

# Autism and Safety Toolkit: Ways for Family Members to Support the Safety of Autistic People

## What Is In This Guide?

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### Introduction

Safety is a critical concern for autistic people and our families. We are more likely to be abused and neglected,<sup>1</sup> less likely to know what abuse and neglect look like,<sup>2</sup> more likely to die from suicide,<sup>3</sup> more likely to experience excessive use of force or violence from law enforcement,<sup>4</sup> and less likely to know critical safety skills that allow us to move safely through our communities.<sup>5</sup> Despite the many threats to our safety, many of us lack the resources, support, and information that we would need to navigate our way around these threats.

All autistic people deserve to be safe while living independently in the broader community. As friends or family members of autistic people, you can play an important role in helping your autistic loved one reach these goals.

### About this Guide

This guide is for family members and friends who want tips on how to help their autistic loved ones stay safe. This guide offers tips on:

- How to recognize and respond to abuse and neglect of people with developmental disabilities;
- Strategies on how to reduce the risk of law enforcement violence toward people with disabilities, including how to reduce law enforcement involvement in crisis situations;
- How to recognize when a person you love might be having suicidal thoughts and how to respond; and
- How to teach your child or loved one skills that will help them remain safe in the community, including how to prepare a safety plan in case they get lost.

### 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 give particular thanks to the over eighty parents of autistic people from the organization Parent to

<sup>1</sup> Patricia M. Sullivan & John F. Knutson, *Maltreatment and Disabilities: A Population-Based Epidemiological Study*, 24 Child Abuse & Neglect 1257, 1268-71 (2000) (finding that children with disabilities were 3.5 times more likely to be abused and/or neglected than children without disabilities); 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).

<sup>2</sup> S.M. Brown-Lavoie et al., *Sexual Knowledge and Victimization in Adults with Autism Spectrum Disorders*, 44 J. Autism Dev. Disord. 2185, 2189-93 (2014) (finding that autistic adults' lack of sexual knowledge correlated with their high rate of sexual victimization, and that greater sexual knowledge partially mitigated their high risk of sexual victimization); Amy Swango-Wilson, *Meaningful Sex Education Programs for Individuals with Intellectual/Developmental Disabilities*, 29 Sex. & Disabil. 113, 114-18 (2011) (finding that adults with intellectual and developmental disabilities were less likely to recognize that they had been abused).

<sup>3</sup> Tatja Hirvikoski et al., *Premature Mortality in Autism Spectrum Disorder*, 208 Br. J. Psychiatry 232, 235 (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).

<sup>4</sup> See Boris Sanchez & Kevin Conlon, *North Miami shooting: Man, Wounded Caretaker Reunite*, CNN (July 28, 2016, 7:24 PM), <http://www.cnn.com/2016/07/28/health/north-miami-police-shooting-reunion/> (describing a case where a police officer, attempting to shoot an autistic man due to a misinterpretation of his behavior, shoots his caregiver instead); 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) (single-region study showing that the victims of police violence in this city were highly likely to have a disability); Nadja Popovich, *Police Shooting of Mentally Ill Woman Reaches U.S. Supreme Court: Why Did it Happen at All?*, The Guardian (Mar. 23, 2015, 7:50 AM), <https://www.theguardian.com/us-news/2015/mar/23/police-shooting-mentally-ill-teresa-sheehan-supreme-court> (discussing Teresa Sheehan and the connection between her case and police mishandling of mental health crises).

<sup>5</sup> For more information on how autism relates to community safety, you can check the [Research section](#) of our safety toolkit.

Parent USA that filled out our parent survey, and Ron Hampton and the members of the District of Columbia Autism Society, 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 people who responded to our two autism and safety surveys in this guide. We also drew our recommendations from our own experience and knowledge of autism self-advocacy and autism and safety.

## Police and Law Enforcement

People with disabilities tend to experience excessive use of force by police and police violence at higher rates than people without disabilities, especially people with mental health disabilities.<sup>6</sup> We discuss some of the possible reasons for this higher risk in our [Research guide](#). Based on our research and feedback from parents, we have created a list of suggestions to help family members protect their autistic loved ones from this excessive use of force. These strategies include:

1. Reducing the likelihood of police involvement in the midst of a mental health crisis
2. Helping your loved one ensure police know they have a disability by using identification bracelets
3. Talking with your loved one about the police, and
4. Advocating for systems change in both your community and your community's law enforcement agencies.

Since different communities may have different relationships with law enforcement, it is up to you to decide which of the following suggestions make sense for you and your loved one.

