

Autism and Safety Toolkit: Research Overview on Autism and Safety

What Is In This Research Overview?

Introduction

Safety is a complex, multi-faceted subject when it comes to autistic people. This is because we have a higher risk of being hurt and victimized than non-autistic people. As people with disabilities, we are more vulnerable to abuse, exploitation, and assault.¹ We have a higher risk of both co-occurring mental health disabilities² and suicide,³ and of being bullied and antagonized in schools. The police tend to misunderstand people with disabilities and have been known to use excessive force on us.⁴ These threats to our safety exist throughout our lifespans, from birth to death. They may contribute to our higher-than-average mortality rate.⁵

Due to these threats, the safety of autistic people is a critical concern for autistic self-advocates, federal and state government agencies, parents, and other stakeholders. Many different coalitions, such as The Arc of South Norfolk Family Autism Center and the Norfolk County District Attorney's Office's joint coalition, A.L.E.C (Autism and Law Enforcement Education Coalition), and the Autism Society's Safe and Sound initiative,⁶ formed out of concern for the safety of autistic people.⁷ The National Center for Missing and Exploited Children has a website that provides tips on how to locate missing autistic children.⁸ Safety is also a top concern of many parents of autistic people, who often say that people do too little to protect their children from harm.

Despite this many autistic people and our family members and friends lack information and resources on these threats to our safety. That is the reason we conducted research on these threats. This guide provides information about common threats to the safety of autistic people and the ways in which those threats relate to one another.

We researched five topics:

- Abuse and neglect of autistic people, in the home, in schools and in settings like residential schools and group homes;

¹ Patricia M. Sullivan & John F. Knutson, *Maltreatment and Disabilities: A Population-Based Epidemiological Study*, 24 Child Abuse and Neglect 1257, 1268-71 (2000) (finding that children with disabilities were 3.5 times more likely than children without disabilities to be abused and/or neglected); Irit Hershkowitz et al., *Victimization of Children with Disabilities*, 77 Am. J. Orthopsychiatry 629, 631-35 (2007) (finding that children with disabilities are more likely to be abused but less likely to be able to report it).

² Luigi Mazzone et al., *Psychiatric comorbidities in asperger syndrome and high functioning autism: diagnostic challenges*, 11 Annals of General Psychiatry 1, 5-8 (2012) (finding that, based on a systematic review of relevant scientific studies, autistic people were more likely to have many mental health disabilities); Ovsanna T. Leyfer et al., *Comorbid Psychiatric Disorders in Children with Autism: Interview Development and Rates of Disorders*, 36 J. Autism & Dev. Disord. 849, 855 (2006) (finding that 72 percent of the autistic children in the study had an additional psychiatric disability).

³ Magali Segers & Jennine S. Rawana, *What Do We Know About Suicidality in Autism Spectrum Disorders: A Systematic Review*, 7 Autism Res. 507, 509 (2014).

⁴ John Swaine et al., *Young Black Men Killed by U.S. Police at Highest Rate in Year of 1,134 Deaths*, The Guardian (December 31, 2015, 3:00 PM), <https://www.theguardian.com/us-news/2015/dec/31/the-counted-police-killings-2015-young-black-men> (media study finding that 1 out of every 5 people killed in a police shooting had a mental health disability); Julie Tate et al., *Fatal Force*, Washington Post, <https://www.washingtonpost.com/graphics/national/police-shootings-2017/> (last visited Oct. 22, 2017).

⁵ Tatja Hirvikoski et al., *Premature Mortality in Autism Spectrum Disorder*, 208 Br. J. Psychiatry 232, 234-35 (2016) (describing the high mortality rate of autistic people, and that one cause of death contributing to this rate is our higher likelihood of committing suicide).

⁶ Autism Soc'y, *Safe and Sound Autism Society*, <http://www.autism-society.org/living-with-autism/how-the-autism-society-can-help/safe-and-sound/> (last visited Oct. 23, 2017).

⁷ Arc of South Norfolk, *ALEC (Autism and Law Enforcement Education Coalition)*, <http://www.arcsouthnorfolk.org/alec-first-responder-training.html> (last visited Oct. 20, 2017);

⁸ Nat'l Ctr. for Missing & Exploited Children, *Missing Children with Autism* <http://www.missingkids.com/autism> (last visited Mar. 17, 2017).

- How likely people with disabilities are to be victims of crimes;
- Police violence against people with disabilities, including autistic people;
- Special concerns faced by autistic people, including the high rate of suicide in our population; and
- Research on autistic people who get lost or leave locations without telling others, which is often called “wandering” or “elopement.”

About Our Sources

We reviewed relevant research studies, writings by safety experts, and news media sources to produce this section. ASAN also conducted two informal surveys on autism and safety: one for autistic self-advocates and one for parents of autistic people. We thank in particular the more than eighty parents of autistic people from the organization Parent to Parent USA that filled out our parent survey, and Ronald E. Hampton and the members of Autism Society District of Columbia, who shared their insights as well as filled out our survey. We also want to thank the autistic people from ASAN’s affiliates and elsewhere who took the time to fill out our survey.

We include quotes from the surveys in this overview. We also include some percentages and general statistics about the people who filled out our parent survey and our survey of autistic self-advocates. The percentage of people who gave a particular response to a question in the survey may be very different from the percentage of parents and self-advocates as a whole who feel that way. For example, although we collected several responses from communities of color, parents who responded were disproportionately likely to be white.

When we developed the recommendations in our Research guide and in the Family Members and Self Advocate guides, we accounted for this disproportionality by consciously selecting suggestions that reflect a diverse range of survey respondents and by supporting our recommendations with additional sources. These additional sources are the opinions, research, and views of a wide variety of news outlets, self-advocate groups, disability rights organizations, disability organizations, general advocacy groups, government agencies, and organizations specializing in the research of the specific issues we discuss in this toolkit. We also drew our recommendations from our own experience and knowledge of autism self-advocacy and autism and safety.

Crime and Violent Victimization of People with Disabilities

Key Points

- People with disabilities are more likely to be victims of crime than people without disabilities.
- People with developmental and/or cognitive disabilities (like autism) and people with mental health disabilities (which many autistic people also have) are the most likely to be victimized.

People with disabilities are more likely to be victims of violence than people without disabilities. This was one of the conclusions of the Bureau of Justice Statistics' (BJS) reports on crimes committed against people with disabilities. The BJS report is based on data from the National Crime Victimization Survey (NCVS).⁹ The NCVS is a cross-national household survey that collects data on crimes committed against U.S. residents from 90,000 households.¹⁰

The BJS found that people with disabilities were **2.5 times more likely** to be the victims of a violent crime. Teenagers aged 12-15 had the highest rate of victimization.¹¹ People with disabilities who were biracial or multiracial had higher rates of violent victimization than people with disabilities who identified as only a single race.¹² According to the BJS, aside from people who were biracial or multiracial, people with disabilities of all races were about equally likely to be the victims of a crime.¹³ Women and men with disabilities were equally likely to be the victims of a crime.¹⁴

People with disabilities were **more than three times as likely** to be victims of a serious crime (such as rape, robbery, aggravated assault) than people without disabilities.¹⁵ Among people with disabilities, people with cognitive disabilities had the highest rates of serious crime victimization.¹⁶ Because the BJS defines "cognitive disability" as "serious difficulty in concentrating, remembering, or making decisions because of a physical, mental, or emotional condition," this category includes many autistic people.¹⁷ Autistic people may also be represented in the categories of people with a "self-care limitation" or "independent living limitation," as defined by the BJS.¹⁸ Because BJS disaggregated its data in ways that may have put autistic people in multiple categories, it is difficult to determine the rate of victimization of autistic people as a whole.

Did You Know?: People with disabilities are **more** likely to be victimized by someone we know than are people without disabilities.¹⁹ We are also more likely to be victimized by family members.²⁰ The BJS hypothesized that their data may underreport some types of crimes against non-speaking or inconsistently verbal people.²¹ A non-speaking person without access to communication may be unable to report a crime committed by their own parents or caregivers. They may also leave or run away from home because they lack another way to communicate that their caregivers are being abusive. Crimes against people with disabilities and our high abuse risk are likely related.

⁹ Erika Harrell, U.S. Dep't of Justice Bureau of Justice Statistics, NCJ No. 250632, *Crimes Against Persons with Disabilities: 2009-2015 Statistical Tables*, 1, 3, 4, 5 (2017); Michael R. Rand and Erika Harrell, U.S. Dep't of Justice Bureau of Justice Statistics, NCJ No. 227814, *Crime Against People with Disabilities 2007*, 1, 2, 3, 4 (2009).

¹⁰ U.S. Dep't of Justice, Bureau of Justice Statistics, *Data Collection: National Crime Victimization Survey (NCVS)* <https://www.bjs.gov/index.cfm?ty=dcdetail&iid=245> (last visited Mar. 17, 2017).

¹¹ Erika Harrell, *Crimes Against Persons with Disabilities: 2009-2015 Statistical Tables*, *supra* note 9, at 3.

¹² *Id.* at 4.

¹³ *Id.*

¹⁴ *Id.*

¹⁵ *Id.*

¹⁶ *Id.* at 4,5.

¹⁷ *Id.* at 1.

¹⁸ *Id.*

¹⁹ *Id.* at 6.

²⁰ *Id.*

²¹ *Id.* at 9.

1 in 5 of all people with disabilities who reported a crime in the BJS data believed that they were targeted because of their disability.²² The report does not include fatal crimes, which may mean that the real proportion of people with disabilities targeted for violence is even higher.²³ Every year at the Autistic Self Advocacy Network's Disability Day of Mourning, the disability community mourns the loss of hundreds of people with disabilities who were killed by their own caregivers.²⁴ However, the number of people with disabilities killed by their caregivers each year listed at the Day of Mourning is likely under-reported because there are few systematic efforts to collect data on fatal violence targeting people with disabilities.

²² Erika Harrell, *Crimes Against Persons with Disabilities: 2009-2015 Statistical Tables*, *supra* note 12.

²³ *Id.* at 1.

²⁴ Autistic Self Advocacy Network, *Disability Day of Mourning: Remembering people with disabilities murdered by their families*, <http://disability-memorial.org/> (last visited Mar. 20, 2017).

