities can thrive.

Relevant Theory

The Social Model of Disability (aka. Minority Group Model of Disability) (see discussion in Robert & Harlan, 2006), combined with a Theory of Mechanism-Based Approaches to Ascriptive Inequalities (Reskin, 2003; Robert & Harlan, 2006) suggest a way to frame activities which seek to reduce bullying in the workplace for individuals with developmental disabilities.

The Social Model of Disability assumes the position “that disability is not a physical or mental property that is located in individuals... (It is a relational phenomenon) that locates disability in the interactions of people with physical or mental impairments and their social, including their built, environments” (Robert & Harlan, 2006, pp. 600-601). Thus, this theory sees disabilities not as something inherent in people, but something that has been ‘ascribed’ to them by society.

Reskin (2003) suggests that previous approaches to inequality have tended to focus on the motivation for enforcing the inequality as opposed to the mechanisms, which sustain the inequality. Robert and Harlan (2006) focus on how inequalities occur, which means considering the mechanisms that support continued prejudice and discrimination. These mechanisms include “differential behavior that can be observed in routine interactions between workers with disabilities and their coworkers and supervisors... (These behaviors include) discriminatory acts of marginalization, fictionalization, and harassment... that are made possible and sustained by the organizational context in which they operate” (p. 602) as well as their interpersonal manifestations.

References

- 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 U.S. Department of Education.
- Griffin, M. (2004). Teaching cognitive rehearsal as a shield for lateral violence: An intervention for newly licensed nurses. *The Journal of Continuing Education in Nursing, 35*(6), 257-263.
- Holzbauer, J. J. (2004). Disability harassment of students in transition from school to work: Implications for rehabilitation counseling. *Journal of Applied Rehabilitation Counseling, 35*(4), 3-7.
- Holzbauer, J. J., & Berven, N. L. (1996). Disability harassment: A new term for a long-standing problem. *Journal of Counseling and Development, 74*(5), 478-483.

- Langan-Fox, J., & Sankey, M. (2007). Tyrants and workplace bullying. In J. Langan-Fox, C. L. Cooper & R. J. Klimoski (Eds.), *Research companion to the dysfunctional workplace: Management challenges and symptoms* (pp. 58-74). Northampton, MA: Edward Elgar Publishing.
- Lutgen-Sandvik, P., Namie, G., & Namie, R. (1990). Workplace bullying: Causes, consequences, and corrections. In P. Lutgen-Sandvik & B. D. Sypher (Eds.), *Destructive organizational communication: Processes, consequences, and constructive ways of organizing* (pp. 27-52). New York: Routledge.
- McGrath, L., Jones, R. S. P., & Hastings, R. P. (2010). Outcomes of anti-bullying intervention for adults with intellectual disabilities. *Research in Developmental Disabilities, 31*, 376-380.
- McKay, R., Ciocirlan, C. E., & Chung, E. (2010). Thinking strategically about workplace bullying in organizations. *Journal of Applied Management and Entrepreneurship, 15*(4), 73-93.
- Reskin, B. F. (2003). Including mechanisms in our models of ascriptive inequality. *American Sociological Review, 68*, 1-21.
- Robert, P. (2003). Disability oppression in the contemporary U. S. capitalist workplace. *Science & Society, 67*(2), 136-159.
- Robert, P., & Harlan, S. L. (2006). Mechanism of disability discrimination in large bureaucratic organizations: Ascriptive inequalities in the workplace. *The Sociological Quarterly, 46*(4), 599-630.
- Smith, C. M. (2011). Scripts: A tool for cognitive rehearsal. *The Journal of Continuing Education in Nursing, 42*(12), 535-536.
- Vega, G., & Comer, D. R. (2005). Sticks and stones may break your bones, but words can break your spirit: Bullying in the workplace. *Journal of Business Ethics, 58*, 101-109
- Vickers, M. H. (2009). Bullying, disability and work: A case study of workplace bullying. *Qualitative Research in Organizations and Management: An International Journal, 4*(3), 255-272.

Families and Advocates for Individuals with Developmental Disabilities

GOAL 2: Increase supports for people with developmental disabilities and their families to deal with bullying

1. Using existing networks of support for parents and family members of people with developmental disabilities (e.g., Parent to Parent), develop an online and/or telephone support network or hotline to assist with problems around bullying and people with developmental disabilities.

Needs Assessment Findings

Hotlines and support groups are designed to help people problem-solve, cope, and access resources. According to parents and adults with disabilities, problem-solving was the most commonly used method of coping with issues related to bullying. Additionally, a number of study participants suggested that support groups, both online and face-to-face, could help parents, families, and individuals deal more successfully with problems around bullying. Likewise, participants suggested hotlines for people who are having immediate challenges with bullying and who may not have anyone else to turn to.

It should be noted that this suggestion does not extend to the types of hotlines that serve as anonymous “tip lines” for reporting bullying. These types of mechanisms seek to provide officials with information needed to investigate an infraction or a crime. Some schools do employ such reporting procedures as a way to reduce bullying. The recommendation offered here, however, does not apply to tip lines in schools, nor does it apply to ones which would generate legal investigations of bullying outside of the school context.

Support Groups and Hotlines

While similar, online or telephone support groups are slightly different from hotlines. Whether conducted asynchronously in chat rooms or in a public forum over the Internet, or synchronously, over the telephone, a support group consists of a group of people seeking mutual support from one another in dealing with a similar concern. A hotline, on the other hand is a specific telephone number or web site to call or log on to, to talk to someone with expert knowledge or information on a particular topic. Whereas the former is a group activity, a hotline is a one-on-one conversation.

Additionally, there are differences between the activities and outcomes characteristic of support groups and hotlines. Support groups are bi-directional interactions that offer emotional connection that provides psychological relief with respect to a particular problem (Baral, Boniel-Nissim, & Suler, 2008). Support group activities are generally a continuous, on-going process. On the other hand, hotlines are a “one-way” avenue of support, often designed to help individuals in crisis or those needing information (e.g., knowledge of resources and how to access them) to address a specific problem. Hotlines are “anonymous venues of contact with little or no longer-term follow-up, systematic referrals for case management, or treatment” (Knox, Kemp, McKeon, & Katz, 2012).

Support groups and hotlines are designed to address many different and diverse issues. A review of literature indicates that support groups and hotlines exist to address a wide variety of problems that people struggle with such as: breast cancer, dyslexia, hearing-impairments, Alzheimer’s, Autism, smoking, dental anxiety, phobias, asthma, rape, diabetes, etc. (Barak et al., 2008).

Research on Online, Telephone, or Hotline Support

Support Groups

Online support groups operate through a number of types of online social media platforms including email, chat rooms, or forums such as bulletin boards, which seem to be the most popular (Barak et al., 2008). Braithwaite, Waldron, and Finn (1999) found that the most frequent type of interaction in an online support group for people with disabilities included information (e.g., advice, situation appraisal, or teaching) and emotional support.

Online support groups have provided the following to participants:

- A sense of empowerment (Barak et al., 2008; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009).
- A reduction in loneliness and social isolation (Barak et al., 2008; Lieberman et al., 2005).
- Improved decision-making skills, being better informed, an enhanced sense of social well-being, and increased optimism and control (Barak et al., 2008).

In general, all support groups have as their primary objective the improvement of overall well-being, an increase in a sense of control, and the generation of feelings of connectedness and empowerment. In addition to these psychological outcomes, support groups that are organized and facilitated by a professional counselor or therapist also seek to change behaviors and cognitions. Support groups that meet outside the formal realm of “therapy,” generally do not involve professionals. Because the outcomes of support group participation are subjective, self-reported, and often more psychological and attitudinal than behavioral or cognitive, research on the effects of support groups is difficult to conduct (Barak et al., 2008).

In a quasi-experimental study of parents of children with Autism, Clifford and Minnes (2013) found that there was no difference between the intervention group and the comparison group in terms of parental mood, anxiety, parenting stress, or positive perceptions. However, participants in the support group indicated that they were satisfied with the support they received and that the support group was helpful.

In a study of the outcomes of professionally led online support groups for people with Parkinson’s disease, participants indicated that they experienced an overall improvement in the quality of their lives and a general reduction in their depressive symptoms (Lieberman et al., 2005). The researchers also found that when the makeup of a group was homogenous (e.g., similar in terms of gender, age, disease onset, and progression of the disease), the outcomes were improved.

Telephone support groups (as opposed to face-to-face support groups) seem to be more appealing to individuals whose reason for participation in the support group involves a stigmatizing condition such as HIV (Rounds, Galinsky, & Despard, 1995).

Hotlines

In an evaluation of domestic violence services in the state of Illinois (Bennett, Riger, Schewe, Howard, & Wasco, 2004), which included information on a hotline, researchers concluded that users gained important information about violence as a result of having used the hotline services.

In an evaluation of a national parent helpline designed to assist parents with advice and support when confronted with child-rearing problems (Boddy, Smith, & Simon, 2005), researchers found that parents reported positive experiences with

the helpline. Users generally indicated that they felt better after speaking with the helpline staff and that they were often able to make changes to improve the situation as a result of the telephone conversation. Similar outcomes were reported in another study from the UK (Ritchie, 2006).

Online peer-chat hotlines, staffed by trained volunteers, have been created to address problems such as suicidal ideation, child abuse and neglect, and sexual assault (Finn, Garner, & Wilson, 2011). In an evaluation of the National Sexual Assault Online Hotline, researchers concluded that the online hotline is needed and useful, citing that in one year alone 20,000 people used the service, with the majority indicating that they would recommend it to others.

In a study of an online and telephone hotline for children aged 8-18 in the Netherlands (Fukkink & Hermanns, 2009), researchers found that children used the online chat feature slightly more than the telephone option. They also concluded that children found that use of the hotline increased their sense of well-being and reduced their perceived burden of the problem.

The establishment and use of hotlines is often paired with a media campaign to advertise the hotline as in the case of the creation of the national AIDs hotline (Randall, 1990) and the Veterans Administration's suicide hotline (Knox et al., 2012).

Mixed Services

Researchers conducted a study of telephone support for caregivers of patients with dementia which included components resembling both a hotline service and an on-going support service (Salfi, Ploeg, & Black, 2005). The two types of telephone services included information and emotional support and were offered by a professional knowledgeable about dementia and Alzheimer's disease.

In the first type of service, caregivers initiated a phone call to a hotline. In the second type of service, persons who were seeking help first participated in a face-to-face interview and assessment with the providing agency. In this case, the person with dementia was part of a formal program which included support for caregivers. Following the initial interview, caregivers could call at any time to seek help.

Additionally, the agency provided follow-up calls to the caregiver to inquire about current needs and status. One of the most important outcomes of this study was caregiver participants' acknowledgement that the support they experienced felt like companionship in an isolating and difficult situation.