### **Create a plan for crises, including plans that can help avoid unnecessary police involvement**

Police are not experts at responding to mental health crises. However, calls to 911 for help with mental health crises often result in police arriving first on the scene. This means that many families make plans for handling crises that reduce the need to call 911.<sup>7</sup> These include:

- Make a plan for how to de-escalate your family member out of 'crisis mode.' Make sure that everyone who spends time with your family member knows the plan.
  - The plan should be based on what works for your family member. Some common strategies include:
    - ♦ Speak calmly while speaking to your family member.
    - ♦ Reassure them that you want to help by saying things like "I care. I'm here for you," and listen carefully to what they have to say. Let them know they are loved.
    - ♦ Repeat things multiple times if you need to. People in crisis might have a hard time understanding you. Autistic people in crisis might not speak at all, but they can still hear you.
    - ♦ Say what you need to say in different ways if you need to. Autistic people in crisis may have a hard time understanding spoken information and may need to hear something rephrased to understand it. If you have tried a couple of different ways of saying things, you could also write them down or type them out.
    - ♦ Be sensitive to which people the person wants to be around. If the person in crisis wants to talk to a particular person, try to bring them over. If the person seems overwhelmed by too many people, tell others to move away and give them space.
    - ♦ Make the surrounding space as safe as possible. If you need to, move any dangerous or sharp objects. Turn off anything that is making a bright light or loud noise.

<sup>6</sup> 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); Julia Tate et. al., *Fatal Force*, Washington Post (finding that, at the time of our last visit, one out of every four people killed by the police had a mental health disability) (last visited Oct. 22, 2017), <https://www.washingtonpost.com/graphics/national/police-shootings-2017/>; 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.sdcda.org/office/ois\\_review\\_rpt.pdf](http://www.sdcda.org/office/ois_review_rpt.pdf) (single region study finding that 81 percent of everyone involved in a police shooting had either a substance use disorder or a mental health disability).

<sup>7</sup> We derived many of the following suggestions from a combination of many of the suggestions offered by the following mental health support groups: (1) The Depression and Bipolar Support Alliance's "How to Help Someone in Crisis," [http://www.dbsalliance.org/site/PageServer?pagename=help\\_crisis](http://www.dbsalliance.org/site/PageServer?pagename=help_crisis); (2) The American Psychological Association's "How to Help Someone In an Emotional Crisis," <http://www.apa.org/helpcenter/emotional-crisis.aspx>, and Mental Health First Aid Australia's "How to Help a Friend, Family Member or Co-worker with a Mental Illness or Crisis" available at:

- ◆ If you are in public, tell strangers and bystanders what is happening. Make it clear that you know the person and know how to respond to the situation. Ask them not to crowd around or to call 911 if you don't think it is necessary.
- ◆ Be patient. Sometimes it may simply take some time for someone to get to the point where they can regulate themselves.
- Avoid doing the following:
  - ◆ Don't say that you "totally understand what they're going through." You might not.
  - ◆ Don't threaten to call 911 or to hospitalize them.
  - ◆ Don't act angry or frustrated while the person is in crisis.
  - ◆ Don't talk more than the person does or talk over them.
- If you can't de-escalate the situation and are worried about safety, consider calling mental health professionals or disability services professionals you or your loved one have relationships with. They may be able to explain to you how you can help your loved one in a crisis. It helps to plan out which mental health professionals to call in advance. This way you can have their contact information easily available in case of a crisis. Knowing that you know who to call may reassure both you and your loved one.
- If you do not know any mental health or disability services professionals or cannot reach them, try calling a local or national crisis hotline. You can find two different types of crisis hotlines in our "Resources" section at the bottom of this guide.
- In some situations, you may not be the right person to respond to a crisis. If you know someone (like a friend) who is good at helping in a crisis, call them over instead. It helps to make a list in advance of people who are good people to call.

### **Use an identification bracelet to ensure that first responders get the information they need**

Many autistic people cannot speak or have trouble speaking in tense or uncomfortable situations. Some advocates have proposed wallet cards or other cards that can contain important information for first responders when an individual cannot speak. While such cards are a well-meaning idea and may be useful in some situations, they can create their own dangers. For example, police could misinterpret a person reaching into their pocket to take out the ID card as someone reaching for a weapon.

Instead, we recommend using something like a medical bracelet. Medical bracelets are common, well-recognized means of giving health and disability information to first responders. Because first responders recognize these bracelets, they are more likely to understand what the bracelet means than to understand what is happening when a person silently reaches for a card. Moreover, because the person would only have to raise an arm to show the bracelet, first responders are less likely to mistake this gesture as someone reaching for a weapon.