Police Violence Towards Persons with Disabilities

Key Points

- Most official data on law enforcement use of force is not very reliable. We used data from news media sources and researchers. Most of the data we found relates to fatal police officer shootings of people with disabilities.
- The police often use excessive force against people with disabilities. People with disabilities are also more likely to be killed by the police. This pattern is especially pronounced for people with mental health disabilities and people of color with disabilities.
- When a person with a disability has a fatal or violent encounter with the police, media outlets initially place the blame on the person's disability rather than on the officer(s) who hurt that person.
- Police violence is be fueled by the militarization of police forces and local governments' over-reliance on police to the detriment of other services. This over-reliance is reflected in disproportionately high budgets when compared to other city expenses.
- Advocates across the country are lending their support to nationwide police accountability campaigns, such as the Black Lives Matter movement, the Campaign Zero movement, the work of the Center for Popular Democracy, and local police accountability campaigns. These campaigns organize their grassroots for protests, provide information on the lack of police accountability and pursue policies that reduce the risk of police violence. These campaigns may also include participatory budgeting campaigns, through which members of a community gain control of a portion of their community's budget and decide how it is spent.
- Children with disabilities, particularly children of color, are referred to law enforcement or arrested at school at disproportionate rates. This phenomenon is referred to as the **school-to-prison pipeline** and is a threat to the academic and social well-being of children with disabilities.

Many autistic self-advocates and parent advocates are concerned about interactions between people with disabilities and the police. Here are some of the things the self-advocates and parent advocates said in our safety surveys.

An autistic self-advocate experienced “assault and battery, refusal to arrange for an interpreter or cuff me in the front, confiscation of a medical device, theft, additional violent threats to taser me after I was already in handcuffs, and a follow-up harassment over the phone.”

One parent advocate worries about potential interactions between the police and his son: “....him being non-compliant will make them think he is resisting and they may kill or hurt him. He may become combative because of sensory overload or fear and they will hurt him”

“I’d be pretty afraid with the police even if my child wasn’t disabled. Training hasn’t been proven to help because the cops had training in Miami when the caregiver was shot with [Arnaldo Rios-Soto]. Or when they taze and kill mentally ill people. Or restrain the disabled to the point they die.”

They have good reasons to be concerned. There is a pattern of excessive police violence towards people with disabilities, especially people of color with disabilities.

There are very few studies on police violence against specific groups of people, such as people with disabilities. Most information we have comes from specific cases or from incidents reported in national or local news. State and local police departments do not report every incident in which they used force against a disabled person.²⁵

Where we do have reliable data, it is more likely to report on victims with mental health disabilities than on victims with cognitive and developmental disabilities. It is likely, however, that a number of the people included in this data are autistic. Many autistic people have mental health disabilities, including ADHD, anxiety disorders, depression, and others.²⁶

About National Databases: National statistics on the number of violent encounters people with disabilities have with law enforcement are still limited and they are not one hundred percent reliable. Most national databases report only fatal encounters, which means the total number of violent encounters is likely to be much higher.

Two of the databases known to keep track of the number of law enforcement related deaths—the Federal Bureau of Investigation (FBI)’s Uniform Crime Report²⁷ and the Centers for Disease Control’s Fatal Injury Reports, a component of the National Vital Statistics System (NVSS)²⁸—are widely known²⁹ to have flaws in their reporting.³⁰

The Bureau of Justice Statistics’ own Arrest-Related Deaths (ARD) database, which collected data on people who died while being arrested, or while in the custody of state or local law enforcement, was suspended in 2014 because the data produced “did not meet BJS data quality standards.”³¹ No national database has a comprehensive list of all fatal shootings by law enforcement in the United States.³² Some federal agencies are trying to create one. The Federal Bureau of Investigation (FBI) announced in 2016 that it would start collecting nationwide data in 2017 on violent encounters between civilians and the police. Former FBI director James Comey called it “embarrassing” that the news media could produce better data on these shootings than the federal government.³³

Studies by Journalists

Sarah, autistic self-advocate: “I censor myself sometimes. I avoid. I dislike police, especially these days.”

Journalists have done studies that keep track of persons who have been killed by law enforcement.

25 See David M. Perry, Lawrence Carter-Long, *The Ruderman White Paper on Media Coverage of Law Enforcement Use of Force and Disability: A Media Study (2013-15) and Overview*, Ruderman Foundation 5, 7 (2016) [hereinafter “Ruderman Foundation”].

26 Ovsanna T. Leyfer *supra* note 2 at 855; Mohammad Ghaziuddin et. al., *Depression in Persons with Autism: Implications for Research and Clinical Care*, 32 J. Autism Dev. Disord. 299, 299-300 (2002) (autistic people and our high risk of depression).

27 Fed. Bureau of Investigation, *Uniform Crime Reporting*, <https://ucr.fbi.gov/> (last visited Mar. 26, 2017).

28 Centers for Disease Control and Prevention, *Injury Prevention & Control: Data & Statistics (WISQARS)* <https://www.cdc.gov/injury/wisqars/> (last updated Aug. 1, 2017) (searchable CDC database that contains Fatal Injury Reports and other components of the NVSS).

29 Tom McCarthy, *The uncounted: Why the U.S. can't keep track of people killed by police*, The Guardian, (Mar. 18, 2015, 10:19AM), <https://www.theguardian.com/us-news/2015/mar/18/police-killings-government-data-count>; Mark Tran, *FBI chief: 'unacceptable' that Guardian has better data on police violence*, The Guardian (Oct. 8, 2015, 9:49AM), <https://www.theguardian.com/us-news/2015/oct/08/fbi-chief-says-ridiculous-guardian-washington-post-better-information-police-shootings>.

30 *Id.*

31 U.S. Dep’t of Justice, Bureau of Justice Statistics, *Arrest-Related Deaths*, <https://www.bjs.gov/index.cfm?ty=tp&tid=82> (last updated Aug. 23, 2017).

32 Issie Lapowsky, *The US Needs Real Data to Confront Bias in Police Shootings*, Wired (Feb. 8, 2017, 12:02 AM), <https://www.wired.com/2017/02/us-needs-real-data-confront-bias-police-shootings/>; Erin Schumaker, *To Stop Police Shootings, We Need to Move Beyond 'Bad Cops'*, Huffington Post (May 18, 2017, 4:38PM), http://www.huffingtonpost.com/entry/police-shootings-state-laws_us_591c9a-c6e4b034684b08f390.

33 Eric Lightblau, *Justice Department to Track Use of Force by Police Across U.S.*, N.Y. Times (Oct. 13, 2016), <https://www.nytimes.com/2016/10/14/us/justice-department-track-police-shooting-use-force.html>.

The Guardian

The Guardian's study "The Counted" includes a database of all people who were killed by law enforcement in the United States that *The Guardian* was able to confirm.³⁴ *The Guardian* collects its information from:

- Police reports,
- Verified witness statements,
- Regional news outlets,
- Research groups, and
- Open-source reporting outlets.³⁵

All of the information is verified by *The Guardian's* journalists.³⁶ It also accepts tips and e-mails from readers of *The Counted*.³⁷

On December 31, 2015, *The Guardian* found that 246 people, or 1 in 5 people killed by law enforcement in 2015, either had a known mental health disability or the person's mental health was somehow involved in the attack.³⁸ On January 8, 2017, the *Guardian* found that 1 in 5 people killed by law enforcement in 2016 either had a mental health disability or were having a mental health crisis when they were killed.³⁹ *The Guardian* found in both articles that young men of color were the most likely demographic to be killed by law enforcement, regardless of disability.⁴⁰

Fatal Force

The Washington Post's Fatal Force project, similar to *The Guardian's* *The Counted*, keeps track of every law enforcement shooting that occurs in a particular year.⁴¹ *The Post* collects data from:

- Local news reports,
- Independent, non-governmental databases such as Killed by Police⁴² and Fatal Encounters,⁴³
- Records requests from police departments,
- Investigative reporting.⁴⁴

As of October 9th, 2017, the *Washington Post* found that 768 people have been killed by law enforcement and one out of every four deaths involved a mental health disability.⁴⁵ *The Washington Post* does not keep track of

³⁴ John Swaine et. al., *The Counted: People killed by police in the U.S., recorded by the Guardian- With your help*, *The Guardian* <https://www.theguardian.com/us-news/series/counted-us-police-killings> (last visited March 20, 2017).

³⁵ John Swaine et. al., *The Counted: About the project*, *The Guardian* <https://www.theguardian.com/us-news/ng-interactive/2015/jun/01/about-the-counted> (last visited Oct. 23, 2017).

³⁶ *Id.*

³⁷ *Id.*

³⁸ John Swaine et. al., *Young black men killed by U.S. police at highest rate in year of 1,134 deaths*, *The Guardian* (December 31, 2015, 3:00PM) <https://www.theguardian.com/us-news/2015/dec/31/the-counted-police-killings-2015-young-black-men> [hereinafter "The Guardian 2015"].

³⁹ John Swaine and Ciara McCarthy, *Young black men again faced highest rate of U.S. police killings in 2016*, *The Guardian* (Jan. 8, 2017, 7:00AM) <https://www.theguardian.com/us-news/2017/jan/08/the-counted-police-killings-2016-young-black-men> [hereinafter "The Guardian 2017"].

⁴⁰ *The Guardian* 2015, *The Guardian* 2017.

⁴¹ Julie Tate et. al., *Fatal Force*, *The Washington Post*, https://www.washingtonpost.com/graphics/national/police-shootings-2016/?tid=a_inl (last visited March 20, 2017).

⁴² Killed by Police, *Killed by Police* 2017 <http://killedbypolice.net/> (last visited March 20, 2017).

⁴³ D. Brian Burghart, *Fatal Encounters* <http://www.fatalencounters.org/> (last visited March 20, 2017).

⁴⁴ Julie Tate et. al., *How the Washington Post is examining police shootings in the United States*, *Washington Post* (July 7, 2016) https://www.washingtonpost.com/graphics/national/police-shootings-2016/?tid=a_inl.

⁴⁵ Julie Tate et. al., *Fatal Force*, <https://www.washingtonpost.com/graphics/national/police-shootings-2017/> (last accessed Oct. 3, 2017) (2017 killings). The number of people listed on the *Fatal Force* page grows with each passing day, and will no longer be accurate upon the publication of this toolkit.

the number of deaths that involve other forms of disability. It is likely that some of the dead had developmental disabilities.

The Ruderman Foundation

The Ruderman Foundation's March 2016 White Paper, *On Media Coverage of Law Enforcement Use of Force and Disability*, hypothesizes that a third to half of all police violence incidents recorded between 2013-15 involve some form of disability.⁴⁶ Most of the incidents Ruderman cites either do not mention the victim's disability or minimize the victim's disability.⁴⁷ For example, according to Ruderman, Eric Garner, a New York man who was killed in 2014 by a police officer who put him in a chokehold, had severe sleep apnea, diabetes, and asthma. These disabilities may have contributed to his death.⁴⁸ Nonetheless, in media coverage of his shooting, Eric Garner's disabilities were minimized.