Recommendations for the design, implementation and evaluation of social support in online communities that "address the interdependencies between online and real-world support and emphasize an inclusion framework of interpersonal and community-based support" (Weiss et al., 2013) include:

Design and implementation

- Address the interdependence between online support and real-world support
- Address the individual's existing social networks (e.g., family, friends, and co-workers)
- Target community-wide outcomes and participation of local community groups

Evaluation

- Adapt and/or develop evaluation measures of support specific to online environments
- Consider all units of analysis (from interpersonal to community-wide measures of support)

Design, implementation, and evaluation

- Employ ecological systems theory and principles of community-based participatory research

References

- Barak, A., Boniel-Nissim, M., & Suler, J. (2008). Fostering empowerment in online support groups. *Computers in Human Behavior, 24*, 1867-1883.
- Bennett, L., Riger, S., Schewe, P., Howard, A., & Wasco, S. (2004). Effectiveness of hotline, advocacy, counseling, and shelter services for victims of domestic violence: A statewide evaluation. *Journal of Interpersonal Violence, 19*(7), 815-829.
- Boddy, J., Smith, M., & Simon, A. (2005). Telephone support for parenting: An evaluation of Parentline Plus. *Children & Society, 19*, 278-291.
- Braithwaite, D. O., Waldron, V. R., & Finn, J. (1999). Communication of social support in computer-mediated groups for people with disabilities. *Health Communications, 11*(2), 123-151.
- Clifford, T., & Minnes, P. (2013). Logging on: Evaluating an online support group for parents of children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 43*, 1662-1675.
- Finn, J., Garner, M. D., & Wilson, J. (2011). Volunteer and user evaluation of the National Sexual Assault Online Hotline. *Evaluation and Program Planning, 34*, 266-272.
- Fukkink, R. G., & Hermanns, J. M. A. (2009). Children's experiences with chat support and telephone support. *The Journal of Child Psychology and Psychiatry, 50*(6), 759-766.
- Knox, K. L., Kemp, J., McKeon, R., & Katz, I. R. (2012). Implementation and early utilization of a suicide hotline for veterans. *American Journal of Public Health, 102*(S1), S29-S32.
- Lieberman, M. A., Winzelberg, A., Golant, M., Wakahiro, M., DiMinno, M., Aminoff, M., & Christine, C. (2005). Online support groups for Parkinson's patients: A pilot study of effectiveness. *Social Work in Health Care, 42*(2), 23-38.
- Randall, T. (1990). CDC's hot line: 'America responds to AIDS.' *Journal of the American Medical Association, 263*(19), 2587-2588.
- Ritchie, C. (2006). Can telephone support improve parent and child well-being? *Journal of Social Work, 6*(3), 361-374.
- Rounds, K. A., Galinsky, M. J., & Despard, M. R. (1995). Evaluation of telephone support groups for persons with HIV disease. *Research on Social Work Practice, 5*(4), 442-459.
- Salfi, J., Ploeg, J., & Black, M. E. (2005). Seeking to understand telephone support for dementia caregivers. *Western Journal of Nursing Research, 27*(6), 701-721.
- van Uden-Kraan, C. F., Crossaert, C. H. C., Taal, E., Seydel, E. R., & van de Laar, M. A. F. J. (2009). Participation in online patient support groups endorses patients' empowerment. *Patient Education and Counseling, 74*, 61-69.
- Weiss, J. B., Berner, E. S., Johnson, K. B., Giuse, D. A., Murphy, B. A., & Lorenzi, N. M. (2013). Recommendations for the design, implementation and evaluation of social support online communities, networks, and groups. *Journal of Biomedical Informatics, 46*, 970-976.

Families and Advocates for Individuals with Developmental Disabilities

GOAL 2: Increase supports for people with developmental disabilities and their families to deal with bullying.

2. Create and disseminate an educational program on bullying for families and advocates of people with developmental disabilities. Emphasize rights and resources, as well as information on bullying and how to help them help their children, both those who are being bullied and those who are bullied.

Needs Assessment Findings

Focus group and interview participants indicated that they felt that parents of children with disabilities often were uninformed about the problem of bullying. They felt that this deficit made it difficult to advocate for or support their children, youth as well as adults, if they were experiencing bullying. Participants suggested that information on bullying be embedded in informational programs on the rights of people with disabilities and on resources that are available to support people with disabilities and their families.

Additionally, survey results found that:

- Service provider/adult directed strategies are more effective (average between somewhat to very effective) than child/individual with disability directed strategies (average between somewhat and very).
- Educating others and attending seminars and presentations about bullying were more effective (somewhat to very effective) according to service providers than to parents (not at all effective to somewhat effective).
- Overall, parents had tried a myriad of strategies and found them to be more effective when their child was the bully than when their child was the target of bullying. This means that parents may have less effective options when their child was bullied than when their child was the bully, or that it may be harder to manage when the child is bullying.
- Parents need to teach their child to not treat others unkindly (all respondents agree).

Research Literature on the Importance of Educating Parents

Numerous approaches have been used to involve parents in school-based anti-bullying activities; however, none of them has been evaluated independently from a comprehensive program. These approaches include:

- Inviting parents to a school anti-bullying conference day to raise their awareness of bullying problems (Olweus, Limber, & Mihalic, 1999);
- Informing parents of the anti-bullying policy and program (e.g., newsletters, PTA meetings; Olweus, 1993; Pepler, Craig, Ziegler, & Charach, 1994);
- Consulting parents in the development of anti-bullying policies and programs (Sharp & Thompson, 1994);
- Providing parents with information about bullying and strategies to help their children through distributing parent brochures, resource packs (Olweus et al., 1999; O'Moore & Minton, 2005), or parent education sessions (Meraviglia, Becker, Rosenbluth, Sanchez, & Robertson, 2003);
- Distributing newsletters to provide information on key concepts and skills taught in the anti-bullying classroom curriculum and describe activities to support their use at home (Frey, Hirschstein, Snell, Van Schoiack Edstrom, MacKenzie, & Broderick, 2005); and
- Contacting and meeting with parents of victims and bullies (Bonds & Stoker, 2000; Olweus, 1993).

Researchers and practitioners suggest that parent involvement plays an essential role in school-based anti-bullying efforts (Meraviglia et al., 2003; Olweus et al., 1999; Stevens, de Bourdeaudhuij, & Van Oost, 2001; Swearer & Doll, 2001) in light of the finding that certain parenting/family factors place children at higher risk for bullying and victimization (e.g., Baldry & Farrington, 1998).

Involving parents in anti-bullying efforts is also believed to enhance the consistency in handling bullying problems, which leads to more promising intervention outcomes (Olweus, 1993; Sharp, 1996).

Providing information to parents or parent meetings were elements of bullying prevention programs found to be effective for reducing bullying and victimization (Ttofi, Farrington, & Baldry, 2008).

Possible Barriers to Parent Involvement

The literature on the effectiveness of parent involvement (PI) throughout their child's education is extensive; however, PI is not widespread practice (Henderson & Berla, 1994). Hornby (2011) identifies four areas of influence and their associated barriers to parental involvement:

- Individual parent and family factors
 - Parents' beliefs about involvement and its positive impact on their child (Hoover-Dempsey & Sandler, 1997), their role in supporting their child's education (Hoover-Dempsey & Sandler, 1995, 1997; Walker, Wilkins, Dallaire, Sandler, & Hoover-Dempsey, 2005), and their perceptions of invitations for PI from the school, teachers, and child;
 - Current life contexts (e.g., knowledge, skills, time, and energy);
 - Socioeconomic status (e.g., class, parent education; Mannan & Blackwell, 1992), ethnicity, and gender
- Child factors:
 - Age of child
 - Learning difficulties, behavioral problems, and disabilities; gifts and talents
- Parent-teacher factors:
 - Differing goals, agendas, and attitudes,
 - Lack of resources for non-English speaking parents (Cross, Pintabona, Hall, Hamilton, & Erceg, 2004).
- Societal factors: Historical and demographic, political, and economic.

Additional Findings from Literature

Parents of students with disabilities may face greater barriers and are less involved in school than parents of students without disabilities (Coots, 1998; Dyson, 1997). In addition, parents' obligation to advocate for their child with a disability is a life-long process that often results in great stress (Wang et al., 2004). Additionally, current life contexts (e.g., lack of work flexibility, extended family responsibilities and other children, and life demands) are a consistent barrier to parent involvement. Parents do best when educational opportunities vary in time commitment, frequency, educational comfort levels, and type (Hoover-Dempsey & Sandler, 1997).

Consistent invitations to parents from school staff may be more important than parental education, family size, marital status, or socioeconomic level in determining parent participation (U.S. Department of Education, 1994). Parents of children with and without disabilities increase their involvement in home- and school-based activities when their child invites their participation (Fishman & Nickerson, 2014; Green et al., 2007). Invitations for involvement from special education teachers may be particularly important to increase involvement of parents of students with disabilities (Fishman & Nickerson, 2014).

Finally, Cross and colleagues (2004) found parents had poor motivation and interest with regards to engaging in anti-bullying activities. In light of these findings, it may be beneficial to encourage students to ask parents for help with bullying related issues, as well as to ask school staff to develop meaningful relationships/partnerships with parents and encourage parent participation in educational programming on bullying.

Advocates and Education about Bullying

Bullying takes place within a larger social context comprised of students, teachers, administrators, other school staff, and the community (Bronfenbrenner, 1979; Espelage & Swearer, 2004, Swearer, Espelage, Vaillancourt, & Hymel, 2010). The research literature suggests that school staff, parents (Sawyer, Mishna, Pepler, & Wiener, 2011), physicians (Lyznicki, McCaffree, & Robinowitz, 2004), and peers (Craig, Pepler, & Atlas, 2000) are all potential advocates who can support the effort to reduce bullying of individuals with disabilities if they have adequate knowledge.

There is significant evidence that students may not report bullying to adults for a variety of reasons including (a) lack of intervention by adults, (b) fear of retaliation or reputation as a rat or tattle tale, and (c) inability to recognize bullying. Advocates could participate in educating students on how to recognize bullying and how to report bullying, <http://www.p12.nysed.gov/dignityact>

Advocates for Children of New York (AFC) protects and promotes the educational rights of students with disabilities by providing community education, trainings, and workshops. AFC also engages in policy work and litigation. AFC may serve as a model or be a potential partner for the NYS DDPC in the development of anti-bullying initiatives and programs for individuals with disabilities. For more information see http://www.advocatesforchildren.org/who_we_serve/students_with_disabilities#sthash.61wYRGX3.dpuf

References

- Baldry, A. C., & Farrington, D. P. (1998). Parenting influences on bullying and victimization. *Legal and Criminological Psychology, 3*, 237-254.
- Bonds, M., & Stoker, S. (2000). *Bully-proofing your school: A comprehensive approach for middle schools*. Longmont, CO: Sopris West.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments in nature and design*. Cambridge, MA: Harvard University Press.
- Coots, J. J. (1998). Family resources and parent participation in schooling activities for their children with developmental delays. *The Journal of Special Education, 31*, 498-520. doi:10.1177/002246699803100406
- Craig, W. M., Pepler, D., & Atlas, R. (2000). Observations of bullying in the playground and in the classroom. *School Psychology International, 21*, 22-36. doi:10.1177/0143034300211002
- Cross, D., Pintabona, Y., Hall, M., Hamilton, G., & Erceg, E. (2004). Validated guidelines for school-based bullying prevention and management. *International Journal of Mental Health Promotion, 6*, 34-42.
- Dyson, L. L (1997). Fathers and mothers of school-age children with developmental disabilities: Parental stress, family functioning, and social support. *American Journal on Mental Retardation, 102*, 267-269. doi:10.1352/0895-8017(1997)102<0267:FAMOSC>2.0.CO;2

