

Tormented

the Bullying of Children with Autism Spectrum Disorder



Massachusetts Advocates for Children Autism Special Education Legal Support Center



Many thanks to MAC staff: Kavita Padiyar for analyzing the survey data, presenting it in this report and writing the accompanying text; Leslie Hughes and Johanne Pino for their key roles in designing, writing and disseminating the survey; and Michael Gregory for assistance with the cover and graphics. Thanks as well to the Asperger's Association of New England for reviewing the survey and report. Thanks most of all to the parents all across Massachusetts who had the courage to share the pain of their children's bullying experiences.

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The Autism Special Education Legal Support Center is a project of Massachusetts Advocates for Children providing training, technical assistance and advocacy services to ensure that children with autism overcome lowered expectations and receive equal educational opportunities. It is funded by the Nancy Lurie Marks Family Foundation, Ronald Ansin Foundation, DLA Piper Foundation, Massachusetts Bar Foundation, and individual donors.

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Massachusetts Advocates for Children is a private, non-profit organization whose mission is to be an independent and effective voice for children who face significant barriers to equal educational and life opportunities. MAC works to overcome these barriers by changing conditions for many children, while also helping one child at a time. For 40 years, MAC has responded to the needs of children who are vulnerable because of poverty, race, limited English or disability.

25 Kingston St. Boston, MA 02111 617-357-8431 www.massadvocates.org Between September 23, 2009 and October 12, 2009, Massachusetts Advocates for Children conducted an online survey in hopes of learning more about the extent of bullying of children on the autism spectrum in Massachusetts schools.¹ Parent respondents were informed that data and examples provided would be used to support the passage of H.3804, An Act Addressing Bullying of Children with ASD.

Almost 400 parents responded.²

These are their answers. These are their stories.

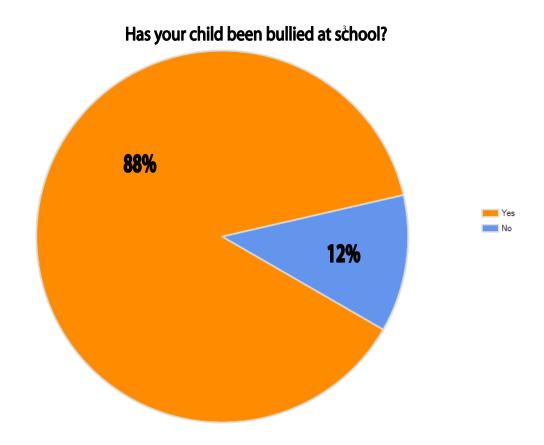
These are their children.

¹ 96% of those questioned regarding residency confirmed that they live in Massachusetts.

² 66% have children diagnosed with Asperger Syndrome, 30% with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and 5% with Classic Autism. 9% of parents grouped their children in the "Other" category of Autism Spectrum Disorder (ASD), which could represent either children with multiple diagnoses (e.g., Autism and a psychiatric disability or mental retardation) or rarer forms of Autism. Percentiles here and in responses in other tables may not add up to 100% as parents may have selected more than one option.

"He has been 'knuckled' black and blue in his upper arms. He has been stabbed repeatedly with a pencil. He has been bullied and harassed for several years."