Tablets or cell phones with texting options could help a nonspeaking autistic person communicate with the police. However, these may cause similar problems if the person has to reach into a pocket or bag to get the cell phone or tablet. You could advise your loved one to only use the cell phone or tablet for this purpose if they are already holding it, or if they are talking to other kinds of first responders such as health care workers.

### **Talk to your loved one or friend about interacting with police and first responders**

Many of the parents we surveyed said that they had introduced their loved ones to the police or other first responders. They also said they had explained to their loved one who the police were and what they did. This helped their loved ones learn who these individuals were and how to respond to them. Other parents said that police and first responders had visited their loved ones' classrooms in order to explain who they were. Here are some examples of what the parents who filled out our survey said about these interactions:

"We make it a point to show him local police, firemen etc. to show them they are safe and helpful."

“We have toured the local fire station and met firefighters, and he has relatives who are firefighters and he knows them.”

“We have taught our son to communicate with the Police or other caregivers/medical personnel - encouraged him to be honest and as clear as possible. We have also had him meet with the Community Liaison for our Police department, which has been helpful, as he has a better feel for the Police and has met a number of them.”

**Note:** sometimes simply being “honest” with police is not the best advice - especially for teenagers and adults who are at risk for antagonistic encounters with police. In some cases, autistic people have falsely confessed to crimes because they thought it was what the police wanted them to say. This can lead to the conviction of innocent people. To avoid this outcome, tell teenagers and adults to speak calmly to police but not to answer questions other than by stating their name, home address, and other information that they may need to give in order to be safe.

These strategies may be more or less beneficial, depending on the relationships between your community and the police. For example, in some communities, it may make more sense to explain the role of law enforcement and other first responders to your loved one rather than set up a meeting between the police and your loved one.

## Advocate for systems change in policing

### Advance the policy priorities of national advocacy organizations, which create greater police accountability

National advocacy organizations across the country have made policy recommendations for creating a safer and more effective police force. For instance, Campaign Zero, founded by the organization We The Protesters, has created a [10-point list of policies](#) that would, when taken as a whole, create more accountable, better trained, de-militarized police forces.<sup>8</sup> The Center for Popular Democracy created a [toolkit on police accountability](#) that recommends similar policies.<sup>9</sup> These policy changes include:

- Creating **independent or special prosecutors’ offices**. These are state agencies separate from both the regular state prosecutor’s office and the police department who prosecute cases where a police officer appears to have committed a crime.<sup>10</sup> Campaign Zero also calls for investigators of police misconduct complaints that are independent of the police department that is being investigated.<sup>11</sup>
- Reforming or eliminating laws that over-criminalize minor offenses, such as jaywalking, disorderly conduct, or loitering.<sup>12</sup> Reforms would also address school disciplinary offenses that are overcriminalized, due to a phenomenon known as the **school-to-prison pipeline**. For more information on the school-to-prison pipeline and how it might affect your child, see page 12 of the Research Guide of this toolkit.
- Banning racial, ethnic, religious, or immigrant status profiling by changing state laws, regulations, and police trainings. These new laws and regulations would not allow police officers to stop, arrest, or otherwise profile people based on their race, ethnicity, apparent or actual religion, and immigrant status.<sup>13</sup> We believe these rules should also cover profiling based on disability.
- Creating civilian oversight commissions or boards. These are agencies made up of citizens of a particular city or municipality who can recommend a course of action when a police officer is accused of police misconduct towards a person in that city or municipality.<sup>14</sup>

<sup>8</sup> Campaign Zero, *The Solution*, <https://www.joincampaignzero.org/solutions/#contracts> (last visited Oct. 18, 2017) [hereinafter “Campaign Zero”].

<sup>9</sup> 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”].

<sup>10</sup> Campaign Zero.

<sup>11</sup> *Id.*

<sup>12</sup> *Id.*

<sup>13</sup> Center for Popular Democracy at 19.

<sup>14</sup> Center for Popular Democracy at 25.

- Revising laws or regulations regarding police use of force, so that use of force is only authorized in extreme situations where there is a high risk of harm.<sup>15</sup>
- De-militarizing the police, such as by passing local legislation that prohibits them from using or acquiring military-grade weapons.<sup>16</sup>

We recommend that family members advocate and advance similar policy priorities in their state or municipality. The policies above may sharply reduce the risk that your loved one and people like your autistic loved one will be harmed by the police. Campaign Zero itself lists different ways that civilians can take action on [the bottom of its website](#).