- Espelage, D. L., & Swearer, S. M. (2004). *Bullying in American schools: A social-ecological perspective on prevention and intervention*. Mahwah, NJ: Lawrence Erlbaum.
- Fishman, C., & Nickerson, A. B. (2014). Motivations for involvement: A preliminary investigation of parents of students with disabilities. *Journal of Child and Family Studies*. Online first. doi:10.1007/s10826-013-9865-4
- Frey, K. S., Hirschstein, M. K., Snell, J. L., Van Schoiack Edstrom, L., MacKenzie, E. P., & Broderick, C. J. (2005). Reducing playground bullying and supporting beliefs: An experimental trial of the Steps to Respect program. *Developmental Psychology, 41*, 479-491.
- Green, C. L., Walker, J. M., Hoover-Dempsey, K. V., & Sandler, H. M. (2007). Parents' motivations for involvement in children's education: An empirical test of a theoretical model of parental involvement. *Journal of Educational Psychology, 99*, 532-544.
- Henderson, A. T., Berla, N., & National Committee for Citizens in Education, W. D. (1994). *A New Generation of Evidence: The Family is Critical to Student Achievement*.
- Hoover-Dempsey, K. V., & Sandler, H.M. (1995). Parent involvement in children's education: Why does it make a difference? *Teachers College Record, 97*, 310-331.
- Hoover-Dempsey, K. V., & Sandler, H. M. (1997). Why do parents become involved in their children's education? *Review of Educational Research, 67*(1). 3-42.
- Hornby, G. & Lafaele, R. (2011). Barriers to parental involvement in education: An exploratory model. *Educational Review, 37-52*. doi:10.1080/00131911.2010.488049
- Lyznicki, J. M., McCaffree, M. A., & Robinowitz, C. B. (2004). Childhood bullying: implications for physicians. *American Family Physician, 70*(9), 1723-1728.
- Mannan, G., & Blackwell, J. (1992). Parent Involvement: Barriers and Opportunities. *The Urban Review, 24*(3), 219-226.
- Meraviglia, M. G., Becker, H., Rosenbluth, B., Sanchez, E., & Robertson, T. (2003). The Expect Respect project: Creating a positive elementary school climate. *Journal of Interpersonal Violence, 18*, 1347-1360.
- O'Moore, A. M., & Minton, S. J. (2005). Evaluation of the effectiveness of an anti-bullying program in primary schools. *Aggressive Behavior, 31*, 609-622.
- Olweus, D. (1993). *Bullying at school: What we know and what we can do*. Oxford, UK: Blackwell.
- Olweus, D., Limber, S., & Mihalic, S. (1999). *The Bullying Prevention Program: Blueprints for violence prevention*. Boulder, CO: Center for the Study and Prevention of Violence.
- Pepler, D. J., Craig, W. M., Ziegler, S., & Charach, A. (1994). An evaluation of an anti-bullying intervention in Toronto schools. *Canadian Journal of Community Mental Health, 13*, 95-110.
- Sawyer, J. Mishna, F, Pepler, D. & Wiener, J. (2011). The missing voice: Parents' perspectives of bullying. *Children and Youth Services Review, 33*, 1795-1803. doi:10.1016/j.childyouth.2011.05.010
- Sharp, S. (1996). Self-esteem, response style and victimization: Possible ways of preventing victimization through parenting and school based training programmes. *School Psychology International, 17*, 347-357.

- Sharp, S., & Thompson, D. (1994). How to establish a whole-school anti-bullying policy. In S. Sharp & P. K. Smith (Eds.), *Tackling bullying in your schools: A practical handbook for teachers* (pp. 23-40). London: Routledge.
- Staples, K. E., & Diliberto, J. A. (2010). Guidelines for Successful Parent Involvement. *Teaching Exceptional Children*, 42(6), 58-63.
- Stevens, V., de Bourdeaudhuij, I., & Van Oost, P. (2001). Anti-bullying interventions at school: Aspects of program adaptation and critical issues for further program development. *Health Promotion International*, 16, 155-167.
- Swearer, S. M., & Doll, B. (2001). Bullying in schools: An ecological framework. In R. A. Geffner, M. Loring, & C. Young (Eds.), *Bullying behavior: Current issues, research, and interventions* (pp. 7-23). New York: Haworth Press.
- 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(1), 38- 47. doi:10.3102/0013189X09357622.
- Ttofi, M. M., Farrington, D. P., & Baldry, A. C. (2008). *Effectiveness of programmes to reduce school bullying: A systematic review*. Stockholm: Swedish National Council for Crime Prevention. Retrieved from U.S. Department of Education. (1994). *Strong families, strong schools: Building community partnerships for learning*. Washington, DC: Author.
- Walker, J. M., Wilkins, A. S., Dallaire, J., Sandler, H. M., & Hoover-Dempsey, K. V. (2005). Parental involvement: Model revision through scale development. *Elementary School Journal*, 106, 85-104. doi:10.1086/499193
- Wang, M., Mannan, H., Poston, D., Turnbull, A., & Summers, J. (2004). Parents' perceptions of advocacy activities and their impact on family quality of life. *Research & Practice for Persons with Severe Disabilities*, 29(2), 144-155. doi: 10.2511/rspd.29.2.144

Additional Resource

- Ferrel, J. (2012). *Family engagement and children with disabilities: A resource guide for educators and parents*. Retrieved from Harvard Family Research Project:
<http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CCMQFjAA&url=http%3A%2F%2Fwww.hfrp.org%2Fcontent%2Fdownload%2F4289%2F116678%2Ffile%2FFEChildrenWithDisabilities.pdf&ei=9wFZVIy6CIWnyATAiYII&usg=AFQjCNFItoOGm9IZhOEH6Sc7A9ydeCZg4Q&bvm=bv.78677474,d.dGY>

Families and Advocates for Individuals with Developmental Disabilities

GOAL 2: Increase supports for people with developmental disabilities and their families to deal with bullying

3. Within NYS, create a location and/or entity that collects, houses, and disseminates information for families, educators, service providers, organizations, and researchers, on bullying and people with developmental disabilities.

Needs Assessment Findings

Findings from the literature review suggest that there is no one single source of information on bullying and individuals with developmental disabilities. What is available seems to be located on various web sites, sponsored by a variety of individuals and groups.

According to our needs assessment, parents and service providers found web resources to be somewhat effective or not at all effective in addressing the problem of bullying and individuals with developmental disabilities. Additionally, approximately 60% of parents and service providers have tried prevention methods that were found in written or web based resources or bullying presentations and seminars. Less than 15% of each finds these to be very effective. This may be due to information that is of poor quality, is not research-based, or is lacking in credibility.

During focus groups, several service providers and family members indicated that there was a lack of information on bullying and individuals with developmental disabilities. These participants suggested that a central repository for what is known about this issue would be helpful to members of the developmental disability community. The research team suggest as well, that such a designated entity would also serve to increase awareness of the need for further research into the issue of bullying and individuals with developmental disabilities.

Online Information Access and Dissemination

Within the past two decades, the Internet has become a main tool for dissemination of information (Fallows, 2005). The wealth of information available from multiple sources, as well as quick and convenient access of information through technology (e.g., computers, cell phones) has led to information sharing between large numbers of people across professions, settings, and geographic regions.

However, there are multiple issues of credibility (i.e., the quality and believability) of information found online (Hovland, Janis, & Kelley, 1953; Metzger, 2007). Issues of credibility of information found online occur because the Internet lacks standardized procedures for:

1. Oversight or editorial review,
2. Identifying authorship including authority, established reputation, or training, and
3. Revisions of websites and information posted online that may be easily altered, plagiarized, misrepresented, or created anonymously under false pretenses (Fritch & Cromwell, 2001, 2002; Johnson & Kaye, 2000; Metzger, 2007; Metzger, Flanagan, Eyal, Lemus, & McCann, 2003; Rieh, 2002).

All of these factors make the need to critically evaluate information found on the Internet more important than ever before (Metzger, 2007).

Evaluating Online Credibility

The skills needed to determine the quality or credibility of online information are similar to those needed to evaluate information found in other channels of communication (Alexander & Tate, 1999; Brandt, 1996; Fritch & Cromwell, 2001).

There are five criteria to assess credibility of Internet-based information (Alexander & Tate, 1999; Brandt, 1996; Fritch & Cromwell, 2001; Kapoun, 1998; Meola, 2004; Scholz-Crane, 1998; Smith, 1997):

1. *Accuracy* refers to the degree a Web site is free from errors.
2. *Authority* of a Web site is determined by evaluating the author of the site in terms of contact information (person or organization), author's credentials, qualifications, and affiliations, and if the Web site is recommended by a trusted source.
3. *Objectivity* involves identifying the purpose of the site, determining if the information provided is fact or opinion, and ruling out conflicts of interest.
4. *Currency* refers to whether the information presented is up to date.
5. *Coverage* refers to the comprehensiveness and depth of the information provided.

Because there is evidence to suggest that individual information seekers lack the skills necessary to assess the credibility and accuracy of Internet-based information (Amsbary & Powell, 2003; Meola, 2004; Flanagin & Metzger, 2007; Metzger, et al., 2003; Scholz-Crane, 1998), it is recommended that a comprehensive Web site that is monitored, updated, and evaluated by qualified professionals be developed to serve as a resource for users to understand, assess, prevent, and intervene during bullying of individuals with disabilities.

The following are resources already in place that may be able to serve as a location and/or entity that collects, houses, and disseminates information for families, educators, service providers, organizations, and researchers, on bullying and people with developmental disabilities. They may also be used as a model for developing such a repository on the topic of bullying and people with developmental disabilities.

- The Alberti Center for Bullying Abuse Prevention: <http://gse.buffalo.edu/alberticenter>
- National website on bullying: <http://www.stopbullying.gov/>
- PACER's National Bullying Prevention Center: <http://www.pacer.org/bullying/>

References

- Alexander, J. E., & Tate, M. A. (1999). *Web wisdom: How to evaluate and create information quality on the Web*. Hillsdale, NJ: Erlbaum.
- Amsbary, J. H., & Powell, L. (2003). Factors influencing evaluations of web site information. *Psychological Reports*, 93(1), 191–198. doi:10.2466/pr0.2003.93.1.191
- Brandt, D. S. (1996). Evaluating information on the Internet. *Computers in Libraries*, 16, 44–46.
- Fallows, D. (2005). Search engine users: Internet searchers are confident, satisfied and trusting—But they are also unaware and naïve. Report for the Pew Internet and American Life Project. Retrieved January 25, 2005, from http://www.pewinternet.org/PPF/r/146/report_display.asp

- Flanagin, A. J., & Metzger, M. J. (2007). The role of site features, user attributes, and information verification behaviors on the perceived credibility of Web-based information. *New Media & Society*, 9, 319–342. doi:10.1177/1461444807075015
- Fritch, J. W., & Cromwell, R. L. (2001). Evaluating Internet resources: Identity, affiliation, and cognitive authority in a networked world. *Journal of the American Society for Information Science and Technology*, 52(6), 499–507. doi:10.1002/asi.1081.abs
- Fritch, J. W., & Cromwell, R. L. (2002). Delving deeper into evaluation: Exploring cognitive authority on the Internet. *Reference Services Review*, 30(3), 242–254. doi:10.1108/00907320210435509
- Hovland, C. I., Janis, I. L., & Kelley, J. J. (1953). *Communication and persuasion*. New Haven, CT: Yale University Press.
- Johnson, T. J., & Kaye, B. K. (2002). Webbelievability: A path model examining how convenience and reliance predict online credibility. *Journalism & Mass Communication Quarterly*, 79, 619–642. doi:10.1177/107769900207900306
- Kapoun, J. (1998). Teaching undergrads WEB evaluation: A guide for library instruction. Retrieved July 24, 2007, from <http://www.ualberta.ca/~dmiall/Brazil/Kapoun.html>
- Meola, M. (2004). Chucking the checklist: A contextual approach to teaching undergraduates Web-site evaluation. *Libraries and the Academy*, 4(3), 331–344. doi:10.1353/pla.2004.0055
- Metzger, M. J. (2007). Making sense of credibility on the Web: Models for evaluating online information and recommendations for future research. *Journal of the Association for Information Science and Technology*, 58(13), 2078-2091. doi:10.1002/asi.20672
- Metzger, M. J., Flanagin, A. J., Eyal, K., Lemus, D., & McCann, R. (2003). Bringing the concept of credibility into the 21st century: Integrating perspectives on source, message, and media credibility in the contemporary media environment. *Communication Yearbook*, 27, 293–335.
- Rieh, S. Y. (2002). Judgment of information quality and cognitive authority in the Web. *Journal of the American Society for Information Science and Technology*, 53(2), 145–161. doi:10.1002/asi.10017.abs
- Scholz-Crane, A. (1998). Evaluating the future: A preliminary study of the process of how undergraduate students evaluate Web sources. *Reference Services Review*, 26(3/4), 53–60. doi:10.1108/00907329810307759
- Smith, A. G. (1997). Testing the surf: Criteria for evaluating Internet information resources. *Public-Access Computer Systems Review*, 8. Retrieved July 24, 2007, from <http://epress.lib.uh.edu/pr/v8/n3/smit8n3.html>

Systems Level: Community, Educational Institutions, Government

GOAL 3: Increase awareness of the problem of bullying of individuals with developmental disabilities through education, inclusion, and cultural change.

1. Develop an educational presentation about people with developmental disabilities by people with disabilities for leaders within communities and community organizations (e.g., faith communities, Rotary/Lions Club, town boards, YMCA, youth development organizations, recreational programs, coaching organizations) to support the inclusion of people with disabilities within their communities.