When the victim has a developmental disability, news outlets sometimes imply that the victim's disability was to blame for the attack.⁴⁹ Ethan Saylor, for example, was a young man with Down Syndrome who was killed by police officers in Maryland after he had attempted to go back into a movie theater without buying another ticket.⁵⁰ Early media coverage of Ethan Saylor's case implied that his disability was to blame for the incident and that it was a "tragic accident." In a separate incident, Reginald "Neli" Latson, an autistic man in Virginia, was tasered and arrested after a police officer confronted him while he was sitting outside a library.⁵¹ A *Washington Post* 2011 article described this as a manifestation of the supposed "dark side" of autism. This stigmatizes autistic people and blames us for the violence that we experience.⁵²

Single-Region Studies

There have been a few single-region studies of specific police departments. An analysis of officer-involved shootings by the San Diego District Attorney's Office found that a staggering 81 percent of all people involved in a police shooting in San Diego had a substance use disorder or mental health disability.⁵³ The Department of Justice in 2014 found that the police department of Albuquerque, New Mexico, engaged in unreasonable and excessive use of force and that many of the excessive use of force incidents involved people who were having a mental health crisis.⁵⁴ The incidents in Albuquerque also tended to involve the excessive use of tasers, and the use of force against people who were unable to respond at the time of the incident.⁵⁵

Nationwide Police Accountability Campaigns

Advocates have created organizations, coalitions, and campaigns dedicated to reducing excessive police violence towards communities of color, including autistic people of color and other people of color with

⁴⁶ See Ruderman Foundation at 5-8. This is the Ruderman Foundation's estimate based on data from their studies of media coverage of shootings by law enforcement. Since the source of this estimate is unknown and not mentioned at any point in the paper, it may be inaccurate.

⁴⁷ *Id.* at 6.

⁴⁸ *Id.* at 15, 16.

⁴⁹ *Id.* at 13.

⁵⁰ David M. Perry, *Justice for Down Syndrome man who died in movie theater*, CNN (Aug. 29, 2013 12:24PM), <http://www.cnn.com/2013/08/29/opinion/perry-down-syndrome-death/>.

⁵¹ Theresa Vargas, *Stafford County woman confronts issues of race, autism after son's arrest*, The Washington Post (Jul. 11, 2010), http://www.washingtonpost.com/wp-dyn/content/article/2010/07/10/AR2010071002633_2.html?tid=a_inl; Ruth Marcus, *Virginia's governor should keep an autistic man out of prison*, The Washington Post (Jan. 8, 2015): https://www.washingtonpost.com/blogs/post-par-tisan/wp/2015/01/08/virginias-governor-should-keep-an-autistic-man-out-of-prison/?utm_term=.29058fba03c8.

⁵² The Ruderman Foundation at 14; Theresa Vargas, *In Va. Assault Case, anxious parents recognize 'dark side of autism'*, Washington Post (Mar. 13, 2011, 12:30AM), <http://www.washingtonpost.com/wp-dyn/content/article/2011/03/12/AR2011031205327.html>.

⁵³ San Diego District Attorney's Office, *Officer-Involved Shooting Review: Analysis of Cases Reviewed by the San Diego County District Attorney's Office 1993-2012* (December 2014), http://www.sdca.org/office/ois_review_rpt.pdf.

⁵⁴ U.S. Dep't of Justice Civil Rights Division, *Re: Albuquerque Police Dep't at 9, 12, 20-22* (April 10, 2014), https://www.justice.gov/sites/default/files/crt/legacy/2014/04/10/apd_findings_4-10-14.pdf (Findings Letter).

⁵⁵ *Id.* at 19-22 (describing incidents involving the beating of a 25 year old man with a significant developmental disability, grabbing and choking an unarmed man with schizophrenia, and otherwise assaulting individuals who were unable to perfectly comply with the police's orders).

disabilities. Some of these are local organizations that work to end excessive police violence in particular cities or municipalities. Some of these are national organizations. Funders for Justice created a list of these organizations, both national and local, on its [website](#).⁵⁶

This section describes a few of these organizations and their priorities. We also describe toolkits and other important resources produced by some of these organizations. This far from a comprehensive list of all organizations or a complete description of the important work that they do. Information on how to become more involved in these movements is available in the Self-Advocate and Family Members sections of our toolkit.

Black Lives Matter Movement

The Black Lives Matter Global Network is an organization that works to end violence and systemic racism against Black people worldwide.⁵⁷ Black Lives Matter is also the name of a larger international movement. The Black Lives Matter Global Network has chapters throughout the continental United States and Canada. Chapters organize protests and advocate for policies that reduce systemic violence against Black people, including the reduction of police violence.⁵⁸ For information on how to get involved with a Black Lives Matter Network chapter, see the Self-Advocates Guide and Family Members Guide of this toolkit.

Campaign Zero

Campaign Zero was founded in 2015 by members of the organization We The Protesters.⁵⁹ Campaign Zero's goals, as stated on its website, are to "implement the right policy changes to end police killings and other forms of police violence in the United States."⁶⁰ Campaign Zero proposes to do this by advocating for a comprehensive package of policies that would:

- End "broken windows policing," or the decades-long policy of prosecuting people for minor offenses such as sleeping in parks, disturbing the peace, loitering, or marijuana possession. These policies lead to the over-criminalization of people of color and people with mental health disabilities.
- Establish significant procedural protections that prevent the police from profiling and using "stop and frisk" searches on people of color, people with disabilities, immigrants, and religious minorities simply because they "look suspicious."
- Create Mental Health Response Teams and other crisis responders to serve people who are in the midst of a mental health crisis. These serve as alternatives to police officers, who are not trained mental health responders and often respond in ways that are dangerous.
- Establish civilian oversight of police conduct, including independent investigative offices that can receive complaints of police violence or excessive force. These offices would have the power to investigate incidents and make disciplinary recommendations to the city's Police Chief.
- Rewrite the laws governing the police use of deadly force, in order to restrict use of deadly force only in the most extreme and threatening situations.
- Create and facilitate the use of independent prosecutors when police officers use unlawful force, such as through the Department of Justice's civil rights investigations or by the creation of an independent prosecutor's office at the state level.
- Increase the number of police officers of color and police officers with disabilities.

⁵⁶ Funders for Justice, *Organizations Addressing Police Accountability and Racial Justice*, <http://fundersforjustice.org/organizations/> (last visited Oct. 19, 2016).

⁵⁷ Black Lives Matter, *What We Believe*, <https://blacklivesmatter.com/about/what-we-believe/> (last visited Oct. 18, 2017).

⁵⁸ Black Lives Matter, *Find a Chapter*, <https://blacklivesmatter.com/take-action/find-a-chapter/> (last visited Oct. 18, 2017).

⁵⁹ We The Protesters, <http://www.wetheprotesters.org/> (last visited Oct. 18, 2017); Nadia Prupis, *Campaign Zero: A 'Blueprint for Ending Police Violence,' Common Dreams* (Aug. 21, 2015) <https://www.commondreams.org/news/2015/08/21/campaign-zero-blueprint-ending-police-violence>.

⁶⁰ Campaign Zero, *The Problem*, <https://www.joincampaignzero.org/problem/> (last visited Oct. 18, 2017).

- Require that police use body cameras and ban police officers from preventing a person from recording police interactions.
- Invest in effective police officer trainings on how to de-escalate dangerous situations, combat implicit bias, and approach a person having a mental health crisis.
- Prohibit the police from confiscating the property of people they arrest and limit practices in which police require low-income people to pay expensive fines for minor traffic and conduct offenses;
- Demilitarize the police; and finally
- Remove barriers to federal, state, and local civilian oversight of police behavior placed by police, including unfair police officers' union deals.⁶¹

Many of Campaign Zero's policy proposals are best-practice policies of existing police departments and organizations.⁶² Campaign Zero also releases reports which explain several of the causes of police violence and their potential solutions to a wider audience.⁶³

National Police Accountability Project

The National Police Accountability Project is a nonprofit organization that includes lawyers, nonprofit attorneys, paralegals, and other advocates who combat excessive police use of force.⁶⁴ The lawyers involved work on police misconduct case, including cases that involve jail and prison guards.⁶⁵ They also provide information to the public about police misconduct, provide support for attorneys working on police misconduct cases, and support broader legislative reform efforts that reduce the risk of police violence.⁶⁶ For more information on how to get involved with the project, check the Self-Advocates and Family Members sections of our toolkit.

Center for Popular Democracy's Justice and Policing Toolkit

The Center for Popular Democracy is an organization dedicated to creating partnerships between advocacy organizations that advance a "pro-worker, pro-immigrant, racial and economic justice agenda."⁶⁷ The Center for Popular Democracy released a toolkit in June 2015 titled: *Building a Movement from the Ground Up: A Toolkit for Promoting Justice in Policing*.⁶⁸ The toolkit describes fifteen policy reforms that are critical for promoting police accountability in America, which it divides into six categories of reform: ending mass criminalization, safe and just police interactions, community control, independent oversight, and improving police department practices.⁶⁹ Many of the policy recommendations in the toolkit are similar to those mentioned by Campaign Zero. These include **civilian oversight commissions or boards, independent prosecutors, and bans on racial, ethnic, or immigrant status profiling.**

Civilian oversight commissions or boards are agencies made up of citizens of a particular city or municipality that are given a voice or the ability to recommend a course of action when a police officer is accused of police misconduct towards a citizen of that city or municipality.⁷⁰ An example of a well-developed civilian oversight

61 Campaign Zero, *Solutions*, <https://www.joincampaignzero.org/solutions/#contracts> (last visited Oct. 18, 2017).

62 Ben Mathis-Lilley, *As of Today, Black Lives Matter Activists Can Point to a Thorough Police Brutality Reform Plan*, Slate (August 21, 2015, 12:17 PM) http://www.slate.com/blogs/the_slatest/2015/08/21/black_lives_matter_coalition_police_brutality_policy_proposals_campaign.html.

63 Campaign Zero, *Reports*, <https://www.joincampaignzero.org/reports/> (last visited Oct. 18, 2017).

64 Nat'l Police Accountability Project, *About Us*, <https://www.nlg-npap.org/about> (last visited Oct. 19, 2017).

65 *Id.*

66 *Id.*

67 Center for Popular Democracy, *About Us*, <http://populardemocracy.org/about-us> (last visited Oct. 19, 2017).

68 Center for Popular Democracy, *Building a Movement from the Ground Up: A Toolkit for Promoting Justice in Policing* 2, 3 (June 2015) <http://populardemocracy.org/news/building-momentum-ground-toolkit-promoting-justice-policing> [Hereinafter "Center for Popular Democracy"].