### **Join national and local organizations that are fighting for greater police accountability**

We recommend that you join national and local advocacy organizations that are doing this work. We feel that adding your perspective, as family members of people who may be impacted by excessive police violence, may enhance and contribute to the work of these groups. We list a few of these national groups below, along with ways that you can get involved. You may find other groups by searching for “police accountability advocacy groups” online or through word of mouth in your community.

#### **Black Lives Matter**

The Black Lives Matter Global Network is an organization that works to end violence and systemic racism against Black people worldwide.<sup>17</sup> 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.<sup>18</sup>

You can join a Black Lives Matter Global Network chapter by [searching their map for a chapter near you](#). You may also be able to [sign up for their action alerts](#). While using the hashtag #BlackLivesMatter does not automatically make you a member of the organization, it may help you connect with other advocates for reduced police violence and systemic racial justice.

#### **National Police Accountability Project**

The National Police Accountability Project is a nonprofit organization made up of lawyers, nonprofit attorneys, paralegals, and other advocates who combat excessive police use of force.<sup>19</sup> It helps people find lawyers and access resources if they have been the victim of police violence. The lawyers involved work on police misconduct case, including cases that involve jail and prison guards.<sup>20</sup> 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.<sup>21</sup>

If you are a lawyer yourself, you can join the project’s listserv. You can also [find a lawyer on the project’s website](#) if you or someone you know has been the victim of police violence.

#### **Funders For Justice List**

The website [Funders for Justice](#) keeps a list of police reform organizations, both national and local.<sup>22</sup> The list contains the contact information and names of many of these organizations, both local and national. You can click on any name in the list to get a brief description of what the organization does and a link to the organization’s website. From the organization’s website, you can find out how to get involved.

<sup>15</sup> *Id.*

<sup>16</sup> *Id.*

<sup>17</sup> Black Lives Matter, *What We Believe*, <https://blacklivesmatter.com/about/what-we-believe/> (last visited Oct. 18, 2017).

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

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

<sup>20</sup> *Id.*

<sup>21</sup> *Id.*

<sup>22</sup> Funders for Justice, *Organizations Addressing Police Accountability and Racial Justice*, <http://fundersforjustice.org/organizations/> (last visited Oct. 19, 2017).

## Take part in government police accountability initiatives

Due to the increased focus on the impact and ubiquity of police violence in recent years, the Obama administration scheduled nationwide conversations on how to reduce the risk police officers pose to marginalized groups, including people with disabilities. President Obama's meetings on 21st Century Policing in 2015 discussed the impact of police violence on African-Americans, LGBTQ individuals, and people with disabilities.<sup>23</sup> Advocates are continuing to host other summits on police reform. It may be beneficial for you and your loved one to participate in similar conversations in the future (if and when they take place), whether national, statewide, or local.

## Advocate for the expanded use of Crisis Intervention Training and other alternative police training curricula, where appropriate

Training in the use of alternative conflict resolution techniques may reduce the likelihood of the police using excessive force on a person with a disability, although these results are not guaranteed. For example, Crisis Intervention Training (CIT) is training that teaches police officers how to help someone having a mental health crisis.<sup>24</sup> There are CIT programs in 45 U.S. states.<sup>25</sup> One parent of an autistic person who responded to our survey said that she provided Crisis Intervention Training and training on how to recognize autistic people. She said that "it needs to be something all officers go through."

However, in some crises situations even officers that have undergone extensive CIT have failed to use it, instead falling back on general training that focuses on aggressively responding to perceived threats.<sup>26</sup> As a result, CIT and programs like it on autism are part of the solution, but should not be the sole focus.

## Advocate for policy proposals or laws that change how the police are trained

Another approach is to revise police training curricula so that officers are trained in de-escalation and use of force when there is a clear risk of imminent harm to themselves or others.

One parent said: "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."

Police officers are often trained to act in ways that lead to the harm of people with disabilities. They tend to misinterpret the unusual actions or movements of people with disabilities (such as the stimming and flapping common to many autistic people) as evidence that the person is dangerous or violent, and police training encourages officers to "act first and think later."<sup>27</sup> People with disabilities are often stigmatized as violent, although they are more likely to be the victims rather than the perpetrators of violence.<sup>28</sup> Even when police know that they are interacting with an autistic person, and

<sup>23</sup> U.S. Dep't of Justice, Office of Community Oriented Policing Services, *Final Report of the President's Task Force on 21st Century Policing* 5, 6 (2015).