Needs Assessment Findings

Adults, parents, and general survey respondents report the main reason individuals with developmental disabilities are bullied is because they are different. Twenty-seven percent of adults with disabilities said that they are bullied out in the community. This was more than twice as high as any other location where bullying is experienced. This suggests that the attitudes and beliefs of the general public may be contributing to bullying of people with disabilities. Instead of changing the individual with a disability, efforts should be made to help the general public understand disabilities.

Parents report that 85% of bullying occurs in school, rather than to or from home or school, or in an outside program. This suggests that youth in schools do not understand disabilities, and need to be made aware of how other youth with disabilities are worthy of respect. As such, the research team sought to explore the literature with regards to educational programs created and/or facilitated by individuals with developmental disabilities that create awareness, acceptance, and inclusion.

A Framework for Social Change

Schalock and Verdugo (2013) suggest that there are fundamental social changes occurring that focus on creating value through transformation, and that this change is affecting everyone including people with disabilities and the organizations that support them. Within this context, there are five major characteristics which point to how disability organizations will change. They include:

1. The person as central.
2. Streamlined organizations.
3. The development of information systems.
4. Continuous quality improvement.
5. Participatory leadership.

This framework suggests that programs and initiatives that involve people with developmental disabilities will undergo pressure to address all five of these factors, and that this will involve all levels of the community, its institutions, and the thinking that guides people in related fields.

Current Research

Although many programs exist which focus on youth or adults with developmental disabilities, few of these programs actually utilize self-advocates themselves within the communities in the development or facilitation of these programs. The programs listed here feature self-advocates as having a major role in implementation. These interventions may be

promising; however, not many provide information about specific program content or evaluation of effectiveness of the program. Nevertheless, they provide us with some ideas of what options are in practice across the United States.

Minnesota Governor’s Council on Developmental Disabilities

In this program, self-advocates, called “Ambassadors for Respect,” receive training on implementing an anti-bullying program called PeaceMaker Minnesota. Self-advocates then present the PeaceMaker Minnesota to 4th grade students across their state.

Paraquad, St. Louis, Missouri

Paraquad’s mission is to empower individuals with disabilities and to increase community accessibility for people with disabilities. Paraquad organizes disability awareness and inclusion presentations presented by self-advocates in schools and in the community. More information is available at <http://www.paraquad.org/>

Paxton Campus: Speak Up!, Leesburg, Virginia

Paxton Campus is a multi-purpose advocacy organization. Its mission is to provide services to underserved families, especially children and adults with disabilities. It includes an ALLY Center which provides self-advocacy information including issues related to education, social support, and advocacy. The organization also offers a Public Speaking and Advocacy Group for adults with disabilities to empower individuals to advocate on their own behalf. There are monthly meetings. More information is available at <http://www.paxtoncampus.org/tag/public-speaking-group-for-people-with-disabilities/>

Institute on Disabilities: Temple University, Philadelphia, Pennsylvania

The Institute on Disabilities at Temple University offers programming designed to promote self-advocacy amongst individuals with disabilities within the greater Pennsylvania community. There are leadership opportunities and trainings available for students. Additionally, the Institute offers two courses centered around public speaking training for individuals with disabilities. One program, “Speak Up! Speak Out!” teaches people to be effective public speakers. The other is called “It’s My Life, Hear My Voice,” and it provides information on opportunities to participate on Advisory Boards. Specific program content is not available, but there is a page of contact information specific to these training initiatives. More information is available at <http://www.temple.edu/instituteondisabilities/>

Online Resources to Promote Self-Advocacy

The Arc is a community based national organization promoting self-advocacy for individuals with intellectual and developmental disabilities and their families. The Arc’s website provides resources created by self-advocates to inform and promote advocacy behavior. The website includes factsheets related to “Abuse of Children with Intellectual Disabilities.” Additionally, in collaboration with the Research and Training Center on Community Living (RTC), the Arc created Self-Advocacy Online. This resource includes videos created by self-advocates promoting wellness (i.e., physical health). This organization also offers paid positions for individuals with disabilities to facilitate outreach and increase their voice beyond the disability community. Also included are topics related to building healthy relationships and speaking up for one’s self. These videos may be more powerful as they are created by self-advocates themselves. They are available at <http://www.selfadvocacyonline.org/>

References

- Institute on Disabilities, Temple University (2014). The Supported Leadership Facilitation Initiative. Retrieved from <http://disabilities.temple.edu/programs/leadership/sl.shtml>
- The Arc. (2014). *The Arc for Individuals with Disabilities*. Retrieved from <http://www.thearc.org/>
- The Minnesota Governor's Council on Developmental Disabilities (2014). *Council-Sponsored Grant Activities: Self Advocacy – Anti-Bullying Campaign*. Retrieved from <http://mn.gov/mnddc/council/grant-activities-respect.html>
- Paraquad (2014). *Disability Awareness Community Presentations*. Retrieved from <http://www.paraquad.org/get-connected-paraquad/disability-awareness-community-presentations>
- Paxton Campus (2014). *Speak Up! Public Speaking Group*. Retrieved from <http://www.paxtoncampus.org/tag/public-speaking-group-for-people-with-disabilities/>
- Research and Training Center on Community Living. *Self Advocacy Online*. Retrieved from <http://www.selfadvocacyonline.org/>
- Schalock, R. L., & Verdugo, M-A. (2013). The transformation of disabilities organizations. *Intellectual and Developmental Disabilities*, 51(4), 273-286.

Systems Level: Community, Educational Institutions, Government

GOAL 3: Increase awareness of the problem of bullying of individuals with developmental disabilities through education, inclusion, and cultural change.

2. Participate in the development of certification requirements (with OPWDD) for direct service providers that develop knowledge and skills to recognize and address bullying among and of the individuals they work with.

Needs Assessment Findings

Survey results indicate that the greatest amount of bullying experienced by individuals with developmental disabilities is verbal or relational, as opposed to physical. Comments from a number of focus group and interview participants acknowledged that there is bullying among individuals with disabilities, as well as bullying by those who work with individuals with disabilities. Adults with developmental disabilities reported that aside from the community at large where 27% of bullying occurs, other places include over the telephone (7%), online (12%), in work or volunteer settings (12%), and in day programs (8%). While not definitive, together these findings may be suggestive of interpersonal bullying among individuals who work, live, or attend day programs together. In many of these settings, individuals with developmental disabilities are in the presence of direct service providers.

Because direct service providers spend so much time with adults with disabilities, study participants suggested that they be trained to:

- Be proactive in preventing bullying.
- Recognize bullying of or by individuals with disabilities.
- Support these individuals in being assertive when being bullied.
- Provide methods for individuals to seek help from support staff if bullying occurs.

Since certification for direct service providers is being developed by OPWDD (New York State Office for People with Developmental Disabilities, 2013), it is recommended that this training include information on bullying prevention and intervention.

Background Information

The majority of the research on bullying prevention training has been done with teachers in general education school settings. There is very limited research on prevention training for direct service providers for individuals with disabilities with regards to bullying. Additionally, there is limited research on bullying prevention for adults with disabilities in any context. The following recommendations for developing a direct service provider course in bullying prevention and awareness have been adapted from bullying prevention training for teachers.

Research on Bullying Prevention for Staff Members in Schools

The majority of bullying prevention research focuses on prevention in school settings. Important findings include:

- Staff connectedness was associated with greater comfort in intervening with bullying. (O'Brennan, Waasdorp, & Bradshaw, 2014)

- A key component to successful intervention implementation is a caring, respectful, and supportive relationship between teachers and administration. This models positive behavior for students. (Sun, Shek, and Siu, 2008)
- Communication and openness between staff members significantly impacted the implementation of anti-bullying programming. (Kallestad & Olweus, 2003)
- It is recommended that staff develop school-wide anti-bullying policies and increase awareness about bullying intervention by incorporating it into the curriculum. (Alberti Center, 2012)
- The Center for Disease Control (CDC) recommends a 4-step approach to bullying prevention: (1) Define and monitor the problem, (2) Identify risk and protective factors, (3) Develop and test prevention strategies, (4) Assure widespread adoption. (CDC, 2011)
- Gladden and colleagues (2014) offer a uniform definition of bullying among youths:
 1. “Bullying is any unwanted aggressive behavior(s) by another youth or group of youths who are not siblings or current dating partners that involves an observed or perceived power imbalance and is repeated multiple times or is highly likely to be repeated. Bullying may inflict harm or distress on the targeted youth including physical, psychological, social, or educational harm.” (Gladden, Vivolo-Kantor, Hamburger, & Lumpkin, 2014)
 2. Modes of bullying are direct or indirect.
 3. Types of bullying include physical, verbal, and relational.

Suggested Topics to be Included in Direct Service Provider Training in Relation to Bullying

Research supports inclusion of these topics in direct service provider training on bullying: strategies to increase staff connectedness and openness (O’Brennan et al., 2014); knowledge of the definition of bullying; ability to recognize bullying among and of individuals; how to support individuals in understanding bullying in the workplace (U.S. Department of Labor, 2014); knowledge of prevention and intervention strategies; ability to support individuals in resolving conflict before it escalates or becomes bullying; the ability to understand, prevent, and respond to retaliation; and the ability to support individuals in learning positive social skills.

Additionally, the Stetson School *Bullying Prevention and Intervention Plan* suggests topics that might be included in direct service provider training:

- Developmentally and age-appropriate strategies to prevent bullying and intervene during bullying incidents.
- Knowledge of risk factors and training to help identify who’s “at-risk” of being an initiator or target of bullying.
- Strategies to prevent retaliation
- How to model appropriate behavior.
- How to collaborate with the community and build relationships.
- How to teach positive social skills to individuals they work with.
- On-going professional development.

References

Alberti Center for Bullying Abuse and Prevention. (2012). *Guide to School-Wide Bullying Prevention Programs*. Retrieved from <http://gse.buffalo.edu/gsefiles/documents/alberti/Bullying%20Prevention%20Program%20Guide%20-%20FINAL%203.16.12.pdf>

- Centers for Disease Control (CDC). (2011). *Understanding Bullying: Fact Sheet*. Retrieved from http://gse.buffalo.edu/gsefiles/documents/alberti/CDC_Bullying_Factsheet.pdf
- 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 U.S. Department of Education.
- Kallestad, J. H., & Olweus, D. (2003). Predicting teachers' and schools' implementation of the Olweus Bullying Prevention Program: A multi-level study. *Prevention and Treatment, 6*, Article 21
- New York State Office for People with Developmental Disabilities (OPWDD). *Code of Ethics for Direct Support Professionals*. Available from <http://www.opwdd.ny.gov/code-of-ethics/person-centered-supports/intro/pdf>
- New York State Office for People with Developmental Disabilities (OPWDD). (2013). *NYS Talent Development Consortium Direct Support Professional Core Competencies Project*. Retrieved from <http://www.opwdd.ny.gov/node/3570>
- O'Brennan, L. M., Waasdorp, T. E., & Bradshaw, C. P. (2014). Strengthening bullying prevention through school staff connectedness. *Journal of Educational Psychology, 106*(3), 870-880. doi:10.1037/a0035957
- Stetson School. *Bullying Prevention and Intervention Plan*. Retrieved from <http://www.sevenhills.org/uploads/publications/StetsonSchool-bullying-prevention-plan.pdf>
- Sun, R. C. F., Shek, D. T. L., & Siu, A. M. H. (2008). Positive school and classroom environment: Precursors of successful implementation of positive youth development programs. *Scientific World Journal, 8*, 1063–1074. doi:10.1100/tsw.2008.126
- U. S. Department of Labor (CareerOneStop). (2014). *Competency Model Clearinghouse: Long-term Care, Supports, and Services Industry Competency Model*. Available from <http://www.careeronestop.org/CompetencyModel/competency-models/long-term-care.aspx>

Systems Level: Community, Educational Institutions, Government

GOAL 3: Increase awareness of the problem of bullying of individuals with developmental disabilities through education, inclusion, and cultural change.