—Parent of a 15-year-old student with Asperger Syndrome

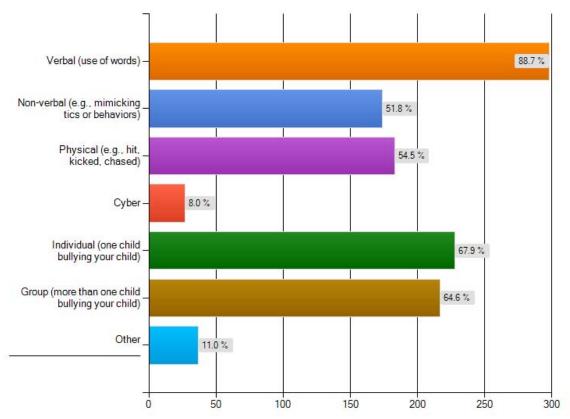


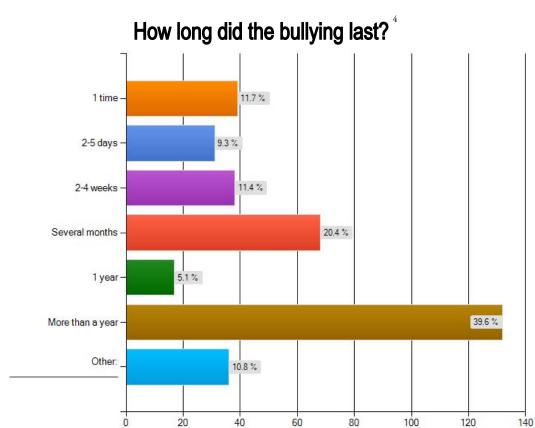
"My son was picked up and thrown to the ground, was kicked, punched, hit in the back of the head, called names ('Sped Kid'), pushed into the wall (tearing skin from his leg), threatened with a pottery pin to be stabbed. All the bullying went on since he was in 1st grade until he got into his freshman year and still now he is intimidated by the kids next door. He had no self-esteem; when I adopted him at 10 years old, he wanted to die."

—Parent of a 17-year-old student with PDD-NOS

³ Though the subject matter of this survey predominantly drew responses from those families who have been affected by bullying, the survey results are consistent with the research, including a study that found that 94% of children with Asperger Syndrome are routinely victimized by other children. Little, Liza (2002), "Middle Class Mothers' Perceptions of Peer and Sibling Victimization among Children with Asperger's Syndrome and Nonverbal Learning Disorders." *Comprehensive Issues in Pediatric Nursing*, *25*:1, pp. 43-54.

If your child has been bullied, what type of bullying was it? (check all that apply)



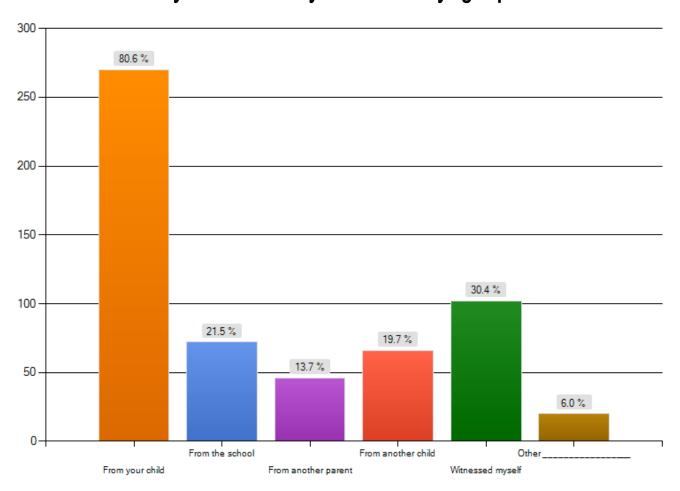


⁴ In this and other graphs in which totals exceed 100%, respondents selected more than one category, likely referring to multiple incidents of bullying.

"He was confused. He knows hitting is wrong and keeps asking why the other student had the 'right' to hit (punch) him."

—Parent of a 16-year-old student with PDD-NOS

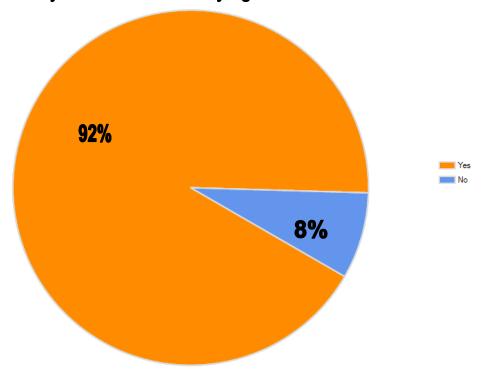
How did you learn about your child's bullying experience?



"We never would have known that another child had his hands around our son's neck and was choking him if another parent didn't call us. The school's response only occurred because we found out and insisted that something be done. Our child does not like school and is afraid while he is at school."

—Parent of a 6-year-old student with Asperger Syndrome

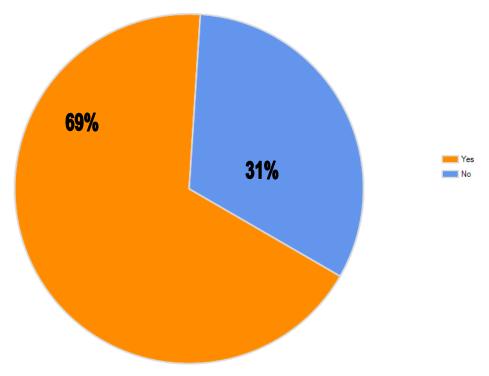
Did you discuss the bullying with school officials?



[&]quot;A child threatened to stab my son with a knife and the school never even called that child's parents. I ended up calling them. The school did nothing."