<sup>24</sup> Nat'l Alliance on Mental Illness (NAMI), *What Is CIT*, [https://www.nami.org/Law-Enforcement-and-Mental-Health/What-Is-CIT#\\_edn1](https://www.nami.org/Law-Enforcement-and-Mental-Health/What-Is-CIT#_edn1) (last visited Aug. 23, 2017).

<sup>25</sup> Megan Pauly, *How Police Officers Are (or aren't) Trained In Mental Health*, The Atlantic (Oct. 11, 2013) <https://www.theatlantic.com/health/archive/2013/10/how-police-officers-are-or-aren-t-trained-in-mental-health/280485/>.

<sup>26</sup> See Scott Greenstone et al., *Get back! Get back!': Seattle police release recordings of fatal shooting of Charleena Lyles*, Seattle Times (June 19, 2017, 3:29 PM) <http://www.seattletimes.com/seattle-news/crime/get-back-get-back-seattle-police-release-audio-of-fatal-shooting-of-charleena-lyles/> (example of the harm that can occur when the police do not use their CIT training).

<sup>27</sup> For more information on violent encounters between the police and people with disabilities, and why they occur, read the Research section of our safety toolkit.

<sup>28</sup> Sarah L. Desmarais et. al., *Community Violence Perpetration and Victimization Among Adults with Mental Illnesses*, 104 Am. J. Pub. Health 2342, 2346-47 (2013) (finding that people with mental health disabilities were more likely to be victims of violence than perpetrators); See Erika Harrell, U.S. Dept of Justice Bureau of Justice Statistics, NCJ 250632, *Crimes Against Persons with Disabilities*,

that the person is having a mental health crisis, they may lack de-escalation skills or lack the motivation to use those skills.

For an example of an alternative police training policy, the Solutions Not Punishment Collaborative in Atlanta, GA has advocated for “the adoption of a de-escalation model” of policing and the end to all policies and racial profiling practices that discriminate against people of color.<sup>29</sup> The advocacy group De-Escalate Washington is advocating for a ballot initiative in Washington state, Initiative Measure No. 940, that would require all law enforcement officers in the state to receive training in de-escalation techniques and on mental health.<sup>30</sup> The measure would also restrict the number of situations in which the police could use fatal force and require an independent investigation of all fatal force incidents.<sup>31</sup>

### Take part in participatory budgeting initiatives

Participatory budgeting is a way for community members to help decide what a city or town spends money on.<sup>32</sup> In participatory budgeting, a community’s members are given control of part of their community’s budget and then choose how they will spend it.<sup>33</sup> Typically, volunteers from the community come up with numerous possible projects and the community votes on the project that they will send to their city or municipal government.<sup>34</sup> The government then accepts their proposal, spending part of its budget on the selected project.<sup>35</sup>

Participatory budgeting is one way to help communities rebalance spending away from police and prisons, and toward other services that the community needs more. Participatory budgeting has been used to redirect funds towards new technology at schools and libraries, as well as improved local bike lanes, playgrounds, and other aspects of communities.<sup>36</sup> One successful example of participatory budgeting is the Hartford, Connecticut project, “Hartford Decides,” in which citizens 13 and over decided how to spend 1.25 million in funds.<sup>37</sup> 22 projects were on the “Hartford Decides” ballot, from citywide graffiti removal to a mobile library.<sup>38</sup> For the first year, the community decided to use the funds for projects that included improving park lighting and recreation opportunities, and installing 14 murals around Hartford’s neighborhoods.<sup>39</sup>

A joint report by the organizations Law for Black Lives, the Center for Popular Democracy, and the Black Youth Project 100, *Freedom to Thrive*,<sup>40</sup> describes the inclusion of members of marginalized communities as a necessary component of any effective participatory budgeting process. According to the report, “Today’s political demands must acknowledge the harms caused by chronic and intentional disinvestment and make democracy real by allowing self-determination in how those communities are funded.”<sup>41</sup>

Autistic people and their families should contribute their voices to these groups and help to develop and fund projects that reinvest funding in their communities. You may be able to use participatory budgeting to advocate for funding for projects such as:

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2009-2015-Statistical Tables, at 1, 3, 4, 5 (2017), <https://www.bjs.gov/content/pub/pdf/capdo915st.pdf> (finding that people with disabilities were 2.5 times more likely to be victims of a crime than people without disabilities).

29 Freedom to Thrive at 10.

30 De-Escalate Washington, *Sign for Reduced Incidents of Violence*, <http://www.deescalatewa.org/> (last visited Aug. 22, 2017).

31 *Id.* For more information on De-Escalate Washington’s work, you can go to their website at: <http://www.deescalatewa.org/>.