3. Strengthen and support peer relationships for youth with and without developmental disabilities through involvement in meaningful activities (recreation, sports, extra-curricular). Focus on natural supports, sustainability, and evaluation of these efforts.

Needs Assessment Findings

Survey results suggest that bullying is more prevalent in school environments than in social or recreational environments where youth with disabilities engage in activities with other youth with whom they do not attend school. This suggests that expanding involvement in non-school activities may afford students with disabilities an environment that is more welcoming and supportive than school.

Additionally, participants in interviews and focus groups repeatedly suggested that programs that bring youth with and without disabilities together are needed to promote inclusion, acceptance, and welcome-ness of people with disabilities. Recreational and extra-curricular activities for youth with and without developmental disabilities allows for meaningful relationships to develop, which naturally fosters awareness and cultural change.

Background

A lack of interaction between individuals with and without disabilities has created a culture, especially in schools, that views people with disabilities as less capable. This widespread belief is illustrated in a study conducted in 2013 that surveyed 5,837 middle school students about their attitudes towards inclusion of students with intellectual disabilities. The majority of participants responded that they:

1. Have limited contact with students with developmental disabilities in their classrooms and school.
2. Perceive students with developmental disabilities as moderately impaired rather than mildly impaired.
3. Believe that students with developmental disabilities can participate in nonacademic classes, but not in academic classes.
4. View inclusion as having both positive and negative effects. (Siperstein, Parker, Bardon, & Widaman, 2007)

Although students do not want to interact socially with a peer with developmental disabilities, particularly outside of school, many students understand that contact with those who are different yields positive benefits such as greater acceptance of youth with disabilities and the understanding that being different is OK (Siperstein et al., 2007).

If students have little contact with other students who have disabilities, but they believe that it is 'OK to be different,' and they see individuals with disabilities as being able to participate in nonacademic endeavors, then programs that promote contact between students with and without disabilities, may be a way to encourage the development of respect, acceptance, and friendship. Stated otherwise, inclusion in activities that provide contact between students with and without disabilities can serve as a gateway to awareness, growth, and equality.

Research

Recreational and social inclusion increases informal social interaction between students with and without developmental disabilities. This can lead to the building of close relationships and lasting friendships. In regards to bullying, this can have a profound effect that includes increased awareness, stronger social support, increased likelihood for bystander intervention, and increased feelings of social connectedness (D'Eloia & Sibthorp, 2014; McConkey, Dowling, Hassan, & Menke, 2013).

Friendships with individuals who have a higher power status in their social network can be protective for individuals with developmental disabilities. This can lead to a gradual culture change that spreads throughout the school or work environment (McConkey et al., 2013; Ochs, Kremer-Sadlik, Solomon, & Sirota, 2001).

Peer role models in recreation, sports, and other extra-curricular activities can assist in skill development through modeling (D'Eloia & Sibthorp, 2014). When students with and without disabilities compete side-by-side, equal status relationships are fostered and grow. This decreases the imbalance of power that is commonly associated with bullying of peers with developmental disabilities (Davis, Rocco-Dillon, Grenier, Martinez, & Aenchbacker, 2012; McConkey et al., 2013).

Participation in recreational activities with individuals without disabilities leads to increased self-sufficiency and community connectedness for youth and adult individuals with developmental disabilities (Kuntsler, Thompson, & Croke, 2013). In some cases, contact can foster a higher likelihood for acceptance of a less restrictive learning environment in the future (Fredrickson, Simmonds, Evans, & Soulsby, 2007).

Issues to Consider When Selecting or Developing Programs

Games and clubs that do not place a high physical demand are often appropriate (i.e. chess club, computer games, card games, camping). Basketball, bocce ball, cycling, swimming, tennis, and bowling are more easily adaptable and appropriate physical choices, according to the American Association of Adapted Sports Programs. Yoga may also be feasible as it is naturally adaptive, and teaches mindfulness and breathing techniques that are accessible to nearly all individuals (Calming Kids Yoga, 2014).

Coaches and other professionals in competitive recreational environments can be insensitive or unaware of specific needs for individuals with developmental disabilities. They may commonly employ a variety of motivational or professional tactics that include shame, guilt, a no pain, no gain mentality etc. (CAPP, Athlete Safety First, 2013). The American Academy of Pediatrics provides a participation possibility chart for physically challenged individuals. The chart specifies what may be most appropriate for a wide variety of conditions and disabilities. Access at:

<https://www.jaaos.org/content/12/2/126/T2.expansion>

Inclusion adaptation and sports modification can have negative effects that includes adapting when unnecessary and decreasing competitive nature by making the activity too easy. This can lead to typically developing peers to begrudge the activity, not take it seriously, or drop out. The Inclusion Fitness Coalition provides useful guidelines for inclusion adaptation. Access at: <http://incfit.org/files/Inclusion%20Resource-1.pdf>

Overall, there is limited training, opportunity for training, and overall comfort and knowledge of individuals with developmental disabilities among practitioners (Carter, McCown, Forest, Martin, Wacker, Gaede, & Fernandez, 2004).

Therefore, it is paramount that proper training be provided for professionals who oversee recreational, extra-curricular, and sports that would allow for inclusion of individuals with developmental disabilities.

Examples of Extracurricular & Community Activity Programs

Recreational activities that connect people with and without disabilities in specific areas of interest are a way to promote independence and social inclusion for individuals with disabilities. Additionally, they are likely to contribute to societal attitudes that see individuals with disabilities as productive, contributing members of society.

Together Including Every Student (TIES)

The TIES program was developed in 1997 as a previous response to the NYS DDPC's request for a cost effective program that promotes social inclusion and well-being for people with developmental disabilities. The program is currently implemented across thirty-four school districts in Western New York and surrounding areas (The Advocacy Center, 2014). It has not been evaluated.

Next Chapter Book Club (NCBC)

The Next Chapter Book Club is a program that provides an opportunity for people with developmental disabilities to improve reading skills, talk about books, make friends, and engage in social interaction with others in the community. A group of five to eight people with intellectual disabilities gather together with two volunteers at a local bookstore, coffee shop or other location to discuss the book of the week. Participants range in reading levels from no letter recognition or understanding to the ability to read full paragraphs. Volunteers can be any student or community member who enjoys reading and would like to help others improve their reading skills. Training workshops are offered to volunteers via the NCBC central office. These workshops are five to six hours long and include an overview of the NCBC training model, the history and rationale for development, and suggested strategies, activities, and tools on how to use the book club. (Fish, Rabidoux, Ober, & Graff, 2009). This program has not been evaluated.

The concept behind the NCBC can also be applied to any type of club to include participants with disabilities and volunteers from the community. Some ideas include: chess club, board game club, movie club, sports club, or cooking group.

Theoretical Support

Intergroup Contact Theory (Pettigrew, Tropp, Wagner, & Christ, 2011) suggests that programs that bring people who do not know each other and may have hostile attitudes towards one another can produce a number of positive outcomes. These include greater trust, inter-group friendship, reduced anxiety and more empathy, and less prejudice. The conditions necessary for the success of intergroup contact includes:

1. Equal status among participants.
2. Common goals.
3. No intergroup competition.
4. Activities that are sanctioned by authorities from both groups.

References

- American Association of Adapted Sports Program. (2012) Retrieved from: <http://www.adaptedsports.org/>
- Calming Kids Yoga: Creating a Non-Violent World. (2014). Retrieved from: <http://calmingkids.org/>
- CAPPA, Athlete Safety First. (2013). *Stop sports bullying: Intervention for child athletes*. Retrieved from: [URL no longer active]
- Carter, M., McCown, K. M., Forest, S., Martin, J., Wacker, R., Gaede, D., & Fernandez, A. (2004). Exercise and fitness for adults with developmental disabilities: Case report of a group intervention. *Therapeutic Recreation Journal*, 38(1), 72-84. Retrieved from: http://www.bctra.org/wp-content/uploads/tr_journals/1007-3948-1-PB.pdf
- Davis, R., Rocco-Dillon, S., Grenier, M., Martinez, D., & Aenchbacher, A. (2012). Implementing disability sports in the general physical education curriculum. *Journal of Physical Education, Recreation & Dance*, 83(5), 35-41. doi: 10.1080/07303084.2012.10598778
- D'Eiola, M. & Sibthorp, J. (2014) Relatedness for youth with disabilities: Testing a recreation program model. *Journal of Leisure Research*, 46(4), 462-482.
- Fish, T., Rabidoux, P., Ober, J., & Graff, V. (2009). *Next Chapter Book Club: A model community literacy program for people with intellectual disabilities*. Bethesda, MD: Woodbine House.
- Fredrickson, N., Simmonds, E., Evans, L., & Soulsby, C. (2007). Assessing the social and affective outcomes of inclusion. *British Journal of Special Education*, 34(2), 105-115. doi: 10.1111/j.1467-8578.2007.00463.x
- Kuntsler, R., Thompson, A., & Croke, E. (2013). Inclusive recreation for transition-age youth: Promoting self-sufficiency, community inclusion, and experiential learning. *Therapeutic Recreation Journal*, 47(2), 122-136.
- McConkey, R., Dowling, S., Hassan, D., & Menke, S. (2013). Promoting social inclusion through unified sports for youth with intellectual disabilities: A five-nation study. *Journal of Intellectual Disabilities Research*, 57(10), 923-935. doi: 10.1111/j.1365-2788.2012.01587.x
- Ochs, E., Kremer-Sadlik, T., Solomon, O., & Gainer Sirota, K. (2001). Inclusion as social practice: Views of children with Autism. *Social Development*, 10(3), 399-419. doi: 10.1111/1467-9507.00172
- Pettigrew, T. F., Tropp, L. R., Wagner, U., & Christ, O. (2011). Recent advances in intergroup contact theory. *International Journal of Intercultural Relations*, 35, 271-280.
- Siperstein, G., Parker, R., Bardon, J.N., & Widaman, K. (2007). A national study of youth attitudes toward the inclusion of students with intellectual disabilities. *Exceptional Children*, 73(4), 435-455.
- The Advocacy Center. (2014). *Together Including Every Student (TIES)*. Retrieved from <http://www.advocacycenter.com/together-including-every-student-ties>

Systems Level: Community, Educational Institutions, Government

GOAL 3: Increase awareness of the problem of bullying of individuals with developmental disabilities through education, inclusion, and cultural change.

4. Support the creation or expansion of programs that bring adults with and without disabilities together (such as Best Buddies Citizens). Evaluate the effectiveness of these programs.

Needs Assessment Findings

Several of the themes that emerged from the interview and focus group data suggested that empowerment, support, and inclusion would reduce the vulnerability of individuals with disabilities in multiple ways, including the risk of bullying involvement. Additionally, participants repeated that people with disabilities experience oppression because of the general public's lack of understanding of disabilities and ignorance of the contributions and value that people with disabilities make to society. All respondents agreed that providing more opportunities for individuals with and without disabilities to interact with each other would be helpful. Additionally, survey results indicated that adults with disabilities experience the greatest amount of bullying (27%) when they are out in the community as compared with other locations. This suggests that contact with the community is a good way to bridge the gaps between people with disabilities and people without disabilities.

Best Buddies Citizens

As a well-known and established program, Best Buddies Citizens is designed to foster one-to-one friendships between adults with and without developmental disabilities in corporate and civic communities (Best Buddies, n.d.). The Best Buddies Citizens program is one of several programs of this nature that seek to develop positive relationships between people with and without developmental disabilities.

Hardman and Clark (2006) studied the Best Buddies College Program. Their findings suggested that both those with intellectual disabilities and the typical college students benefited from the experience. Both groups indicated that their lives had been improved by participating in this program; however, college students reported this with higher frequency. This study also found that 8 of 10 College Buddies indicated having a more positive attitude about people with intellectual disabilities and a more thorough understanding of the challenges experienced by those with intellectual disabilities. However, less than 50% of the Buddies indicated that they were more comfortable participating in social interactions and in speaking up for themselves after the program.