—Parent of a 14-year-old student with Asperger Syndrome

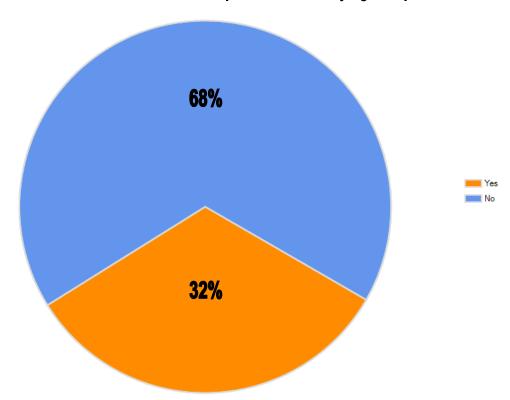
If you discussed the bullying with school officials, did the school district address the bullying?



"SPED department wouldn't even put 'bullying' in his IEP. When my son was repeatedly hit and punched in the stomach, the principal said, 'Children this age are physical.'

—Parent of a 7-year-old student with PDD-NOS

Was the school district's response to the bullying adequate?



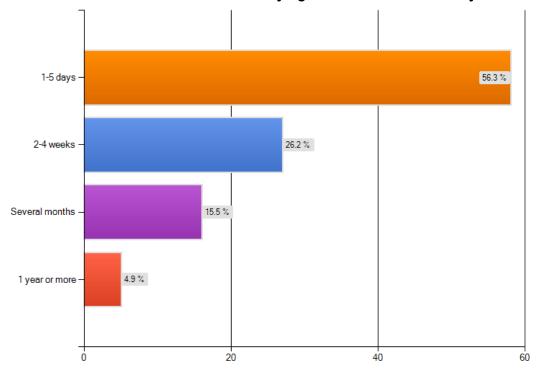
"They addressed it, but wanted to sweep it under the rug and be done with it as soon as possible. At least they acknowledged it. My son feels he does not fit in and that he is worthless and friendless. He does not understand why the other kids will not accept him and he is unhappy at school."

—Parent of a 15-year-old student with Asperger Syndrome

"They say they don't tolerate it...however they never address [my child's bullying] directly."

-Parent of a 17-year-old student with PDD-NOS

If your child missed school because of the bullying, how much school did your child miss?



"My child was hospitalized from this event. He shut down and went into a psychotic state and depression. He had to get help from a psychiatrist and therapy ever since and is only now getting back to school. He missed most of 7th grade and we could get only 2 hours a day of home schooling from the school. This incident had a huge impact on my son, and our family was traumatized the entire year. We had to pay for therapy and social camps during the summer to get my son back to his own self again."

—Parent of a 13-year-old student with Asperger Syndrome

"My son developed physical ailments from stress, including headaches, stomach aches, and urinary frequency; he was repeatedly dismissed early for 'sickness' issues. He was unable to focus on academic issues/struggles because of bullies, and he developed nervous tics that escalated prior to school restarting in the fall. He was physically assaulted by a group of kids who held him down and repeatedly hit him, refusing to let him run away. Our school principal and school psychologist were useless in this situation. These kids were only in second grade and were this vicious."

—Parent of an 8-year-old student with Asperger Syndrome

⁵ Nearly a third of the parents responding reported that their child missed school because of being bullied.

Bullying of Children with ASD is Statewide

While the majority of parents surveyed chose not to disclose where they live, the following is a list of the cities and towns that were noted in the survey responses.

114 Massachusetts Communities Impacted By Bullying of Children on the Autism Spectrum

(representing approximately 1/3 of survey respondents)

Acton Allston Amesbury Amherst Andover Arlington **Attleboro** Auburn Barnstable Billerica Boston Bradford Braintree **Brewster** Bridgewater Brockton Brookline Cambridge Chelmsford Chicopee Cohasset Concord Danvers Dorchester Douglas Dracut Duxbury East Bridgewater East Longmeadow Easthampton **Everett** Fall River Falmouth Forestdale Framingham Franklin Gardner Plainville Gloucester Quincy

Grafton

Greenfield Raynham Groveland Reading Hanover Revere Holliston Rockland Hudson Sagamore Beach Huntington Salem **Ipswich** Seekonk Lancaster Sharon Leominster Shrewsbury Lexington Somerset Littleton Somerville South Easton Lunenburg Lynnfield South Hamilton Malden South Weymouth Marblehead Southwick Marlborough Springfield Marshfield Sterling Marstons Mills Stow Maynard **Swampscott** Medford Taunton Melrose Quincy Methuen Ware Middleboro Warren Milford Wellesley Natick West Bridgewater Westford Needham Newburyport Westwood Newton Weymouth North Andover Whitman North Chelmsford Wilbraham Northampton Wilmington Norwell Winchendon Norwood Winchester Peabody Winthrop Pembroke Woburn Pepperell Worcester