69 Center for Popular Democracy at 3.

70 Center for Popular Democracy at 25.

board is the Citizen Police Commission in San Francisco.⁷¹ According to the toolkit, the Commission has broad disciplinary powers.⁷² San Francisco also uses the Department of Police Accountability (formerly the Office of Citizen Complaints) to review allegations of police misconduct, rather than an internal division within the city's police department.⁷³

Independent prosecutors are offices at the state level, independent of the normal state prosecutor's office and the police, that would specifically prosecute cases where a police officer has been accused of a crime.⁷⁴ The broader police accountability advocacy community determined that independent prosecutors were necessary because most state prosecutors receive much of their evidence and testimony for their cases from police officers, with whom they may have strong relationships.⁷⁵ Without an independent prosecutor, the state prosecutor may be biased in favor of the police officer. Although few such offices exist, the Center for Popular Democracy recommends their creation and describes a powerful agency with the ability to prosecute police officers in criminal court.⁷⁶

Bans on profiling would be revisions to existing state laws, regulations, and police training that prohibit police officers from stopping, arresting, or otherwise profiling civilians based on their race, ethnicity, apparent or actual religion, and immigrant status.⁷⁷ We also suggest similar bans on any profiling based on the person's actual or perceived disability, absent other signs that a person may be an immediate threat to themselves or others. The Center for Popular Democracy uses the work of Communities United for Police Reform as an example, which lobbied successfully for the passage of legislation in New York City which bans police profiling based on race, ethnicity, age, housing status, disability, sexual orientation, and several other salient immutable personal characteristics.⁷⁸

Law for Black Lives

Law for Black Lives,⁷⁹ the Center for Popular Democracy, and the Black Youth Project 100 jointly released a report titled: *Freedom to Thrive: Reimagining Safety and Security in Our Communities*.⁸⁰ The report shows that over the last 30 years, the United States has increased funding for police and incarceration and cut social programs. Those budgetary changes have devastated Black and Latinx communities.⁸¹ Some of the significant statistics present in the report are:

- 40% of the budget of Oakland, California, goes to policing, while human services programs (such as Head Start, violence prevention programs, and income support programs) receive just 30 cents for every dollar spent on policing - or about 12% of the budget⁸²
- Atlanta, GA continues to invest 30% of its general fund into policing at the same time that acts of police violence continue to increase in the city and people of color continue to be jailed for low-level offenses⁸³

71 Center for Popular Democracy at 26.

72 *Id.*

73 Center for Popular Democracy at 26; City and County of San Francisco, *Department of Police Accountability*, <http://sfgov.org/occ/> (last visited Oct. 19, 2017).

74 Center for Popular Democracy at 35.

75 Center for Popular Democracy at 35, 36.

76 Center for Popular Democracy at 36.

77 Center for Popular Democracy at 19.

78 Center for Popular Democracy at 20.

79 Law for Black Lives, *Values*, <http://www.law4blacklives.org/#values-section> (last visited July 21, 2017).

80 Kate Hamaji et. al., *Freedom to Thrive: Reimagining Safety and Security in Our Communities* 1, 3 (Jul. 5, 2017), <https://static1.squarespace.com/static/5500a55ae4b05a69b3350e23/t/595cf69b1b631b031e0542a5/1499264677929/Freedom+to+Thrive+Web.pdf> [hereinafter "Freedom to Thrive"].

81 *Id.* at 4.

82 *Id.* at 3.

83 *Id.* at 9, 10, 11.

- 44% of all Baltimore’s police stops occur in predominantly Black districts containing only 11% of the city’s population. The police stops, according to the report, have not led to any significant improvements in the city’s homicide or drug overdose rates. Instead, the city’s homicide and drug overdose rates have increased.⁸⁴
- 30% of Detroit’s general fund went to policing, while only 1.1% went to affordable housing and the Department of Health and Wellness received only 0.5%.⁸⁵

The report also describes some of the advocacy movements in major U.S. cities that have dedicated themselves to the reduction of police violence and the improvement of communities of color, and their priorities.⁸⁶

The report also promotes **participatory budgeting**.⁸⁷ In participatory budgeting, a community gets control of a particular portion of their city, town, or district’s budget and decides how to spend it. Participatory budgeting usually consists of four steps: (1) the community brainstorms ideas for projects--- things they want their local government to fund; (2) community volunteers develop the ideas into viable policy proposals; (3) the community votes on the best ideas; (4) the local government accepts and funds the winning projects using a specific portion of the municipality’s budget.⁸⁸

Most participatory projects occur only at the city district or ward level.⁸⁹ Despite this, past projects have had extremely promising results. The involvement of people with disabilities in participatory budgeting projects (especially in areas that already use participatory budgeting) could lead to initiatives that reduce the autistic community’s likelihood of being hurt by the police.

Policing in Schools, the School-to-Prison Pipeline, and Children with Disabilities

The **school-to-prison pipeline** is a phenomenon in which young people of color, particularly young people of color with disabilities, are disciplined harshly by school staff and disciplined and referred into the criminal justice system at disproportionately high rates.⁹⁰ For example, Black students are three times more likely to be suspended than white students, and students with disabilities are more likely to be suspended than students without disabilities.⁹¹ Black students make up 16% of the U.S. student body, but make up 27% of the students referred to law enforcement and 31% of the students who were arrested in school.⁹²

Some of the following factors may contribute to the school-to-prison pipeline: (a) the “zero tolerance policies” used by school districts; (b) the criminalization of minor school rules violations previously handled by the school discipline system; (c) the unmet behavioral and mental health needs of many students with disabilities in schools; (d) the lack of consideration of those needs by school personnel and School Resource Officers (SROs) (police officers stationed at schools); and (e) SROs’ discretion to arrest, interrogate, and search students under less stringent standards than those that apply to ordinary citizens.⁹³

⁸⁴ *Id.* at 14.

⁸⁵ *Id.* at 34.

⁸⁶ *Id.* at 8-74 (at least one movement is described in each section of the report).

⁸⁷ *Id.* at 79.

⁸⁸ Participatory Budgeting Project, *How PB Works*, <https://www.participatorybudgeting.org/how-pb-works/> (last visited July 25, 2017).

⁸⁹ Freedom to Thrive at 79-81.

⁹⁰ Amanda Merkwae, *Schooling the Police: Race, Disability, and the Conduct of School Resources Officers*, 21 Mich. J. Race & L. 147, 151 (2015) (describing the school-to-prison pipeline); Nat’l Council on Disability, *Breaking the School-to-Prison Pipeline for Students with Disabilities* 5 (June 18, 2015) (stating that the school-to-prison pipeline refers to “policies and procedures that push children from school into the criminal justice system”).

⁹¹ U.S. Dep’t of Educ. Office of Civil Rights, Issue Brief No. 1, *Civil Rights Data Collection Data Snapshot: School Discipline* 1 (Mar. 21, 2014), <https://www2.ed.gov/about/offices/list/ocr/docs/crdc-discipline-snapshot.pdf>.

⁹² *Id.*

⁹³ See Merkwae at 151, 153-57 (mentioning each of the factors listed in the paper’s analysis of different aspects of the school-to-prison pipeline); Nat’l Council on Disability, *Breaking the School to Prison Pipeline* at 47-51 (finding that implicit biases on the part of educators can cause them to disregard the student’s eligibility for disability services, which may relate to factor (c) above).

Students with disabilities are more likely to be victims of the school to prison pipeline. Amanda Merkwae (2015) determined from Department of Education data that African-American students with disabilities were disproportionately likely to be arrested, relative to the number of such students in the student body.⁹⁴

Autistic people, particularly autistic people of color, have specifically been impacted by the school-to-prison pipeline. Merkwae begins her analysis of the phenomenon by introducing us to a ten year old Black autistic child who was arrested for “acting up in class” and climbing up a tree.⁹⁵ Another case involved Kayleb Moon-Robinson, an eleven-year-old autistic boy who was charged with a felony for struggling against a school resource officer at least twice his size, as seen in the Specific Cases section.⁹⁶

We recommend that people with disabilities and their families combat the school-to-prison pipeline by joining together with advocacy organizations focused on police and school reform. For more information on some ways for you to do this, please refer to our Self Advocate and Family Members sections.

Specific Cases

As the following case examples illustrate, when the police use excessive force on a person with a disability, there is often an intersection between race, class, and disability. In fact, in many of these examples the police used excessive force in response to behavior caused by disability.

Teresa Sheehan⁹⁷

The Case: In 2008, 57-year old Teresa Sheehan was shot multiple times by police officers.⁹⁸ Sheehan had been experiencing a mental health crisis. Her case workers had called 911, asking for an emergency mental health examination. The police arrived, and Ms. Sheehan retreated into her apartment and refused to let them in. Instead of waiting for the trained mental health crisis team to arrive, the police tried to force their way into her apartment. The situation escalated and police shot Sheehan.⁹⁹ Ms. Sheehan survived the attack, but was gravely injured and needed multiple hip replacements.¹⁰⁰

Sheehan sued the city for damages, arguing that the city police department’s failure to take her disability into account was a violation of Title II of the Americans with Disabilities Act (ADA), and that the entry into her home violated the Fourth Amendment.¹⁰¹ The case was appealed all the way to the United States Supreme Court, who heard it in 2015.¹⁰² The Supreme Court did not rule on the ADA question due to procedural defects, but it did rule that the unwanted intrusion into Ms. Sheehan’s home did not violate the Fourth Amendment.¹⁰³

What This Case Shows: A woman with a significant disability was injured because of behavior substantially related to her disability, and yet the police did not take her disability into account.

94 Merkwae at 157.

95 Merkwae at 147.

96 Scott Eric Kaufman, *Autistic 11-year old arrested for leaving class early: “He slammed me down, and then handcuffed me”* Salon (April 13, 2015, 3:39 PM): http://www.salon.com/2015/04/13/mental_issues_are_no_excuse_virginia_middle_school_has_autistic_11_year_old_boy_arrested_for_leaving_class_early/.

97 This incident led directly to the Supreme Court case *City and County of San Francisco v. Sheehan*.

98 Nadja Popovich, *Police shooting of mentally ill woman reaches U.S. Supreme Court: Why did it happen at all?* The Guardian (Mar. 23, 2015, 7:50AM): <https://www.theguardian.com/us-news/2015/mar/23/police-shooting-mentally-ill-teresa-sheehan-supreme-court>.

99 *Id.*

100 *Id.*

101 *City and County of San Francisco California et. al. v. Sheehan*, No. 13-1412, 135 S.Ct.1765, 1767 (2015).

102 *Id.*

103 *Id.* at 1773-77.