West, Wehman, and Wehman (2005) evaluated the Best Buddies Jobs program in Los Angeles. The study found that individuals with intellectual disabilities who participated were able to attain entry-level positions, such as Office Services Assistant, Table Busser, File Clerk, Floor Attendant, and Office Support Staff. Buddies seemed to have great longevity in their job placements, with 88.5% of them lasting at least a year in their original position (West et al., 2005). A similar study conducted in Miami had comparable results to those found in the Los Angeles study (West et al., 2005).

Contact and Increased Acceptance

Relationships and interactions between peers with and without disabilities can result in several favorable outcomes that include a greater understanding and appreciation of individual differences by those without disabilities, development of

age-appropriate social behaviors by individuals with disabilities, and expanded friendship networks as well as improved quality of life for both groups (McDonnell, Hardeman, McDonnell, Kiefer-O'Donnell, 1995; Schleien, Green, & Heyne, 1993; Abery, Schoeller, Simunds, Gaylord, & Fahnestock, 1997).

Friendships with individuals who have a higher power status in their social network can be protective for individuals with developmental disabilities. This can lead to a gradual culture change that spreads throughout the school or work environment (McConkey, Dowling, Hassan, & Menke, 2013).

In an evaluation of a fitness program for people with developmental disabilities and their caregivers, the staff who conducted the program indicated that their initial fears of working with people with disabilities was unfounded, and that in their future careers they would be interested in working with people with developmental disabilities (White, Biren, & Spencer, 2012).

In a three-year program that brought students with disabilities together with students without disabilities at the college level, outcomes suggested that strong relationships were developed between the two groups of students (Eskow & Fisher, 2004).

In a study of an intervention involving people with profound intellectual disabilities, individuals with disabilities who were taught to interact with peers who were not disabled increased their contact with peers who were not disabled, reduced the amount of contact they had with service professionals, and experienced the improvement of specifically targeted behaviors (Nijs & Maes, 2014).

Theoretical Support

Intergroup Contact Theory (Pettigrew, Tropp, Wagner, & Christ, 2011) suggests that programs that bring people who do not know each other and may have hostile attitudes towards one another can produce a number of positive outcomes. These include greater trust, inter-group friendship, reduced anxiety and more empathy, and less prejudice. The conditions necessary for the success of intergroup contact includes:

1. Equal status among participants.
2. Common goals.
3. No intergroup competition.
4. Activities that are sanctioned by authorities from both groups.

References

- Abery, B., Schoeller, K., Simunds, E., Gaylord, V. & Fahnestock, M. (1997). *Yes I can social inclusion program*. Minneapolis, MN: University of Minnesota, Institute on Community Integration.
- Best Buddies International. (n.d.). *Our Programs*. Retrieved from <http://www.bestbuddies.org/our-programs>
- Eskow, K. G., & Fisher, S. (2004). Getting together in college: An inclusion program for young adults with disabilities. *Teaching Exceptional Children, 36*(3), 26-32.
- Hardman, M. L., & Clark, C. (2006). Promoting friendship through Best Buddies: A national survey of college program participants. *Mental Retardation, 44*, 56-63.

- McConkey, R., Dowling, S., Hassan, D., & Menke, S. (2013). Promoting social inclusion through unified sports for youth with intellectual disabilities: A five-nation study. *Journal of Intellectual Disabilities Research, 57*(10), 923-935. doi: 10.1111/j.1365-2788.2012.01587.x
- McDonnell, J., Hardman, M., McDonnell, & Kiefer-O'Donnell, R. (Eds.) (1995). *An introduction to persons with severe disabilities*. New York: Simon & Schuster.
- Nijs, S., & Maes, B. (2014). Social peer interactions in persons with profound intellectual and multiple disabilities: A literature review. *Education and Training in Autism and Developmental Disabilities, 49*(1), 153-165.
- Pettigrew, T. F., Tropp, L. R., Wagner, U., & Christ, O. (2011). Recent advances in intergroup contact theory. *International Journal of Intercultural Relations, 35*, 271-280.
- Schwartz, D., McFayden-Ketchum, S., Dodge, K. A., Pettit, G. S., & Bates, J. E. (1999). Early behavior problems as a predictor of later peer group victimization: Moderators and mediators in the pathways of social risk. *Journal of Abnormal Child Psychology, 27*, 191-201.
- Schleien, S., Green, F., & Heyne, L. (1993). Integrated community recreation. In M. Snell (Ed.) *Instruction of students with severe disabilities* (4th ed.). New York: Merrill.
- West, M. D., Wehman, P. B., & Wehman, P. (2005). Competitive employment outcomes for persons with intellectual and developmental disabilities: The national impact of the Best Buddies Jobs Program. *Journal of Vocational Rehabilitation, 23*, 51-63.
- White, B., Biren, G., & Spencer, L. (2012). Fitness interventions for adults with developmental disabilities and their caregivers. *Therapeutic Recreation Journal, 46*(4), 245-267.

Systems Level: Community, Educational Institutions, Government

GOAL 3: Increase awareness of the problem of bullying of individuals with developmental disabilities through education, inclusion, and cultural change.

5. Create, implement, and evaluate a course for pre-service or master's level teachers and educators where they work closely with an individual with developmental disabilities for a semester. Promote the course for those studying to be teachers but who are not getting certified in special education.

Needs Assessment Findings

Findings from the surveys, focus groups, and interviews suggest that many students with developmental disabilities experience bullying in school. Across the board, participants felt that educators were underprepared to work with students with special needs, and that this deficit contributed to bullying of students with disabilities. Since many general education teachers have had little to no exposure to students with disabilities, it is recommended that a course be developed and tested to see if general education teachers who take a course where they work directly with individuals with disabilities develop attitudes aligned with acceptance and inclusion.

Teacher Education

'Pre-Service' refers to activities that take place before a person takes a job. Courses for graduate students that provide the competence needed to perform new 'services' is also included in the pre-service category. For the education field, the pre-service teacher begins as an observer, and finishes the experience as a competent professional. The pre-service experience provides a controlled learning situation in which a teacher can put principles and methods learned in class into practice. 'In-Service' training refers to training of persons already employed. However, courses that are offered to all without pre-requisites of work experience, can also be considered pre-service courses, as anyone is able to take them for more training/knowledge in certain areas.

Research on Pre-Service and In-Service Courses for All Teachers

An overview of pre-service level courses for general education teachers found that:

- Half of course credits for bachelor degrees in elementary education are designated towards teacher preparation. Of that, only 7-10% of coursework is specific to topics of educating students with disabilities in inclusive settings (Allday, Neilsen-Gatti, & Hudson, 2013).
- Of over 100 universities and colleges, one-third of the education related programs did not require pre-service teachers (i.e. students in the program) to participate in courses with content related to education of diverse learners (Allday et al., 2013).

Teacher Preparation for Working with Students with Disabilities: Research Findings

Education programs that require at least one course related to special education have significantly improved feelings and instructional competencies in pre-service teachers (Powers, 1992).

McCray and Alvarez (2011) found that a pre-service course offered to general education teachers resulted in teachers feeling better prepared to meet the needs of students with disabilities in their classrooms. They also found that a majority of the pre-service teachers indicated that the course changed their attitudes towards students with disabilities in that they had a greater appreciation for students with disabilities and felt more comfortable working with them. Teachers also indicated that to initiate a change in their perceptions and beliefs about teaching students with disabilities (in inclusion classrooms), they need to be provided with the skills and specific knowledge to address the needs of students with disabilities.

Providing teachers with experiential learning rather than instructional based learning proved to be more effective for teacher use of classroom management techniques (Fabiano et al., 2012). There is a need for linking instruction to practice in teacher education programs (Zeichner & Liston, 1990). Campbell, Gilmore, and Cuskelly (2003) found that courses that include fieldwork and formal instruction related to students with disabilities improved student teacher attitudes toward disability and inclusion as well as improved their perceptions about the abilities of students with a disability (from a developmental standpoint). They also found that student teacher attitudes toward disability, in general, also positively improved as a result of coursework and fieldwork related to inclusion and disability. Students reported significantly less discomfort, uncertainty, fear, and vulnerability when interacting with people with disabilities at the end of the course. Shippen, Crites, Houchins, Ramsey, and Simon (2005) found that in an introductory course about special education for future general educators, participants decreased their level of anxiety over including students with disabilities in their classrooms. They also found that dual training in special and general education may produce teachers who are more prepared and inclined to work with students with disabilities in the general education classroom due to results that demonstrated teachers who received training for dual certifications (special and general education) were more receptive and less anxious than the other groups (only general or special education teachers) before and after the course about special education.

Inclusive College Settings and Service-Learning

Carroll, Petroff, and Blumberg (2009) found that those who participated in an inclusive college course that entered with initial apprehension about being in class with classmates with intellectual disabilities, collectively expressed a reduction in their anxiety and increased comfort with interactions with people with disabilities at the conclusion of the course. The inclusive college course provided students without intellectual disabilities with direct involvement with students with intellectual disabilities. Students without disabilities learned that students with intellectual disabilities can manage more intensive academic material and benefit from such content than typical classes that address life skills for individuals with disabilities.

Several groups of researchers have found that students involved in direct service-learning also gained a better appreciation for individuals with disabilities and expanded their understanding of course content. Additionally, the effects of service-learning were extended beyond the course, instilling a sense of caring for individuals with disabilities (Bordelon & Phillips, 2006; Schine, 1997; Muwana & Gaffney, 2011).

References

- Allday, R. A., Neilsen-Gatti, S., & Hudson, T. M. (2013). Preparation for inclusion in teacher education pre-service curricula. *Teacher Education and Special Education, 36*, 298-311.
- Bordelon, D., & Phillips, I. (2006). Service learning: What students have to say. *Learning in Higher Education, 7*, 143-153.

- Bringle, R. G., & Hatcher, J. A. (1996). Implementing service learning in higher education. *Journal of Higher Education*, 67, 221-239.
- Campbell, J., Gilmore, L., & Cuskelly, M. (2003). Changing student teachers' attitudes towards disability and inclusion. *Journal of Intellectual & Developmental Disability*, 28, 369-379.
- Carroll, S. Z., Petroff, J. G., & Blumberg, R. (2009). The impact of a college course where pre-service teachers and peers with intellectual disabilities study together. *Teacher Education and Special Education*, 32, 351-364.
- Fabiano, G. A., Vujnovic, R. K., Waschbusch, D. A., Yu, J., Mashtare, T., Pariseau, M. E., Pelham, W. E., Parham, B. R., & Smalls, K. J. (2012). A comparison of workshop training versus intensive, experiential training for improving behavior support skills in early educators. *Early Childhood Research Quarterly*, 28, 450-460.
- McCray, E. D., & McHatton, P. A. (2011). "Less afraid to have them in my classroom": Understanding pre-service general educators' perceptions about inclusion. *Teacher Education Quarterly*, 38, 135.
- Muwana, F. C., & Gaffney, J. S. (2011). Service-learning experiences of college freshman, community partners, and consumers with disabilities. *Teacher Education and Special Education*, 34, 21-36.
- Olweus, D. (1993). *Bullying at school: What we know and what we can do*. Cambridge, MA: Blackwell.
- Powers, P. J. (1992). *The effect of special education coursework upon the preparation of pre-service teachers* (Eric Document Reproduction Service No. ED 377 183). Paper presented at the annual meeting of the Northern Rocky Mountain Educational Research Associations, Custer, SD.
- Ross, D.M. (2003). *Childhood bullying, teasing, and violence: What school personnel, other professionals, and parents can do*. (2nd ed.) Alexandria, VA: American Counseling Association.
- Schine, J. (1997). Looking ahead: Issues and challenges. In K. J. Rehg (Series Ed.) & J. Schine (Vol. Ed.), *Ninety-sixth yearbook of the National Society for the Study of Education, Part 1. Service-learning* (pp. 186-199). Chicago, IL: University of Chicago Press.
- Shippen, M. E., Crites, S. A., Houchins, D. E., Ramsey, M. L., & Simon, M. (2005). Preservice teachers' perceptions of including students with disabilities. *Teacher Education and Special Education*, 28, 92-99.