H.3804: An Act Addressing Bullying of Children with Autism

(Lead sponsors: Rep. L'Italien, Sen. Jehlen)

Bullying is a critical concern for all children, children with and without disabilities. Bullying of any child is unacceptable, and there are many important bills pending in the legislature that focus on the need for critical school-wide bullying prevention programs.

In addition to implementation of these school-wide anti-bullying initiatives, it is imperative to simultaneously accommodate the unique learning needs of children with Autism Spectrum Disorder (ASD), because these children are bullied at a much higher rate than their nondisabled peers. One study found that 94% of children with Asperger Syndrome are routinely victimized by other children. This victimization can include verbal, physical and cyber bullying and attacks by individuals or groups.⁶

As demonstrated by the data and stories presented here, the Commonwealth's children with Autism Spectrum Disorder are especially vulnerable targets for bullying. This is because children with ASD are generally viewed as atypical or "odd" by their peers, and are relatively defenseless in social situations. Children on the spectrum are generally unable to understand bullying incidents and protect themselves like other students due to the nature of ASD, which impacts communication, social, and behavioral skills.

In addition to critical school-wide bullying prevention programs, these students, because of their disability, require specialized teaching, supports, and services to develop strategies to help deal with bullying. The experiences of specialists who work with children on the spectrum indicate that children with autism can learn the critical skills necessary to help respond to and avoid bullying with the provision of targeted instruction and services.

H.3804 will ensure that IEP Teams address bullying of children on the Autism Spectrum, specifically focusing on the skills necessary to help individual children avoid and respond to bullying. By requiring Teams to address bullying as it impacts individual students through the IEP process, H.3804 would work towards effectively mitigating the instances and effects of the immensely damaging and inexcusable bullying discussed throughout this report.⁷

⁶ Little, Liza (2002), "Middle Class Mothers' Perceptions of Peer and Sibling Victimization among Children with Asperger's Syndrome and Nonverbal Learning Disorders." *Comprehensive Issues in Pediatric Nursing*, 25:1, pp. 43-54. In the study, 75% were emotionally bullied, 73 % were hit, and 10% were attacked by a group of peers in the one year leading up to the study.

⁷ While H.3804 amends the Autism IEP Act, Massachusetts Advocates for Children recognizes that children with other types of disabilities are also targets of bullying. MAC would hope and expect that the legislature would consider further legislation in the future to ensure that IEP teams consider and address bullying of children with all types of disabilities.



A CALL TO ACTION...

"As a result of the bullying and denial for services, life has been very difficult for [our son]...Our son has finally begun to experience joy, the feelings of acceptance and true friendship while in residential school with other peers with Asperger Syndrome...He is in 12th grade and has attended six schools! We wonder what his life would have been like if he was provided with social skills teaching and issues like bullying were addressed when he was younger. He is such a good kid – very kind and considerate – and has come far working on his issues of anger and rage through the years. Please help the many children like our son so they don't have to miss their childhood! Thank you."

—Parent of a 17-year-old student with Asperger Syndrome

HELP CHILDREN WITH AUTISM SPECTRUM DISORDER

SUPPORT H.3804:
An Act Addressing Bullying of Children with Autism

Additional Stories

Parents responding to the survey provided an overwhelming number of personal stories and accounts related to their children's experiences with bullying. The previous quotes and the following stories were selected from those provided in the survey responses.



"My daughter gets very nervous near other children now and vomits in school frequently due to nerves. She tries so hard to fit in and will often take out her frustration on herself by punching her own stomach and/or head."

—Parent of a 5-year-old student with Asperger Syndrome/PDD-NOS

"...My child already knows he is different, and therefore his selfesteem is low to begin with. Having kids making fun of him in front of the class made him feel worse. Kids were throwing pencil shavings on him while standing in line, pointing at him for others to laugh at him. He became frustrated and acted out by yelling. He wanted to stay home from school. You or I could never imagine what it must feel like to be him. He is high-functioning and verbal, and big for his age, which benefits him a little. To live in your mind must be a challenging experience that you or I will never know. So, as a parent, anything I can do to make life better for my son, I will do..."