Arnaldo Eliud Rios Soto and Charles Kinsey

The Case: Arnaldo Eliud Rios Soto, a 26-year old autistic man, left his group home in 2016. Charles Kinsey, his therapist, followed him.¹⁰⁴ Mr. Soto was playing with a toy truck on the ground. A neighbor called 911, believing that Mr. Soto had a gun and was suicidal. Numerous officers came to the scene. Even though Charles Kinsey repeatedly told officers that Mr. Soto was autistic and unarmed, one officer tried to shoot Mr. Soto but shot Mr. Kinsey instead.¹⁰⁵ The police officer claimed he mistook Mr. Soto's truck for a gun, despite Mr. Kinsey's raised hands and attempts to tell police that it was a truck.

What This Case Shows: If police do not understand the behavior of a person with a disability, they might mistake it for violence. Police are often sent to respond to 911 calls about possible mental health crises even though they not well suited to respond to such situations.

Reginald "Neli" Latson

The Case: Neli Latson was sitting outside in front of the library until it opened, which is not a crime.¹⁰⁶ Someone felt that a man of color in a hoodie looked "suspicious" and called the police, who questioned Neli.¹⁰⁷ When Neli tried to walk away from the police officers, they attempted to arrest him.¹⁰⁸ Neli retaliated out of fear and an officer was injured.¹⁰⁹ Neli was arrested for assault of an officer and was kept in solitary confinement for years until he was pardoned by the state governor.¹¹⁰ Neli was only able to receive a pardon if he agreed to be institutionalized, and as a result he remains confined in a facility known for discriminatory and abusive practices towards its residents.¹¹¹

What This Case Shows: Racism and ableism intersect during police violence to harm people of color with disabilities. Neli is a Black man and was wearing a hoodie when he was sitting in front of the library. It is likely that the person who made the call about Neli interpreted his behavior as "suspicious" in large part because of his race.¹¹²

Kayleb Moon Robinson

The Case: Kayleb, an autistic eleven-year-old African-American boy, left his classroom to go talk to friends in the hallway. A School Resource Officer (SRO) arrested him. Kayleb was charged with felony assault for trying to get away, even though he posed no threat to the SRO.¹¹³

104 Boris Sanchez and Kevin Conlon, *North Miami shooting: Man, wounded caretaker reunite*, CNN (July 28, 2016 7:24PM), <http://www.cnn.com/2016/07/28/health/north-miami-police-shooting-reunion/>.

105 *Id.*

106 Ruth Marcus, *Virginia's governor should keep an autistic man out of prison*, The Washington Post (Jan.8, 2015):https://www.washingtonpost.com/blogs/post-partisan/wp/2015/01/08/virginias-governor-should-keep-an-autistic-man-out-of-prison/?utm_term=.29058fba03c8.

107 Raven's Wing Poetry, *Racial Profiling and the Black Autistic: the Case of Neli Latson*, The Digital Hyperlexic (Dec. 11, 2014), <https://thedigitalhyperlexic.wordpress.com/2014/12/11/racial-profiling-and-the-black-autistic-the-case-of-neli-latson/>.

108 *Id.*

109 *Id.*

110 Am. Civil Liberties Union of Virginia, *ACLU of Virginia Applauds Governor's Pardon of Man with Autism* (Jan. 20, 2015), <https://acluva.org/16561/aclu-of-virginia-applauds-governors-pardon-of-man-with-autism/>.

111 Neli is currently confined in the same institution as Arnaldo Rios Soto. See Autistic Self Advocacy Network, *Statement on the Institutionalization of Arnaldo Rios Soto* (Aug. 26, 2016): <http://autisticadvocacy.org/2016/08/statement-institutionalization-of-arnaldo-rios-soto/>.

112 For more information on the advocacy community's response to Neli's case, see Raven's Wing Poetry, *Racial Profiling and the Black Autistic: the Case of Neli Latson*, Autism Women's Network (Dec. 15, 2014): <https://autismwomensnetwork.org/racial-profiling-and-the-black-autistic-the-case-of-neli-latson/>.

113 Morenike Giwa Onaiwu, *End the Prosecution Against Kayleb, an autistic 6th grader unfairly charged with a felony*, Change.org (last updated Mar. 14, 2016): https://www.change.org/p/justiceforkayleb-an-autistic-6th-grader-unfairly-convicted-of-a-felony?source_location=minibar; Scott Eric Kaufman, *Autistic 11-year old arrested for leaving class early: "He slammed me down, and then handcuffed me"* Salon (April 13, 2015, 3:39 PM): http://www.salon.com/2015/04/13/mental_issues_are_no_excuse_virginia_middle_school_has_autistic_11_year_old_boy_arrested_for_leaving_class_early/.

What This Case Shows: Children of color with disabilities are disproportionately arrested at school. These arrests are often for minor school disciplinary concerns that would not ordinarily be considered crimes in the case of other same-age peers.

ASAN Surveys

Self-Advocates

The Data:

- Around 60% of the self-advocates we interviewed were worried about interactions with the police.
- Around 60% of self-advocates had encountered the police.
- 30% of survey respondents said the police “responded very well.” Another 30% said the police “sometimes responded well and sometimes responded badly.” 20% said they responded “okay, but not particularly well,” and 10% said they responded “badly or very badly.”

The Suggestions:

Most self-advocates felt that much more needs to be done to improve relationships between law enforcement and the disability rights community.

“Police need to be reminded they are public servants. They need sensitivity training in general and on us in particular. They need to be demilitarized. Terms like ‘assault’ and ‘battery’ need to be very clearly redefined and re-defined.”

“1. All police officers must be disarmed. 2. New police hires must complete a training program similar to that of a lawyer in its subject matter, rigor, and length. 3. Police departments must have diversity quotas, including the hiring of disabled officers, with regular checks and heavy fines.”

Police should be “treated respectfully, as human beings doing their job,” but “trends of aggressive handling by an officer should be escalated and addressed immediately and followed up on frequently.”

“There must be more dialogue among the community, disabled people, and the police in promoting disability awareness/acceptance and correct ways to approach people with various disabilities.”

The police need to have “policies that include people who are nonverbal and may make rapid hand movements or have severe spasticity, especially when stressed or touched. Also they must realize that many disabilities mimic intoxication, and policies need to include these people especially at times like stops for drunk drivers.”

Parent Surveys

The Data:

- 50% to 60% of parents were at least somewhat concerned about their autistic children potentially interacting with law enforcement.
- Around 30% to 40% said their child had or probably had encountered the police
- Most said that the interaction went well (47.6%) or other (32.6%) but around 20-21% said it went badly.

The following are some examples of interactions with law enforcement that the parents in our surveys had:

“He has interacted with the DARE officer at his school. Another officer gave him a badge when he attended a meeting with me. None of the interactions thus far have been in times of pressure or confrontation.”

“He has been tackled and handcuffed because of non-compliance. He is unable to describe the interaction to me, so all I know is what the police tell me.”

His son interacted with the police at “a suicide threat assessment; this one particular deputy was very calm and wanted to help my son, although I don’t know if he understood autism, but he was calm and I felt like he truly wanted to help.”

The Suggestions:

“Training for interacting with all members of the public needs to happen in police academies. The academy seems to be preparing a militarized police force and teaching things in a more black and white way than everyday reality presents. Crisis Intervention Training (which is how I ended up training officers) is offered to some officers within a precinct every couple of years. It needs to be something all officers go through. Career officers (those with 5-25 years on the force) should not be learning from me about flapping and pacing and suddenly going mute or avoiding eye contact as normal signs that someone is autistic.”

“Police should always use de-escalation strategies first unless they are actively dodging bullets. Every instance where the police kill a civilian must be investigated thoroughly by the federal DOJ with the strong burden of proof on the police. There must be heavy consequences for excessive force. Also, police academies should all require proven mastery of diversity skills before graduation, including understanding various developmental disabilities and mental health issues, so police can recognize atypical behaviors and use appropriate techniques to ensure everyone’s safety. There should be mandatory anti-racism training as well, with implicit bias testing before anyone can become a police officer.”

There should be “coordinated police departments with the same systems for communication.” She also mentioned that in the metropolitan area where she lives, “each sheriff and police department have their own way of doing things and their own technology.”

Abuse and Neglect of People with Disabilities

As people with disabilities, we are likely to experience abuse and neglect at much higher rates than our peers without disabilities.¹¹⁴ Countless members of our community have provided us with stories of the trauma and abuse they suffered at the hands of those who were supposed to care for them. Even though this abuse is much more likely to be at the hands of a friend, support provider, or loved one than a stranger,¹¹⁵ abuse by caregivers and school personnel is often minimized by the media¹¹⁶ and prosecuted only to a limited extent.¹¹⁷ Abuse and neglect are major reasons so many people with disabilities are not safe.

Key Points

Abuse in the Home

- Children with disabilities are much more likely to suffer abuse and neglect in the home.
- People with developmental disabilities who have been abused may be more likely to display signs of stress, depression or discomfort. They may also attempt to leave the abusive setting, which could be misinterpreted as “wandering” or “elopement.”
- Abuse of children with disabilities is more likely to go unreported and unprosecuted, and even when it is prosecuted the perpetrators are more likely to get lenient sentences.

Abuse in Schools and Residential Treatment Centers (RTCs)

- Bullying is a form of abuse by same-age peers. Bullying of autistic children happens often and can make it very hard for autistic children to access an education.
- Abuse of children with disabilities is more common in settings that are segregated and isolated from the community, like Residential Treatment Centers and residential segregated schools.
- In public schools, corporal punishment is the most typical form of abuse, followed by restraint and seclusion. These two types of abuse are much more commonly used on students with disabilities than students without disabilities.

Abuse in the Home

Although disabled adults also experience abuse at home, much of the available data relates to abuse of children with disabilities. A study in 2000 found that children with disabilities are 3.4 times more likely than children without disabilities to suffer abuse and neglect.¹¹⁸ A 2007 study found that children with disabilities were more likely to experience sexual abuse than children without disabilities and were more likely to have difficulty reporting it.¹¹⁹

People with developmental disabilities who have been abused may be more likely to display signs of stress, depression or discomfort. A 2003 study in the United Kingdom found that people who had experienced sexual abuse were more likely to: (a) experience social withdrawal (b) be sluggish or inactive (c) self-injure (d) be

¹¹⁴ Patricia M. Sullivan & John F. Knutson, *Maltreatment and Disabilities: A Population-Based Epidemiological Study*, 24 *Child Abuse and Neglect* 1257, 1268-71 (2000) (finding that we are 3.5 times more likely to be abused and/or neglected).

¹¹⁵ Erika Harrell, *Crimes Against Persons with Disabilities: 2009-2015 Statistical Tables* at 6.