32 Kate Hamaji et al., *Freedom to Thrive: Reimagining Safety and Security in Our Communities* 79, 80 (July 5, 2017), <https://static1.squarespace.com/static/5500a55ae4b05a69b3350e23/t/595cf69b1b631b031e0542a5/1499264677929/Freedom+to+Thrive+Web.pdf> [hereinafter “Freedom to Thrive”].

33 *Id.*

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

35 *Id.*

36 Participatory Budgeting Project, *Our Impact*, <https://www.participatorybudgeting.org/impacts/> (last visited Oct. 8, 2017).

37 Vinny Vella, *Hartford Inmates Help Decide How City Spends 1.25 Million*, Hartford Courant (Mar. 30, 2016, 5:25 PM), <http://www.courant.com/community/hartford/hc-hartford-inmates-voting-0330-20160330-story.html>.

38 *Id.*

39 Hartford Decides, 2015-2016 Winners, <http://www.hartforddecides.org/2015-2016> (last visited Oct. 8, 2017); Hartford Decides, *Paint the City*, <http://www.hartforddecides.org/paint-the-city> (last visited Oct. 8, 2017).

40 Freedom to Thrive, *supra* note 8, at 3.

41 *Id.* at 76.



- Unarmed mobile crisis response teams or crisis prevention teams, i.e. first responders who are trained to respond compassionately and effectively to help someone in a mental health crisis;
- Better social services and community centers in your neighborhood; or
- Improved lighting or safety features for parks and outdoor spaces.

For more information on participatory budgeting and other subjects, you can read the [Research section](#) of our safety toolkit.

*Freedom to Thrive* describes how activists in cities all across the country are fighting for accountable city police forces and city budgets that address the community’s priorities.<sup>42</sup> In Baltimore, the Campaign for Justice, Safety, and Jobs (CJSJ), as part of a coalition of Maryland-based advocacy organizations, successfully negotiated for legislative reforms that changed police training and improved procedures for filing complaints against law enforcement.<sup>43</sup> Similarly in Minneapolis, Minnesota, the activists of Neighborhoods Organizing for Change successfully convinced the Minneapolis city council to allocate \$1.5 million to fund what they referred to as “safety beyond policing” strategies.<sup>44</sup> These strategies included funding for violence prevention strategies in struggling communities, funding for a hate crimes investigator, and more.<sup>45</sup>

Family members and allies of autistic people should join us in our efforts to collaborate with other rights-based organizations on the matters that concern all of us: the excessive use of punitive systems like police and incarceration on vulnerable communities and people and the consideration of potential alternatives.

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42 *Id.* at 3-74.  
43 *Id.* at 14-16.  
44 *Id.* at 51-53.  
45 *Id.*

## Safety in the Community

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Autistic people may be more likely to leave a place without telling anyone. This is often called “wandering” or “elopement” in scientific studies.<sup>46</sup> We may be more likely to get lost and may be less likely to know safety skills (such as swimming or traffic safety) that help us get back home or get where we want to go safely.

The research on this subject, and on what the behaviors called “wandering” and “elopement” are, is inconclusive. A summary of our research into this issue and the conclusions we drew from it is available in the [Research section](#) of this toolkit. We recommend coming up with multiple strategies that support your loved one’s safety in the community. Based on our research and survey responses, we compiled the following suggestions on how you can help your loved one stay safe when they are out and about.

### Form a plan in case your loved one gets lost or doesn’t know how to get back home

Having a plan will reduce the likelihood that your family member will be unable to find their way back home if they get lost. Depending on your circumstances, these strategies may help:

- Make sure your loved one always has a way to contact you or someone else. This may involve:
  - Always carrying a list of important phone numbers.
  - Using mnemonic shortcuts to memorize important numbers. One survey respondent suggested using an emergency contact’s cell phone number as one’s phone entry password.
- Teach your loved one how to use GPS on their phone or communication device (if they have one), so that they can use it to find their way back if they get lost
- Use the “Find Phone” feature or “Find a Friend” app to determine where your loved one is. This suggestion comes from another parent that filled out our survey.
- If your loved one is nonspeaking or inconsistently verbal, help them rehearse weekly a list of phrases to say or type into the communication device if that they cannot find anyone they know.
- Teach your loved one how to call 911 and or use text-to-911.