—Parent of a 13-year-old student with Classic Autism

"The school denied that any incident happened. Then the principal said that if my daughter did not speak with him directly about the incident, it didn't happen."

—Parent of a 10-year-old student on the Autism Spectrum

"I could go on forever, but our child wants to quit school, sports, and 'life.' "

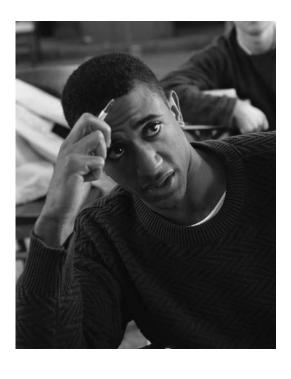
—Parent of an 11-year-old student with Asperger Syndrome

"He became suicidal in 5th grade and continued to express the wish to commit suicide until he went to high school."

—Parent of an 18-year-old student with Asperger Syndrome

"My son's self-esteem has suffered; he already believes at 8 that there is something very wrong with him and it has made him afraid to approach other children."

—Parent of an 8-year-old student with Asperger Syndrome



"At first the aide and other playground monitors did not believe my son's story (probably he was anxious and it seemed fictional). The other boy was

calling him 'SPED' and coercing him to stand in mud puddles. My son was complying to 'appease' the bully, and didn't seem to understand that the bully was not playing, as a friend would. His aide and other adults on the playground told him repeatedly that it was his fault too and to 'go work it out' on his

own. That, of course, was

impossible without guidance due to his disability. He told me at home, and I instructed him to go directly to his classroom teacher or the principal,

which he did when the other boy choked him. The principal called us to apologize, banned the other child from the playground, and told his aide to be

present on the playground when it coincided with her lunch (and to take lunch at another time), since recess was when he most needed social guidance (or at least monitoring). However, this is not yet addressed in his IEP...Because my son is not aware of his own presentation, he can't see how unusual his use of vocabulary, lack of volume control,

repetitive movements and lack of eye contact appear to other children..."

—Parent of a 12-year-old student with Asperger Syndrome

"It became difficult for him to feel he could trust adults at school and he was fearful for his safety."

—Parent of a student with High Functioning Autism

"My son withdraws and his self-esteem suffers. He feels he 'deserves' the abuse because he is 'not a good person.' "

—Parent of an 11-year-old student on the Autism Spectrum

"...My son was socially isolated and severely afraid of other kids. He developed depression and anxiety. Several months after a severe beating he was pressured into committing a crime he did not understand by a group of kids involving the same child who had assaulted him. According to Massachusetts law, my son was an adult at the time. The case is pending, but it appears that this incident will most likely be with him for the rest of his life."

—Parent of an 18-year-old student with PDD-NOS



"Our son was bullied over a period of 4-plus years on the bus, on the playground, at lunch, in the hallways and sometimes even in the classroom. The most severe bullying occurred on the bus and the playground when kids were be

the playground when kids were beyond the recess monitors' view. Unfortunately, our bus concerns seemed to fall into no man's land...Eventually, we got a new school principal who was more proactive and a new SpEd director who responded to our concerns – 2-plus years after the bullying had begun...This year, by sheer luck because our son is off to junior high school, he has not only a different bus driver but a different bus route; many of the children who bullied him for years are no longer on his bus. We were appalled as parents that this level of continued harassment and bullying was allowed to continue unchecked for so long – until it had become an entrenched pattern of social ostracism that has impacted our son's self-esteem and social acceptance..."

—Parent of a 12-year-old student with Asperger Syndrome

"He's been impacted by poor self-esteem, rage (unable to process or really understand what was going on, and most recently he's 'taken control' of the situation by directing the teasing (coming up with a theme song for his faults, making kids laugh, etc.). He feels that this allows him to have more control over the situation. It just makes me sad."

—Parent of a 10-year-old student with Asperger Syndrome

"He sits all alone in the cafeteria, he has depression over it, and his 'friend' tells him to shut up and won't sit with him in the cafeteria because he doesn't want to be teased, too."

—Parent of a 16-year-old student with Asperger Syndrome

"It got so bad that he expressed the desire to harm himself."

—Parent of a 10-year-old student with Asperger Syndrome

"My son was unaware that he was being bullied because he has no social awareness. But other kids saw him being taunted and that automatically tagged my son as a 'weirdo.' My son has a hard enough time making friends to begin with (other kids merely 'tolerate' him) and now he has fewer kids who think they might want to befriend him solely because a bully has targeted my son as 'weird.' "

—Parent of an 11 year-old student with Asperger Syndrome

"His self-esteem is shot as well; he now hates school and is a very bright boy. We are considering Catholic school because of it."