¹¹⁶ See David Perry, *The Ruderman White Paper on Media Coverage of the Murder of People with Disabilities by Their Caregivers*, Ruderman Foundation 3, 4 (March 2017), http://rudermanfoundation.org/white_papers/media-coverage-of-the-murder-of-people-with-disabilities-by-their-caregivers/ (murder of people with disabilities by their caregivers is often minimized); John Garcia, *Mother, Godmother who killed autistic teen released from prison*, ABC 7 News (Dec. 14, 2016): <http://abc7chicago.com/news/mother-godmother-who-killed-autistic-teen-released-from-prison/1656353/> (Alex Spourdalakis' killers punished only to a limited extent as compared to crime).

¹¹⁷ See John Garcia.

¹¹⁸ Patricia M. Sullivan, and John F. Knutson, *supra* note 117, at 1268-71.

¹¹⁹ Irit Hershkowitz et al., *Victimization of Children with Disabilities*, *supra* note 2.

prone to outbursts or sudden changes in mood.¹²⁰ Abuse survivors were also more likely to have co-occurring mental health disabilities, such as PTSD or an anxiety disorder.¹²¹

Abuse of people with disabilities is more likely to go under-prosecuted and under-reported than abuse of people without disabilities. Manders and Stoneman (2009) found that when child abuse was reported to Child Protective Services (CPS) children with disabilities were more likely to be seen as “the cause” of their own abuse by CPS’ case workers.¹²² Most CPS workers empathized with the child’s parents at least to some degree, particularly when the child had disabilities related to either their emotions or behavior.¹²³

Society’s lenient attitude towards caregiver abuse is reflected in the punishments given to those who murder people with disabilities. For example, Alex Spourdalakis, a 16-year old autistic boy, was stabbed to death by his own mother and grandmother.¹²⁴ Alex Spourdalakis’ mother received only three years in jail for the crime of stabbing her own autistic son to death.¹²⁵

Abuse and Neglect in Schools and Residential Treatment Centers (RTCs)

Abuse and neglect in schools tends to present in three forms: Bullying, abuse by teachers and support staff, and restraint and seclusion.

Bullying

We define bullying as the physical or verbal abuse and denigration of students by similar-age peers.¹²⁶ Bullying of autistic people is unfortunately very common.

- A 2012 study found that 46.3% of the autistic students studied were victims of bullying, which was substantially higher than the rate of bullying the study found for the general population of students of the same age without disabilities (10.6%).¹²⁷
- A 2001 study found, using a sample of 411 autistic children, that the autistic children were four times more likely to have been bullied than a nationally representative sample of non-autistic children.¹²⁸
- A 2009 study found that, in a study of 34 parents of autistic children, 65% reported that their child had been bullied.¹²⁹
- The Interactive Autism Network (IAN) also found, in a survey, that 63% of the children in a sample of 1,167 autistic children between the ages of 6-15 had been bullied at least once.¹³⁰

With regards to children with disabilities and bullying generally, PACER’s National Bullying Prevention Center summarizes important statistics drawn from studies about children with disabilities and bullying for

¹²⁰ See Heather Sequeira et. al., *Psychological disturbance associated with sexual abuse in people with learning disabilities: Case control study*, 183 Br. J. Psychiatry 451, 454 (2003).

¹²¹ *Id.* at 455.

¹²² Jeannette E. Manders, Zolinda Stoneman, *Children with disabilities in the child protective services system: an analog study of investigation and case management*, Child Abuse and Neglect, April 2009, at 229-37.

¹²³ *Id.*

¹²⁴ John Garcia, *Mother, Godmother who killed autistic teen released from prison*, ABC 7 News (Dec. 14, 2016), <http://abc7chicago.com/news/mother-godmother-who-killed-autistic-teen-released-from-prison/1656353/>.

¹²⁵ *Id.*

¹²⁶ We recognize that this definition is limited, and that there are many other forms of bullying that do not fit this description. Most available data on bullying, however, relates to bullying in schools. As a result, for the purposes of this guide, we limit our discussion to bullying during K-12 education or college.

¹²⁷ Paul R. Sterzing et al., *Bullying Involvement and Autism Spectrum Disorders: Prevalence and Correlates of Bullying Involvement Among Adolescents with an Autism Spectrum Disorder*, 166 Arch. Pediatr. Adolesc. Med. 1058, 1061 (2012).

¹²⁸ Liza Little, *Peer Victimization of Children with Asperger Spectrum Disorders*, 40 J. of Child and Adolescent Psychiatry 995, 995-96 (2001) (finding that a sample of 411 autistic children between the ages of 4 and 17 were four times more likely to have been bullied than non-autistic children in two nationally representative samples from the same time period).

¹²⁹ Susan Carter, *Bullying of students with Asperger Syndrome*, 32 Issues in Comprehensive Pediatric Nursing 145, 149-54 (2009).

¹³⁰ Connie Anderson, *IAN Research Report: Bullying and Children with ASD*, Interactive Autism Network https://www.iancommunity.org/cs/ian_research_reports/ian_research_report_bullying (last updated Oct. 7, 2014).

a wide audience.¹³¹ PACER reports: (1) that, while as of 2009 only 10 national studies had been done on the connection between bullying and developmental disability, all of those studies found that children with disabilities were two to three times more likely to be bullied than children without disabilities; and (2) that students with disabilities were more worried that they would be bullied than children without disabilities.¹³²

Cappadocia, Weiss, and Pepler (2011) found that bullied children had poorer mental health and showed more evidence of “hyperactivity,” and compulsive self-injurious behaviors.¹³³ The IAN study said bullying is “a social problem” that leads to greater physical health problems and “depression, anxiety, and suicide.”¹³⁴

ASAN Safety Surveys, on Bullying

ASAN Safety Surveys, Self-Advocates

The Data:

- 80% of the self-advocates reported that they had been bullied in school.
- 22.2% were bullied “all the time.”
- Many described extreme forms.

One self-advocate experienced: “Constant name calling, mocking, and fights at after school program and during school.”

One self-advocate said they were bullied during public school, “mostly just isolated and made fun of, also included death threats, some cyber bullying, occasional fights,” and said they were sexually abused by their best friend. This high rate of bullying was not limited to childhood. They described similar bullying in college, including transphobic violence.

Suggestions:

When asked to describe policy changes that would help prevent and address bullying, self-advocates focused on policies that empowered victims, including giving school-aged children more tools for self-advocacy.

“definitely a combination of better definitions of abuse, and more rights for minors, and making it harder for parents to strip disabled youth of their rights due to due disability. however this would also require a significant overhaul of the foster care system. allowing for youth to be in charge of medical decisions however is another important piece of policy.”

One self-advocate requested a stringent, zero-tolerance anti-bullying policy and mandatory diversity and/or awareness training for all school staff that included autism.

¹³¹ PACER, National Bullying Prevention Center, *Bullying statistics*, <http://www.pacer.org/bullying/resources/stats.asp> (last updated Dec. 8, 2016).

¹³² *Id.*

¹³³ Catherine Cappadocia et al., *Bullying Experiences Among Children and Youth with Autism Spectrum Disorders*, 42 *J. Autism and Dev. Disord.* 266, 271 (2011).

¹³⁴ Connie Anderson, *IAN Research Report: Bullying and Children with ASD*, *supra* note 133.

ASAN Safety Surveys, Parents

The Data:

- 40% of parents reported that their child was bullied in school and other school settings (such as day programs and residential treatment centers).
- 25% weren't sure one way or the other
- 28.6% said "not at all."
- A very small percentage reported their child was bullied "all the time."

"At least one boy tells him to kill himself. They hide his belongings. He believes they push him into lockers."

Suggestions:

Most parents who took our survey said that there needed to be much more attention paid to the problem.

"stronger accountability for bullying investigations."

"PE and recess are (and I think always have been) the easiest places for bullies to attack. I notice that the adults rarely look up at the kids. Much more attention and more eyes need to be on kids."

"All public schools should include emotional intelligence, good mental health hygiene, and pro-social relationship and community building skills as part of the core curriculum."

Abuse by Teachers and Support Staff

"The policies that need to change are too many to list. Mainly [my] School District needs to rewrite the policy on handling these kids. The "if you don't like it sue us" attitude is disgusting, unfair, and a disgrace to the school system."

Abuse by teachers and support staff is common. It might be more common in segregated settings due to the lack of oversight and visibility of the school.

An example of a segregated environment in which abuse is more common is **residential treatment facilities**, places where parents sometimes send youth with mental health and substance abuse disabilities.

These facilities are rife with abuse. The Government Accountability Office (GAO) in 2007, a federal agency, reported on the scope of the problem.¹³⁵ It looked at residential treatment facilities across the nation and found thousands of allegations of abuse and even death at these programs.¹³⁶ More than ten years later, the abuse in these programs is still rampant. An August 2016 news report by the Huffington Post describes abuses at a residential facility called Island View that are nearly identical to the abuses the GAO reported nearly a decade earlier.¹³⁷

Segregated settings exclusively for people with disabilities appear to abuse people at the same high rates as residential treatment facilities. *ProPublica* issued a damning report in 2016 showing the pattern of significant abuse and neglect of people with developmental disabilities at residential schools and group homes.¹³⁸ The

¹³⁵ U.S. Gov't Accountability Office, GAO-08-146T, *Residential Treatment Programs: Concerns Regarding Abuse and Death in Certain Programs for Troubled Youth* 2, 3 (2007).

¹³⁶ *Id.*

¹³⁷ Sebastian Murdock, *The Troubled Teen Industry Has Been a Disaster for Decades, and It's Still Not Fixed*, Huffington Post Test Kitchen (Aug. 23, 2016), <http://testkitchen.huffingtonpost.com/island-view/#>.

¹³⁸ Heather Vogell, *Unrestrained*, ProPublica (Dec. 10, 2015), <https://www.propublica.org/article/advoserv-profit-and-abuse-at->

most infamous of all segregated schools, the Judge Rotenberg Educational Center in Massachusetts, abuses and tortures people with disabilities trapped within its walls using devices designed to deliver painful electric shocks to the skin.¹³⁹

Public school teachers also abuse children with disabilities. The most common forms of abuse and neglect in schools are **restraint and seclusion** and **corporal punishment**.