**Note:** Text-to-911 services are slow to develop, but they are being piloted in some cities.<sup>47</sup>

- Decide on a meeting place in case your loved one gets lost and doesn’t know how to find you. Choose a place that both of you know very well and can easily find. You may want to choose different meeting spots for each place you go.
- Create a plan to move to a specific place in any building, such as the front door or bathroom, in case you are separated from each other.
- Teach your loved one to ask for directions.
- Talk about how to recognize the uniforms of various first responders, so that your loved one can identify them if they get lost.
- Talk about places that are not safe, such as busy streets or train tracks. That way, your family member will know where not to go if they are lost.

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<sup>46</sup> 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, 2, 3; Catherine E. Rice et. al., *Reported Wandering Behavior Among Children with Autism Spectrum Disorder and/or Intellectual Disability*, J. Pediatrics, July 2016, at 232.

<sup>47</sup> Federal Communications Commission (FCC), *Text-to-911: what you need to know*, <https://www.fcc.gov/consumers/guides/what-you-need-know-about-text-911> (last visited Aug. 23, 2017). Note that on this page, it includes a list of areas, updated monthly, that support text-to-911 service. Check to see if your city or town supports text-to-911.

## **Determine why your loved one has left and find ways to address your loved one's desires or concerns**

If your autistic loved one often leaves a place unexpectedly, they most likely have a reason for leaving: such as to achieve a goal, avoid something unpleasant, or communicate something to others. Ask yourself:

- Do they leave without telling anyone only in specific situations? For instance, only from school, only from home, or only when a specific person appears?
- Do they leave when they see something of interest to them?
- Do they leave when they are anxious, uncomfortable, or upset? Is your loved one sensitive to bright lights or loud noises, etc.?

If you can find out why your loved one is leaving places, you may be able to predict their behavior and help them meet their needs. This may help reduce the number of times that they leave without you knowing where they are. One parent advocate allowed her autistic son to leave, but her husband followed close behind her son. This helped the parents find out that, when he tried to leave the house, he had a destination in mind: the nearby mall.

You could also try to find a safe way to accommodate your loved one's reason for leaving. For instance, if someone wants to go to the water but cannot be around water safely without supervision, it may help to go with them to safe parts of nearby lakes or streams and watch them as they enjoy and interact with the scenery. These can be good opportunities to teach water safety.

If your loved one is leaving areas out of fear of something, find out what is frightening them. If they are frightened of a person or place, for example, investigating might not only help to prevent your loved one from leaving unexpectedly. But also may help you find out if your loved one is being abused or bullied.

If your loved one is sensitive to some aspect of a specific location, you may be able to reduce their exposure to what they are sensitive to. For example, if your loved one is afraid of a bright, overwhelming grocery store, it may help to take them to a smaller store for your groceries. If that is not possible, it may help to bring headphones to help dampen noises, to bring a comforting item, or to arrange for them to wait in a quieter and less overwhelming part of the store such as one of the edges of the store, or an in-store eating area.

## **Teach your child safety skills, like swimming and traffic safety**

### **Swimming**

Like everyone, some autistic people enjoy swimming or being near water. We will be safer around water if we know how to swim and know water safety skills. If regular swim classes do not work well for your loved one, there are a number of swimming courses specially designed for autistic people and our sensory sensitivities.

A number of YMCA locations, for example, offer autism-friendly swimming courses. Although the national YMCA doesn't keep a list of these courses, you can check with your local YMCA to see if they offer one. Your loved one may also be able to get a reasonable accommodation if they need one in order to access regular swim classes.

You can also try to teach your loved one how to swim yourself, or help reinforce their swimming lessons through weekend practice. If you don't know how to swim, consider taking a course and learning together.

## Traffic Safety

Autistic people may take longer than others to learn traffic safety. We may need extra support when learning. The following strategies may help autistic people learn traffic safety:

- Constant reinforcement of these skills, such as daily or weekly walks through the neighborhood<sup>48</sup>
- Using the “Stop-Wait-Look Both Ways-Don’t Move Unless the Walk Sign Is On” method of crossing busy intersections<sup>49</sup>
- Giving a very careful overview of the basics of traffic safety, including street sign colors, machines that allow street crossings in cities, proper pedestrian etiquette, etc.
- Using worksheets, pictures, virtual learning such as apps or programs that teach traffic and street safety skills,<sup>50</sup> or whichever learning method works best for your loved one
- Learning by doing, including “trial runs” to allow the person to practice skills

You should also teach what to do in unusual traffic conditions, such as waiting for emergency vehicles and street crossing when there is no crosswalk. An autistic person might fail to generalize the traffic safety they have learned to atypical situations.