—Parent of an 8-year-old student with Asperger Syndrome



"My child became suicidal and has become so depressed that she now is in psychiatric care; she has also been prescribed medication to help with her fears of being further attacked and isolated. I had to remove my daughter from school as she stated she had to end the bullying by hurting another child. The school faculty was aware of the bullying and kept it quiet due to her nonverbal communication...Our story is so bad it is difficult to keep reliving it..."

—Parent of an 11-year-old student with PDD-NOS



"He thinks everyone hates him. Kids goad him and tease him, waiting for his reaction. If/when he finally responds, and it is inappropriate, they laugh and gloat, especially if he gets in trouble...He holds it together in school, and 'blows' once he is in the car (he doesn't take the bus), even before leaving the parking lot. Although it is clear that he has been bullied for a long time, he also has difficulty perceiving social situations accurately, and sometimes just assumes it's bullying even though it may not be. His social confidence is nil. He believes that most kids hate him and laugh at him. As he has gotten older, his outbursts at home have become worse. Our school put on a cyberbullying presentation recently, which was put on by a father who lost his teenage son to suicide as a result of bullying. That message struck a very sensitive nerve in our family and our son is still talking about it."

—Parent of an 11-year-old student with Asperger Syndrome

"My child became increasingly paranoid and became agitated to the point of hospitalization."

—Parent of a 14-year-old student with Asperger Syndrome

"My son was verbally abused and humiliated in class; he didn't understand what was happening but knew the kids were laughing at him and was upset, but because he didn't understand he couldn't defend himself."

—Parent of a 14-year-old student with Asperger Syndrome

"He still, at times, refers to himself as 'a stupid sped.' He never made friends at the public school because it was cool for the other kids to make fun of him..."

—Parent of a 19-year-old student with Asperger Syndrome

"Our son knows that if he asks for help, often he will not be believed. If he tells, he may be ostracized for advocating for himself."

—Parent of a 14-year-old student with Asperger Syndrome



"In my son's first four weeks of Kindergarten, he was pushed, elbowed, name called, etc. The school's stance was that all of the children were adjusting to being in school..."

—Parent of a 5-year-old student with PDD-NOS

"My son lost faith in the school's teachers and administrators and their ability to help him in bullying situations. He thought that they were not interested in protecting him or addressing the problems. He then decided to take matters into his own hands and became verbally defensive when bullying instances occurred. He lost confidence in himself, and because he generalized his feelings that school personnel would not help him, he refused to believe that any adult in the school would help him...this left him feeling isolated and unprotected..."

—Parent of a student with Asperger Syndrome

"His self-esteem, which was once very high, is demolished; he has gone from a happy boy to a sad and angry boy."

—Parent of a 9-year-old student with PDD-NOS



"Our son actually missed out on 3 of his 4 middle school years because he was unable to function in the classroom due to the ever-present bully..."

—Parent of an 18-year-old student with Asperger Syndrome



"My son stopped speaking for months and was treated as if he caused the problem. It has taken a child with a willingness to try new adventures and turned him into a child who doesn't like leaving his house."

--Parent of a 14-year-old student with Asperger Syndrome

"They either ignored the issue when I brought the issue up or claimed they never saw anything to indicate he was being bullied by his classmates. He became suicidal in 5th grade and continued to express the wish to commit suicide until he went to high school."

—Parent of an 18-year-old student with Asperger Syndrome

"My son has had such negative bullying experiences that his view of social interaction is extremely negative. He now has no desire to attempt to interact with other kids his age."

—Parent of a 14-year-old student with PDD-NOS/Asperger Syndrome

"School response to bullying incidences, and to an IEP in general, was extremely inadequate...We were told that he needed to learn how to deal with people in the world! Bullying was not addressed on the IEP...he would be mimicked and made fun of while he was eating, etc. They talked to the student, but she would continue her teasing; our son was extremely upset about it. And, they believed her – that she wasn't doing it, and they basically said our son was overly sensitive. He had salt or sugar poured down his back on the bus, his hat would be taken and thrown, but he was not allowed to sit in the front of the bus; the school told us only the younger kids were allowed to sit in the front of the bus: he wasn't allowed to sit there...He still talks about the bullying....and how very hurtful peers were (at school and in the neighborhood). He desperately wanted friends..."

—Parent of a 17-year-old student with Asperger Syndrome



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