The ACLU released “*Impairing Education: Corporal Punishment of Students with Disabilities in U.S. Public Schools*” in 2009.¹⁴⁰ It found that corporal punishment was more common for disabled students versus non-disabled students, and that it consisted of everything from being “paddled” to being “pinched, spanked, smacked, grabbed, bruised, and beaten” by teachers.¹⁴¹

- The Council of Parent Attorneys and Advocates (COPAA) found in its report that children with disabilities were frequently locked into tiny rooms, restrained, and subjected to painful punishments.¹⁴² One student was held down and forced to color the same piece of paper for 1-2 hours.¹⁴³

These practices are **dehumanizing, traumatizing, and ineffective**. They do not lead to better behavior and can in fact lead to the loss of skills the student had previously, particularly in autistic people.¹⁴⁴

Restraint and Seclusion

Restraint and seclusion are common abusive discipline tactics that are not recognized as abuse by many school districts. Restraint is when a child or other person is held down, either by mechanical means or with human hands (called physical restraint). Seclusion is when a group of people, usually staff members, isolate and trap another person in a locked room. These two forms of abuse are most often used on children and adults with disabilities. A March 2014 report by the Department of Education found that students with disabilities represented 12% of the student body, but 75% of those placed in physical or mechanical restraints in schools.¹⁴⁵

The Government Accountability Office (GAO), in its 2009 report, found that there was at the time no consistent federal oversight or law governing these practices and that hundreds of deaths could be connected to their use.¹⁴⁶ Nevertheless, seclusion and restraint continue to be used despite these findings and the existence of safe alternatives. A February 2014 report by the Congressional Health, Education, Labor, and Pensions (HELP) Committee recommended that their use be completely eliminated or only utilized when there is a risk of imminent harm. The Committee recommended using Positive Behavioral Interventions and Supports (PBIS), a data-driven and evidence-based alternative to restraint and seclusion used in 20 percent of U.S. schools, instead.¹⁴⁷

[homes-for-the-profoundly-disabled.](#)

¹³⁹ Quentin Davies, “*Prisoners of the Apparatus: The Judge Rotenberg Center*,” Autistic Self Advocacy Network (Aug. 9, 2014), <http://autisticadvocacy.org/2014/08/prisoners-of-the-apparatus-the-judge-rotenberg-center/>.

¹⁴⁰ Am. Civil Liberties Union Human Rights Watch, *Impairing Education: Corporal Punishment of Students with Disabilities in Public Schools* 1 (2009), <https://www.aclu.org/sites/default/files/pdfs/humanrights/impairingeducation.pdf>.

¹⁴¹ *Id.* at 15-21.

¹⁴² Council of Parent Attorneys and Advocates, *Unsafe in the Schoolhouse: Abuse of Children with Disabilities 5-9* (May 27, 2009), http://cymcdn.com/sites/www.copaa.org/resource/collection/662B1866-952D-41FA-B7F3-D3CF68639918/UnsafeCOPAA-May_27_2009.pdf.

¹⁴³ *Id.* at 5-6.

¹⁴⁴ *Id.* at 9-12.

¹⁴⁵ U.S. Dep’t of Education, Office of Civil Rights, Issue Brief No. 1, *Civil Rights Data Collection Data Snapshot: School Discipline* (2014): <https://www2.ed.gov/about/offices/list/ocr/docs/crdc-discipline-snapshot.pdf>.

¹⁴⁶ Gov’t Accountability Office, GAO-09-719T, *Seclusions and Restraints: Selected Cases of Death and Abuse at Public and Private Schools and Treatment Centers* 3 (2009).

¹⁴⁷ Staff of S. Health, Educ., Labor, and Pensions Committee, 113th Cong. *Rep. on Dangerous Use of Seclusion and Restraint in Schools Remains Widespread and Difficult to Remedy: A Review of Ten Cases* (Majority Committee Staff Report, issued Feb. 10, 2014) <https://www.help.senate.gov/imo/media/doc/Seclusion%20and%20Restraints%20Final%20Report.pdf>.

ASAN is aware of several alternatives to the use of restraint and seclusion that promote more positive outcomes, including those compiled by the Substance Abuse and Mental Health Services Administration (SAMHSA)¹⁴⁸ and commercially available training modules such as Ukeru System.¹⁴⁹ These alternatives enable educators to ensure classroom safety and de-escalate potentially dangerous situations without the use of physical restraint or seclusion.

ASAN Surveys- Abuse by Staff and Restraint and Seclusion

Self Advocates

The Data:

30% of the self-advocates we surveyed said that they had been abused or attacked, restrained or put into isolation by school staff. Most of the self-advocates either did not describe specific incidents or requested that we not quote them. The incidents they did describe were alarming. One student reported that she was isolated for any behavior deemed to be disruptive and taken there in humiliating positions in full view of other students.

Suggestions:

Self-advocates' recommendations on how to reduce abuse and neglect in schools focused on policy changes that would decrease police presence in schools, change school culture, and take bullying seriously:

“School must be declared police-free zones to ensure the safety of all students, with exceptions made only under the condition that the school has been evacuated.”

Parents

The Data:

70% of parents were worried about the safety of their children in schools, day programs, and residential centers. Around 30% of parents said that their children actually had experienced abuse in schools, day programs, and other settings.

“Teacher hit my son, shoved his fist in his mouth, physically restrained him, berated him in front of his peers, and antagonized behaviors that we working on with ABA therapists.”

“One teacher attacked him during a walk”

“In preschool, he was inappropriately restrained (taken to floor) because he was banging his head during a meltdown. The teacher was trying to keep him from hurting himself, but made situation worse. He has had paraprofessionals inappropriately grab his face or hands to force him to do things. He lost recess a couple of times for not following directions and then, subsequently, looking like he was “about to” violate a rule.”

“I worried most about the school system’s handling of my son’s behavior which caused escalation and led to prone physical restraints on many occasions, often without legally required communication and documentation”

¹⁴⁸ Substance Abuse and Mental Health Services Admin., *Alternatives to Seclusion and Restraint* <https://www.samhsa.gov/trauma-violence/seclusion> (last visited Mar. 20, 2017).

¹⁴⁹ Ukeru Systems, <http://www.ukerusystems.com/> (last visited Mar. 23, 2017).

Suggestions:

Parents' recommendations included improvements in training and accommodations to help prevent behaviors that may lead to seclusion or restraint:

“Constant training, effective oversight, and constant vigilance. Also clear communication and immediate response to any issues. There is new guidance that has been issued about use of restraints, etc.”

“We built in breaks into his schedule and a way for him to request a break. More OT. More sensory things...”

“Explain the dangers and consequences. Alert the school staff about improving safety.”

“Our state has policies in place for school systems but there is poor education and oversight so parents are not aware they exist and the state [doesn't] monitor school districts' compliance. Better support of properly educated consultants with adequate experience working with individuals with autism and severe language deficits.”

Autism and Suicide

Members of the autistic community may be at dramatically heightened risk for suicide.

Key Points

- Autistic people die of suicide at much higher rates than non-autistic people.
- Although there is limited research on suicide prevention for autistic people in particular, people who have friends and the support they need to manage any co-occurring mental health disabilities are far less likely to die from suicide.
- Self-advocates and our allies should focus our efforts on helping autistic people get the supports and services we need to reduce our likelihood of dying from suicide.

Although the connection between autism and suicide risk is not widely known, an international body of research shows that autistic people die from suicide at higher rates than non-autistic people. A Swedish study found that the mortality rate for the autistic population was nearly double that of the non-autistic population.¹⁵⁰ One of the reasons for the disparity was that autistic people died of suicide at much higher rates than non-autistic people.¹⁵¹ In the United States, one 2014 literature review described studies where researchers found suicidal ideation in 10.9.-50% of the samples of autistic people studied.¹⁵² In the same literature review, they describe a study in which 7-15 percent of people hospitalized for suicide attempts were autistic - far more than the rate of autism diagnoses in the general population.¹⁵³

Autistic people who are socially isolated and those with mental health disabilities are more likely to die of suicide.¹⁵⁴ The U.K. autism organization Autistica published a report titled, “*Personal tragedies, public crisis: The urgent need for a national response.*”¹⁵⁵ Autistica found that between 30 to 50 percent of autistic people have considered suicide,¹⁵⁶ that mental health disabilities are connected to this high suicide rate, and that 70% of autistic people have at least one mental health disability.¹⁵⁷

The report recommends autism-focused groups and research organizations collaborate to better understand mental health conditions as they appear in autistic people, in order to reduce the likelihood that mental health disabilities will contribute to our suicide risk. It also recommends that government agencies in the U.K. make the problem of early mortality in autistic people a national priority.¹⁵⁸ We recommend that U.S. autism research groups and government agencies consider making similar investments. While we do not fully understand why suicide is more common in autistic people, investigating the high rate of co-occurring mental health disabilities in our population is a good place to start.

For more tips that self-advocates can use when they are feeling suicidal, see the section of our toolkit for self-advocates. For more tips that family members can use to reduce the risk of suicide in their autistic loved ones, see our family members section.

150 Tatja Hirvikoski et. al., *Premature mortality in autism spectrum disorder*, *supra* note 5.

151 *Id.* at 235.

152 Magali Segers, Jennine S. Rawana, *What Do We Know About Suicidality in Autism Spectrum Disorders: A Systematic Review*, 7 *Autism Research* 507, 509 (2014).

153 *Id.*

154 Sami Richa et. al., *Suicide in autism spectrum disorders*, 18 *Archives Suicide Res.* 327, 327 (2014).

155 Autistica, *Personal tragedies, public crisis: The urgent need for a national response to early death in autism 2* (2016), <https://www.sciencemag.org/sites/default/files/documents/AUTISTICA%20REPORT%20-%20Personal%20Tragedies.%20Public%20Crisis.pdf>.

156 *Id.* at 5.

157 *Id.* at 5, 6.

158 *Id.* at 9, 10.

Autism, Getting Lost, and Environmental Safety Research

Key Points

- Research shows that autistic people may be more likely to leave an area unexpectedly or get lost without the knowledge of others. Most studies refer to this as “wandering” or “elopement.”
- “Wandering” and “elopement” are probably not a single type of behavior solely committed by autistic people. Instead, it is more likely that autistic people leave areas unexpectedly for a variety of reasons. The behavior of the autistic person is later interpreted as “wandering” by the person’s caregivers.
- Several major research studies on “wandering” don’t define what “wandering” and “elopement” are, or give these terms an overbroad definition that encourages parents to consider every situation in which their child leaves without prior knowledge to be “wandering.”
- Parents’ feelings about an incident often determine whether the incident is considered “wandering” and “elopement.”
- Research shows that if we instead try to find out **why** the person is leaving, “wandering” decreases.

The most well-known study on wandering is Connie Anderson et. al.’s (2012) *Pediatrics* article. It has been cited by Autism Speaks,¹⁵⁹ the Centers for Disease Control and Prevention (CDC),¹⁶⁰ the American Academy of Pediatrics,¹⁶¹ and the National Center for Missing and Exploited Children.¹⁶² Each organization has used the study as evidence that half of all autistic children “wander.”