Systems Level: Community, Educational Institutions, Government

GOAL 3: Increase awareness of the problem of bullying of individuals with developmental disabilities through education, inclusion, and cultural change.

6. Convene a state level conference that includes national experts on bullying and national experts on individuals with developmental disabilities to discuss a variety of issues including the challenge of the CDC definition of bullying and its usefulness for this population. Produce a “white paper” or other type of conference document that could become a resource for scholars, agencies, organizations, and individuals to guide research, policy and programmatic efforts to address bullying of and among people with developmental disabilities.

Needs Assessment Findings

Our initial literature review revealed a lack of a coherent program of research on bullying of and among individuals with developmental disabilities. Aside from one or two researchers who have written several articles on this topic, there are no national research sites or cohorts of researchers that have committed to studying this issue.

Our research team argues that one way to focus attention on this issue would be to bring together national leaders from the fields of bullying research and developmental disability research. This first-of-its-kind conference would serve to:

- Draw attention to the problem of bullying and individuals with developmental disabilities.
- Increase awareness of the need for research on this issue.
- Develop and appropriate funding sources for research on this issue.

Additionally, the conference might produce a document such as a “white paper” (i.e., a document that proposes a solution to a problem), or a book chapter, that could become a resource to guide policy, practice, and programmatic efforts. Likewise, a conference of this sort could prompt an academic journal to devote a special issue to the problem of bullying and individuals with developmental disabilities. Any of these efforts would further the goals stated above.

Conferences, Knowledge Creation, and Information Dissemination

“Conferences can be - and should be – vital sites for creating knowledge and stimulating further knowledge production. This is true for the conference itself and the papers presented at it, especially if they are published” (Louw & Zuber-Skerritt, 2011).

“Conferences offer attendees opportunities to share and receive information, stimulate creative thinking, rekindle or establish contacts, and a myriad other personal and professional objectives” (Weissner, Hatcher, Chapman, & Storberg-Walker, 2008). Jacobs and McFarlane (2005) characterize conferences as “presenting, evaluating, and discussing disciplinary and methodological developments as a reflective community of practice; ensuring that, as a whole, research and/or professional practice progresses both substantially and methodologically” (p. 503).

Fowler, Shimmin, and Dykman (2012) suggest that attending a conference, particularly with a group of colleagues, can begin a learning process which continues long after the conference has ended. In a discussion of workplace conferencing

within organizations, de Boer (1996) asserts that when a group of people with the need to create change come together in an intense conferencing environment, opportunities for new development are enhanced. Such activities may involve simulations or creative procedures which allows for exploration, analysis, and aspiration which conspire to open new ways of thinking and collaboration.

Ward (2003) suggests that good conferences include:

- Easily accessible locations.
- High quality and knowledgeable speakers who are experts in their fields.
- Well prepared pre-conference registration and conference program materials.
- Experienced chairs and facilitators for round-table discussions.
- Electronically available presenter materials following the program.
- Time for socialization with colleagues.
- Plentiful on-site food options.

Sutherland (2012) also suggests that conferences be designed for outsiders to be able to contribute, that planners consider the tastes and needs of outsiders who may attend, and that it be easy to be able to volunteer for the conference.

Potential National Experts on Bullying and Individuals with Disabilities:

Chad Rose, Ph.D. – Dr. Rose is an Assistant Professor of Special Education at the University of Missouri. Dr. Rose received his Ph.D. from the University of Illinois in 2010. His research explores the intersection of disability labels and the bullying-dynamic, predictive and protective factors associated with the overrepresentation of students with disabilities within the bullying dynamic, and multi-tiered systems of support for establishing anti-bullying policies and programs.

Thomas W. Farmer, Ph.D. - Dr. Farmer is an applied developmental scientist in the School of Education at Virginia Commonwealth University. His research focuses on the development and evaluation of classroom and school context interventions that are designed to promote the academic, behavioral, and social adjustment of students with disabilities and students who are at-risk for school failure. He has conducted numerous federally funded studies that focus on bridging the special education and prevention and developmental sciences that are aimed at understanding how natural social dynamic processes in school can be leveraged to reduce bullying and aggression and used by teachers as an ally to promote students' productive academic engagement across elementary, middle, and high school years.

Carol Gray was the Director of the Gray Center for Social Learning and Understanding in Grand Rapids, Michigan, until it recently closed. She is best known for her creation of social stories, short stories used as a teaching tool for autistic children that describe a potentially challenging situation, skill, or concept in terms of relevant social cues, perspectives, and common responses. Gray has also published several resources on topics related to children and adults with autistic spectrum disorders, including articles on bullying, death and dying, and how to teach social understanding. Before establishing her own organization, Gray was employed as a teacher and later an educational consultant who worked with children with autistic spectrum disorders in the Jenison, MI public school district. Gray obtained a B.S. from Central Michigan University in 1973; completed additional coursework at Grand Valley State University (from which she received an endorsement for special education for mentally impaired, learning impaired, and emotionally impaired individuals) and Western Michigan University (from which she received an endorsement to teach autistic individuals; and completed postgraduate work at Calvin College.

Faye Mishna, Ph. D. – Dr. Mishna is Dean and Professor at the Factor Inwentash Faculty of Social Work at the University of Toronto and is cross-appointed to the Department of Psychiatry. Dr. Mishna holds the Margaret and Wallace McCain Family Chair. Her program of research is focused on bullying; cyber abuse/cyber bullying and cyber counselling; and school-based interventions for students with learning disabilities. An integral component of her research entails collaboration with community agencies and organizations. Her scholarly publications have focused on bullying, social work education, and clinical practice. Prior to joining the Faculty, she was Clinical Director of a children’s mental health center serving children and youth with learning disabilities. She is a graduate and faculty member of the Toronto Child Psychoanalytic Program. She maintains a small private practice in psychotherapy and consultation.

Amy S. Hewitt, Ph. D. - Dr. Hewitt has an extensive background and work history in the field of intellectual and developmental disabilities and has worked in various positions over the past 30 years to improve community inclusion and quality of life for children and adults with disabilities and their families. At the University of Minnesota she is the Director of the Research and Training Center on Community Living, Training Director of Institute on Community Integration and the Associate Director for the MN LEND. Dr. Hewitt directs several federal and state research, evaluation and demonstration projects in the area of community services for children and adults with intellectual and developmental disabilities, including autism. She currently has research projects that focus on community living, autism prevalence, direct support workforce development, person centered planning/thinking and positive behavior support. Dr. Hewitt has authored and co-authored many journal articles, curriculum, technical reports, and she co-authored a book entitled, *Staff Recruitment, Retention and Training*. She is on the editorial board of *Inclusion* and a guest editor of *Intellectual and Developmental Disabilities* both journals of the AAIDD. Dr. Hewitt is currently on the Board of Directors for Arc Greater twin Cities, Arc Minnesota, Association of University Centers on Disability (AUCD) and American Association on Intellectual and Developmental Disabilities (AAIDD).

Michaelene Ostrosky, Ph.D. – Dr. Ostrosky is a Professor and the Head of Special Education at the University of Illinois, Urbana-Champaign. Her research has focused on social and communication interventions for preschoolers with disabilities and on establishing the efficacy of *Special Friends* as an effective class-wide program that improves the social acceptance of children with disabilities. <http://education.illinois.edu/people/ostrosky>

Bob Algozzine, Ph.D. – Dr. Algozzine has taught students labeled educable mentally retarded, disabled readers, and emotionally handicapped. He has been a teacher in a vocational institution and center for students with serious emotional problems as well as an educational diagnostician in a large school system. He taught at the University of Florida for 12 years and has been a faculty member at the University of North Carolina, Charlotte, since 1987. For five years, he was a research associate at the University of Minnesota’s Institute for Research on Learning Disabilities. Dr. Algozzine has been on the editorial review board of more than 15 professional journals dealing with special education and educational research. He currently is the coeditor of *Exceptional Children*.

Julie Hertzog is director of PACER’s National Bullying Prevention Center. She has led the development of various curricula and resources, including creating content for the Center’s innovative websites, PACERKidsAgainstBullying.org and PACERTeensAgainstBullying.org. She has served as co-chair of Minnesota’s Governor’s Task Force on the Prevention of School Bullying and as an external reviewer for “Bullying Surveillance Among Youths: Uniform Definitions for Public Health and Recommended Data Elements” by the Centers for Disease Control and Prevention <http://www.pacer.org/bullying/about/directors-blog.asp>

References

- de Boer, L. (1996). Change by working conferences. *The Journal for Quality and Participation*, 19(5), 64-72.
- Fowler, S. A., Shimmin, S., & Dykman, A. (2012). Capturing conference learning. *Literacy Learning: The Middle Years*, 20(3), 28-38.
- Jacobs, N., & McFarlane, A. (2005). Conferences as learning communities: Some early lessons using 'back-channel' technologies at an academic conference - distributed intelligence or divided attention? *Journal of Computer Assisted Learning*, 21, 317-329.
- Louw, I., & Zuber-Skerritt, O. (2011). The learning conference: Knowledge creation through participation and publication. *The Learning Organization*, 18(4), 288-300.
- Sutherland, S. (2012). Conferences and family reunions. *Partnership: The Canadian Journal of Library and Information Practice and Research*, 7(2), 1-4.
- Ward, P. L. (2003). Continuing professional development and workplace learning 4: Conferences, wonderful conferences... *Library Management*, 24(6/7), 367-369.
- Weissner, C. A., Hatcher, T., Chapman, & Storberg-Walker, J. (2008). Creating *new learning* at professional conferences: An innovative approach to conference learning, knowledge construction and programme evaluation. *Human Resource Development International*, 11(4), 367-383.

Systems Level: Community, Educational Institutions, Government

GOAL 3: Increase awareness of the problem of bullying of individuals with developmental disabilities through education, inclusion, and cultural change.

7. Create a public relations/media campaign that promotes awareness of the contributions of people with developmental disabilities. Target the workplace and public transportation as being particularly needy regarding this message.

Needs Assessment Findings

Across the focus groups, participants cited ignorance as a factor with regards to bullying and people with developmental disabilities. To combat stereotypes and misinformation, education of the general public on the contributions of people with developmental disabilities is viewed as a way to change societal attitudes and reduce bullying of people with disabilities. Almost 60% of service providers indicated that “educating others about bullying” was “somewhat” effective in reducing bullying of people with developmental disabilities.

Topics Addressed through Media Campaigns

Media campaigns are a general way to address issues of public concern. When they have been evaluated, they tend to measure the recall that randomly selected members of the target audience have of the specific campaign messages. Outcomes of behavior change due to media campaigns are difficult to measure objectively. Bullying is one of many topics which have been the focus of media campaigns. Others include:

- Food handling among college students (Abbot, Policastro, Bruhn, Schaffner, & Byrd-Bredbenner, 2012),
- Posttraumatic Stress Disorder following a natural disaster (Beaudoin, 2009),
- Parental communication with adolescent children about sex (DuRant, Wolfson, LaFrance, Balkrishnan, Pharm, & Altman, 2006),
- Sexual health for men (Flowers, McDaid, & Knussen, 2013),
- Smoking cessation (Gibson, Parvanta, Jeong, & Hornik, 2014),
- Back pain (Gross et al., 2010),
- The link between obesity and cancer (Morley, Wakefield, Dunlop, & Hill, 2009),
- Child sexual abuse (Rheingold, Campbell, Self-Brown, de Arellano, Resnick, & Kilpatrick, 2007),
- Emergency contraception (Trussell, Koenig, Vaughn, & Stewart, 2001),
- Traffic crashes and young drivers (Whittam, Dwyer, Simpson, & Leeming, 2006)
- The stigma of mental health (Rosen, Walter, Casey & Hocking, 2000)
- Autism awareness (Ad Council⁶), and
- Bullying prevention (Ad Council).