Despite the frequency at which the study is used to show that half of all autistic children wander, the actual findings of the study are more limited. The study found that 49% of the children studied had attempted to “elope” at least once after the age of four.¹⁶³ Half of this group was missing long enough to cause concern.¹⁶⁴ Of those who went missing, parents reported that 24% had close calls with drowning and 65% had close calls with traffic injury.¹⁶⁵

Anderson et. al. drew their data only from members of the Interactive Autism Network, which may not be representative of the full community.¹⁶⁶ The questionnaire also used the term “eloped” or “elopement,” which was used to refer to any case in which their child left a “safe” place - even to go to another equally safe place.¹⁶⁷ This encourages parents to view all incidents of their autistic child leaving the area unexpectedly as one behavior: “wandering.” Finally, even though survey respondents included parents of teenagers up to age 17, the survey did not solicit responses or input from the autistic children and teenagers, who might have been able to explain why they had “wandered.”¹⁶⁸ While the survey did ask the parents of autistic children what their child’s mood had been when they had “wandered” or “eloped,” and what goal the parents thought that the child had, the responses were chosen from multi-response checklists from within the study itself, which limits the types

¹⁵⁹ Laurie Tarkan, *Study Confirms: Autism Wandering Common and Scary*, Autism Speaks (Oct. 8, 2012): <https://www.autism-speaks.org/science/science-news/study-confirms-autism-wandering-common-scary>.

¹⁶⁰ Centers for Disease Control & Prevention, *Wandering (Elopement)*, <https://www.cdc.gov/ncbddd/disabilityandsafety/wandering.html> (last updated July 13, 2015).

¹⁶¹ American Academy of Pediatrics, *Study Finds Nearly Half of Children with Autism Wander Off* (October 8, 2012): <https://www.aap.org/en-us/about-the-aap/aap-press-room/pages/Study-Finds-Nearly-Half-of-Children-with-Autism-Wander-Off.aspx>.

¹⁶² Nat’l Center for Missing & Exploited Children, *Missing Children with Autism*, <http://www.missingkids.com/autism> (last visited Mar. 17, 2017).

¹⁶³ Anderson et. al., *Occurrence and Family Impact of Elopement in Children with Autism Spectrum Disorders*, 130 *Pediatrics* 870, 872-73 (2012).

¹⁶⁴ *Id.* at 874.

¹⁶⁵ *Id.* at 873.

¹⁶⁶ *Id.* at 871.

¹⁶⁷ *Id.* at 871, 872.

¹⁶⁸ See Anderson et. al. (2012) at 871-72 (no questions on the survey elicit the opinions of the children studied themselves).

of possible motivations the parents could report for their child.¹⁶⁹ The motivations for “wandering” or “elopement” behavior suggested by the parents also may not reflect their child’s true motivations in some cases.¹⁷⁰

Kiely et. al published a study of “elopement” in February 2016.¹⁷¹ This study used a nationally representative sample of 4,032 families of children with developmental disabilities, drawn from the CDC’s “Pathways” telephone survey.¹⁷² The study found that 26.7% of all children with developmental disabilities unexpectedly left or got lost at least once within the last 12 months.¹⁷³ Autistic children were more likely to leave or get lost than non-autistic children with other developmental disabilities.¹⁷⁴ Rice et. al. in July 2016 conducted a substantially similar study on the “Pathways” data.¹⁷⁵ It found that autistic children were more likely to leave their parents or get lost than non-autistic children.¹⁷⁶ While the studies did examine which autistic traits (such as stimming, resistance to change, history of “behavioral problems,” etc.) correlated with “wandering,” neither study discussed why autistic children wandered, or differentiated between when wandering was a safety threat and when it was not.

One study addresses the issue in a different way. Olga Solomon and Mary Lawlor’s 2013 study focused on the cultural context of the autistic person’s departure, specifically addressing the different experience of African-American mothers.¹⁷⁷ The study found that the specific terms “wandering and “elopement” have a clinical connotation that obfuscates both the child’s intent and the fear the parents feel when their child goes missing.¹⁷⁸ A child’s “wandering” behavior may just mean the child likes to explore, but the event is pathologized due to the child’s disability.¹⁷⁹ Although the mothers used the terms “wandering” and “elopement” to express their need for support services, they described the actual events as the trauma-inducing, harrowing experience of their child being missing.¹⁸⁰

Another recent study illustrates that all behavior, regardless of whether it is done by a person with a developmental disability, has a purpose -- including “wandering.” The study, published in the journal *Autism*, studied eleven autistic children ages 5 to 12 (who were in an “intensive day treatment clinic”) who had a history of leaving unexpectedly or getting lost.¹⁸¹ The study examined a “treatment program” that identified which factors were motivating each child to wander and attempted to modify the behavior through clinic-based behavioral interventions.¹⁸² The researchers concluded the children were 86 percent less likely to wander after the “treatment,” suggesting that “wandering” behavior can change. However, this study should be treated with caution due to its small sample size, clinical setting, and failure to address whether the intervention offered children alternate ways of communicating that they want to be elsewhere.

While not all instances of an autistic person leaving or getting lost are dangerous, some proportion of them may lead to accidental death or injury if the autistic person does not have relevant safety skills. One study, published in the *American Journal of Public Health*, found that the median age of death for autistic people was

169 *Id.* at 873, 874-76.

170 See Anderson et. al. (2012) at 874 (study describes this data as “the children’s subjective experience while eloping, as described by parents”).

171 Kiely et. al., *Prevalence and Correlates of Elopement in a Nationally Representative Sample of Children with Developmental Disabilities in the United States*, PLoS ONE, February 2016, at 1.

172 *Id.* at 2.

173 *Id.* at 4, 5.

174 *Id.* at 5.

175 Catherine E. Rice et. al., *Reported Wandering Behavior Among Children with Autism Spectrum Disorder and/or Intellectual Disability*, *Journal of Pediatrics*, July 2016, at 232.

176 *Id.* at 235.

177 Olga Solomon & Mary C. Lawlor, “*And I look down and he is gone*”: *Narrating autism, elopement, and wandering in Los Angeles*, *Soc. Sci. Med.*, July 2013, at 106-114.

178 *Id.* at 107, 108.

179 See Olga Solomon & Mary C. Lawlor at 107, 108.

180 See Olga Solomon & Mary C. Lawlor at 109-114 (describing how the African-American mothers in the study reported on their child’s “wandering” or “elopement,” and how they framed it in order to gain access to the services they needed).

181 Nathan A Call et. al., *Clinical outcomes of behavioral treatments for elopement in individuals with autism spectrum disorder and other developmental disabilities*, 21 *Autism* 375, 375-79 (2017).

182 *Id.*

36.7 years and that we were three times more likely to die from injury than non-autistic people.¹⁸³ Although only a small percentage of these accidental injuries are likely to have been caused by “wandering”, this statistic further highlights the need for safety skills training and other relevant safety interventions.

A note on GPS tracking devices: Some companies have begun marketing GPS tracking devices as an answer to “wandering.” These devices are intended to be worn by the autistic individual. Another person, such as a parent or police department, can then access data on these devices to locate the individual.

There is limited data on the effectiveness of these devices, and many causes for concern:

- Most effectiveness studies are privately commissioned by the companies that profit from sale of the devices. These studies are also commonly focused on decreased police search times rather than on reduced likelihood of injury or death.
- GPS tracking devices cannot prevent injuries - such as traffic injuries or drowning - that occur shortly after the individual leaves a safe place. Often, parents or teachers do not notice that an autistic person has left for several minutes or even hours.
- Some GPS tracking devices are designed to be difficult or impossible to remove. This opens the possibility that they will be used by abusive individuals to prevent a person from leaving an unsafe place.
- If GPS devices broadcast location to law enforcement, location data may be used by law enforcement for the purpose of prosecution of the individual, such as by helping police establish that the individual was at a location where a crime took place.
- Use of GPS devices may make parents or caregivers less likely to attend carefully to the triggers that cause autistic people to leave a location. This may make it harder to notice when an autistic person is trying to communicate discomfort or fear.
- According to preliminary results of a study on parents’ approaches to wandering, GPS devices were rated as among the most costly and least effective interventions.¹⁸⁴

ASAN Surveys

The Data:

- No adult autistic self-advocate in the sample was concerned about getting lost or navigating their own community safely.
- However, leaving safe places was a very significant concern of the parents of autistic children. 60% to 80% of the parents we surveyed were very worried that their child might go somewhere unsafe.
- Most parents believed that either curiosity or avoidance of unpleasant stimuli was motivating their children when they left.
- Many of those surveyed did not have any plan for what they should do when their child goes missing, but an equal number had one or more plans.
- 70% of the parents we surveyed had taught their child some basic survival skills, including swimming (60 to 70%) and traffic safety (50 to 60%). Many were concerned about how effective these skills were.

¹⁸³ Joseph Guan & Guoha Li, *Injury Mortality in Individuals with Autism*, 5 Am. J. Pub. Health 791, 791-93 (2017).

¹⁸⁴ Paul Lipkin, M.D., Director, Interactive Autism Network, Remarks at the Meeting of the Interagency Autism Coordinating Committee (July 26, 2017) (transcript available at: https://iacc.hhs.gov/meetings/iacc-meetings/2017/full-committee-meeting/july26/transcript_072617.pdf).

Parents were asked which strategies they had used to address safety in public. Parents' suggestions included:

- Teaching the person other people's phone numbers in the event that the person gets lost. Mnemonic devices or other means of memorization may be helpful.

“...he has my phone number memorized. I made it the code to get into his iPad to make him memorize it...but this question makes me think this is a good idea.”

- Having local police and fire departments aware of the existence of the autistic person.
- Using identification bracelets or other forms of ID.
- Some autistic people may be afraid of the dogs used by first responders. It may help to train the search and rescue responders who use dogs.

“Dogs trained to hold and bark may induce greater panic/flight. I've done a training for search and rescue responders who use dogs. The sensory reactions were what the responders found most useful.”

Several parents noted the importance of ensuring that first responders understand how to recognize a meltdown. They felt that first responders should undergo training in order to understand how autistic people do and don't communicate, including autistic people's ability to understand and respond to specific kinds of verbal instructions. Almost all parents felt that police and other first responders should be better coordinated around disability issues.

Autistic self advocates who want safety tips for when they are out and about in their communities can check ASAN's Self Advocate section of the toolkit. Parents who want tips for how they might be able to help their children navigate the world safely can check the Tips for Family Members section of the toolkit.

Conclusion

No safety issue exists in a vacuum. An autistic person who leaves unexpectedly might be running from abuse and neglect. We might be victimized by law enforcement officers. We are likely at a greater risk for suicide because of the terrible things that can sometimes happen in our lives, like bullying and abuse.

To address the many issues that affect us and truly keep autistic people safe, we must consider how these issues are related and attempt to change the culture that devalues and segregates people with disabilities. We will not be any safer in institutions or with tracking devices on us. Instead, we should try to make reforms to the systems that serve people with disabilities. Our allies should provide us with knowledge about the world and advocate for the services and supports that help us protect ourselves from harm.