⁶ The Advertising Council (The Ad Council) (www.adcouncil.org) is a private, non-profit organization that marshals talent from the advertising and communications industries, the facilities of the media, and the resources of the business and non-profit communities to produce, distribute and promote public service campaigns on behalf of non-profit organizations and government agencies. The Ad Council addresses issue areas such as improving the quality of life for children, preventive health, education, community well-being, environmental preservation and strengthening families.

Types of Media Used in Campaigns

Media campaigns include the following:

1. PSA's on radio and TV, in newspapers and print outlets (magazines), in online social media such as Facebook (Korda & Itani, 2013).
2. Billboards, posters, city bus signs, and transit cards.
3. Video creation and dissemination through YouTube (Jarboe, 2011).
4. Multiple, simultaneous forms of media including print, video, and social media (see Ad Council initiatives).

Research on Mass Media Campaigns

Effective media campaigns seem to be preceded by extensive research which includes the following:

1. Evaluation of knowledge, attitudes, and self-reported behaviors of the target audience related to the topic.
2. Assessment of actual behaviors among the target population regarding the topic.
3. Use of the information to formulate the content of the campaign, and to develop, implement, and evaluate the campaign. (Abbot et al., 2012)

Additionally, market research suggests that media campaigns that are targeted at "everyone" have little impact on anyone. (Abbot et al., 2012)

Other related findings suggest:

1. Individuals with disabilities are the most effective spokespersons in media campaigns (ter Haar & Besemer, 2004).
2. Reinforcement of the message through repetition is crucial to success (DuRant et al., 2006).
3. Mass media campaigns are difficult to evaluate because of the indirect nature of the change that is desired (Mitchie, Fixsen, Grimshaw, & Eccles, 2009).
4. Public relations or media advocacy campaigns tend to be more successful when they are coupled with some sort of actionable practice, opportunity, or behavior (Wakefield, Loken, & Hornik, 2010). This means, for example, that a media campaign to increase inclusion of more individuals with disabilities in the community is accompanied by an opportunity for people with and without disabilities to gather and engage one another in a program such as *Best Buddies Citizens*. Another example would be a media campaign to make use of a hotline, although use of the hotline would have to be the final outcome measure (Trussell et al., 2001). In interventions of the two just mentioned, change would have to be measured in terms of the effectiveness of the program or hotline to address specific outcomes such as more inclusion of people with disabilities or improved functioning in a particular context, not just participation in an intermediate activity such as Best Buddies or the hotline.

Theory and Mass Media Campaigns

In addition to having a narrow focus, a specific target-audience, and defined goals, effective media campaigns are based on sound theory. Theories should be selected based on the goals of the media campaign, and should be used to guide the development, implementation, and evaluation of the campaign. Examples of theories which have been used to guide the creation of media campaigns include the following:

1. KAP Theory (knowledge, attitude, practice) (Valente, Paredes, & Poppe, 1998)
2. Hierarchy of Effects Model (McGuire, 1984)
3. Theory of Reasoned Action (Montano, Kasprzyk, & Taplin, 2002)
4. Theory of Planned Behavior (Ajzen, 1991; Montano et al., 2002)

References

- Abbot, J. M., Policastro, P., Bruhn, C., Schaffner, D. W., & Byrd-Bredbenner, C. (2012). Development and evaluation of a university campus-based food safety media campaign for young adults. *Journal of Food Protection*, 75(6), 1117-1124.
- Ad Council. (n.d.). *Autism Awareness*. Retrieved from <http://www.adcouncil.org/Impact/Research/Impact-Highlights>
- Ad Council. (n.d.). *Bullying Prevention*. Retrieved from <http://adcouncil.org/Our-Campaigns/Safety/Bullying-Prevention>
- Ad Council, AOL, Facebook and Free to Be Foundation unite for National Bullying Prevention Campaign. (2011). *Education Business Weekly*. Retrieved from <http://search.proquest.com/docview/902740463?accountid=13567>
- Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, 50(2), 179-211.
- Beaudoin, C. E. (2009). Evaluating a media campaign that targeted PTSD after Hurricane Katrina. *Health Communication*, 24, 515-523.
- DuRant, R. H., Wolfson, M., LaFrance, B., Balkrishnan, R., Pharm, M. S., & Altman, D. (2006). An evaluation of a mass media campaign to encourage parents of adolescents to talk to their children about sex. *Journal of Adolescent Health*, 38, 298.e1-298.e9.
- Flowers, P., McDaid, L. M., & Knussen, C. (2013). Exposure and impact of a mass media campaign targeting sexual health amongst Scottish men who have sex with men: An outcome evaluation. *BMJ Public Health*, 13, 737-747.
- Gibson, L. A., Parvanta, S. A., Jeong, M., & Hornik, R. C. (2014). Evaluation of a mass media campaign promoting using help to quit smoking. *American Journal of Preventive Medicine*, 46(5), 487-495.
- Gross et al. (2010). Evaluation of a Canadian back pain mass media campaign. *SPINE*, 35(8), 906-913.
- Jarboe, G. (2011). *Youtube and video marketing: An hour a day. (2nd edition)*. Sybex. Retrieved from <http://site.ebrary.com.ezp.lib.rochester.edu/lib/rochester/detail.action?docID=10503026>
- Korda, H., & Itani, Z. (2013). Harnessing social media for health promotion and behavior change. *Health Promotion Practice*, 14(1), 15-23.
- McGuire, W. J. (1984). Public communication as a strategy for inducing health promoting behavioural change. *Preventive Medicine*, 13, 299-319.
- Michie, S., Fixsen, D., Grimshaw, J. M., & Eccles, M. P. (2008). Specifying and reporting complex behaviour change interventions: The need for a scientific method. *Implementation Science*, 4(40).

- Montano, D. E., Kasprzyk, D., & Taplin, S. H. (2002). The theory of reasoned action and the theory of planned behavior. In K. Glanz, F. Lewis & B. Rimer, (Eds.), *Health behavior and health education: Theory, research, and practice*, (pp. 67-98). Jossey-Bass, San Francisco.
- Rheingold, A. A., Campbell, C., Self-Brown, S., de Arellano, M., Resnick, H., & Kilpatrick, D. (2007). Prevention of child sexual abuse: Evaluation of a community media campaign. *Child Maltreatment, 12*(4), 352-363.
- Rosen, A., Walter, G., Casey, D., & Hocking, B. (2000). Combating psychiatric stigma: An overview of contemporary initiatives. *Australasian Psychiatry, 8*, 18-26.
- ter Haar, J. A. A., & Besemer, R. (2004). *The Challenge*: Evaluation of a multi-media campaign to raise awareness and change attitudes. *Journal of Intellectual Disability Research, 48*(4-5).
- Trussell, J., Koenig, J., Vaughn, B., & Stewart, F. (2001). Evaluation of a media campaign to increase knowledge about emergency contraception. *Contraception, 63*, 81-87.
- Valente, T. W., Paredes, P., & Poppe, P. R. (1998). Matching the message to the process: The relative ordering of knowledge, attitudes and practices in behavior change research. *Human Communication Research, 24*, 366-385.
- Wakefield, M. A., Loken, B., & Hornik, R. C. (2010). Use of mass media campaigns to change health behavior. *Lancet, 376*, 1261-1271.
- Whittam, K. P., Dwyer, W. O., Simpson, P. W., & Leeming, F. C. (2006). Effectiveness of a media campaign to reduce traffic crashes involving young drivers. *Journal of Applied Social Psychology, 36*(3), 614-628.

APPENDIX E

PROGRAM EVALUATION

Introduction

Program evaluation is often an afterthought, something that program developers or funders think about long after a program has been rolled out. At some point in a program's life, someone will ask, "How are we doing? Is this a good program? Has our hard work made 'things' better? Is this effort a success?" Attempting to answer those questions once a program is up and running can be very difficult if no thought was given ahead of time to how those questions would or could be answered. Program evaluation should be part of the equation when a program is being designed, and while it can be rather expensive, it may save money in the long run because the answers to the above questions can tell us what we are doing well, what more we need to do, what needs to change, and most importantly, if our program is really the solution to the problem that concerns us.

What is program evaluation?

"Evaluation is the process of determining the merit, worth, and value of things, and evaluations are the products of that process" (Scriven, 1991, in Rossi, Lipsey, & Freeman, 2004, p. 17). Evaluation is "a social science activity directed at collecting, analyzing, interpreting, and communicating information about the workings and effectiveness of social programs" (Rossi et al, p. 2).

Program evaluations can look at one or more aspects of a program and its development. These include:

1. the need for the program,
2. the design and theory behind the program,
3. the process of program implementation,
4. the outcomes and impact of the program, and
5. the cost effectiveness of the program (Rossi et al., 2004).

Why do program evaluation?

The purpose of conducting a program evaluation is to provide answers to questions about a program that will be useful and will be used (Rossi et al., 2004). Evaluations are designed with a specific audience or set of stakeholders in mind who will take action and make decisions based on the outcomes of the evaluation. Thus, evaluations become a tool for learning more about what services or content should be included in programs or modified in existing programs, whom the program should be targeting and if the desired target is receiving the program, how the program should be implemented or modified if already in existence, and what outcomes are desired and or have been accomplished.

Program evaluation can be used to improve a program, bring a program back to its intended focus if it has drifted in some way, determine whether the cost is appropriate for the benefits achieved, or in some cases, to end a program. Ultimately, program evaluation should contribute to general knowledge about program design, implementation, and effectiveness. In some cases, program evaluation adds knowledge to a particular field of study within the social sciences.

Evaluating an Existing Program

What should an evaluation include?

Any program evaluation should first be laid out in a formal plan prepared by an evaluator or a team of evaluators. A well-constructed evaluation plan should include:

- A listing and/or description of the stakeholders who are requesting the evaluation and a statement of their purpose in asking for the evaluation.
- A discussion of the role that stakeholders, program managers and providers, and program recipients will play in the development, implementation, and outputs of the evaluation itself.
- A thorough description of the program to be evaluated including information on:
 - The program’s purpose, creation, content, implementation, longevity, goals, objectives, funding structure, and target audience.
 - Data that may exist regarding program content and services; program managers and providers, and recipients; previous evaluations; and any formal or informal outcome assessments.
 - A logic model (also referred to as a program theory) which articulates how the program is supposed to work including inputs, activities, outputs, initial outcomes, intermediate outcomes, and distal or long-term outcomes.
- A set of evaluation questions to be answered.
- A carefully developed set of goals and objectives that reflect the program’s purpose and that are measurable.
- A list or description of key informants who will be solicited for participation in the evaluation (e.g., program recipients), how these individuals will be approached, and what measures will be put in place to protect them.
- A list and/or description of measures that will be used to assess the program.
- A description of how the data will be analyzed.
- A timeline for implementation of the measures including who within the program will be responsible for providing access for the evaluators.
- A schedule of progress reports, their content, and a timeline indicating when they will be delivered and to whom.
- A date for the delivery of a final report and a scheduled presentation of the evaluation findings to the appropriate stakeholders.
- A follow-up meeting to answer questions and discuss how the findings are being used.

Program Development and Evaluation

How do you design a program with evaluation in mind?

Programs that are developed with evaluation in mind are usually well-conceived, successfully implemented, and generally more likely to be effective than programs that aren’t. Programs that are created with little thought to evaluation can lead to a variety of problems including:

- Poorly conceptualized programs that lack theoretical support.
- Programs that do not reflect knowledge of relevant research.
- A poorly-defined problem.
- An inaccurate assessment of the target population.
- Poorly articulated and unmeasurable goals.
- Unreasonable and unachievable objectives.
- Activities that are not logically connected to the desired outcomes.
- A lack of resources including funding, personnel, and infrastructure.
- Inadequate organizational capacity.

As the NYS DDPC moves forward and extends or initiates programs, it is recommended that the organization commits to evaluating these programs.

References

Rossi, P. H., Lipsey, M. W., & Freeman, H. E. (2004). *Evaluation: A systemic approach* (7th ed.). Thousand Oaks, CA: Sage.

Scriven, M. (1991). *Evaluation thesaurus* (4th ed.). Newbury Park, CA: Sage.