## Public Transportation and Driving

Your loved one, when they reach a suitable age, can gain greater independence by either driving or learning how to use public transportation (depending on the specific circumstances of your loved one). You can help your autistic relative learn these skills by accompanying them on their first few trips and helping them plan the series of steps that they need to take in order to make their trip. Autistic people may take longer to acquire these skills, or we may need supports in order to use them effectively. This does not mean that we cannot learn these skills or should not have the chance to try.

You could also introduce your loved one to **travel training programs**. Travel training programs help your loved one learn how to use public transportation. You can look up travel training programs in your area by searching “travel training” in your transportation authority’s website (to find a city or municipality’s official program), or you can look up “travel training programs” and the name of your city or transit authority. For more information on travel training programs, read the “Know how to get around and use safety skills” section of the Self-Advocates section of our safety toolkit.

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<sup>48</sup> The Organization for Autism Research has produced a guide on safety, from which we derived some of these recommendations. Org. for Autism Research, *Life Journey through Autism: A Guide to Safety* 22, 83, 84 (2014) [hereinafter “Life Journey Through Autism”], <https://researchautism.org/resources/a-guide-to-safety/> (safety strategies we recommend are on the page numbers listed).

<sup>49</sup> *Id.*

<sup>50</sup> Bryn Nelson, *Virtual reality helps autistic kids develop skills*, NBC News (April 21, 2008, 9:19 AM) [http://www.nbcnews.com/id/24100671/ns/technology\\_and\\_science-innovation/t/virtual-reality-helps-autistic-kids-develop-skills/#.WZ35FCiGOUk](http://www.nbcnews.com/id/24100671/ns/technology_and_science-innovation/t/virtual-reality-helps-autistic-kids-develop-skills/#.WZ35FCiGOUk); Brenda Kosky Deskin, *Traffic Safety for Children with Special Needs*, Friendship Circle Blog (July 25, 2012), <http://www.friendshipcircle.org/blog/2012/07/25/traffic-safety-for-children-with-special-needs/>.

## How to Help Autistic People Stay Free from Abuse and Neglect

Autistic people, like other people with developmental disabilities, are much more likely to suffer abuse and neglect than non-autistic people. This risk is higher in all settings and throughout our lives.<sup>51</sup> Family members may be able to do many things to protect their loved ones from abuse and neglect. We offer the suggestions below.

### Teach your autistic child or loved one, in a cognitively accessible way, about abuse and neglect

Many people with developmental disabilities, including autistic people, are not taught how to recognize abuse and neglect when it happens to us. We are also rarely taught about related subjects, such as sex and relationships, that might help us recognize abusive behavior.<sup>52</sup> People with disabilities who were not taught about abuse and neglect have a higher risk of abuse.<sup>53</sup> It is therefore critically important to talk with your loved one about abuse and neglect.

Here are some tips on how to talk to your family member about abuse and neglect:

- Think through in advance how you will respond and what next steps you will take if your family member or child says or conveys to you they have been abused and/or neglected.
- Make sure your statements are clear, direct, and accurate while being age-appropriate. Many of us might have difficulty understanding you if you speak indirectly.
  - For example, “your body belongs to you” may not be sufficiently detailed. Consider statements like “it’s okay to tell people not to touch you if you don’t want them to.”
  - Make sure that your behavior is consistent with the things you are telling your family member. If you tell your family member that it’s okay to say “no” to being touched, don’t pressure them to accept hugs or other forms of touch by other family members. Autistic people may have trouble understanding why people are making exceptions to the rule. If someone is abusive towards one of us, we may assume that that behavior is also an “exception” to the rule that we learned.
- Have multiple conversations. Some autistic people might hear what you say or write, but be unable to respond until later.
- Listen carefully to your family member and ask direct questions, even if they take a while to respond. Keep an eye out for the typical way that your loved one responds to direct questions. The response could be verbal, written down, signed, indicated using pictures or videos, or expressed in behavior or actions.
- General questions (“How was your day?”) may not work as well as questions with yes or no answers, or specific questions (“What did you and this person do on Friday?”).

Keep in mind:

- Your family member may not know how to recognize abuse and neglect if you have not told them what abuse and neglect look like.
- Your family member may believe that they deserve to be abused, or that the abuse is their fault. This may be something that the abuser told them. If you find out that your family member has been abused, try to validate their feelings while explaining that abuse is never the fault of the victim.

<sup>51</sup> Irit Hershkowitz et al., *Victimization of Children with Disabilities*, *supra* note 1, at 631-35; American Civil Liberties Union Human Rights Watch, *Impairing Education: Corporal Punishment of Students with Disabilities in Public Schools 15-21* (2009) (abuse and neglect at schools).

<sup>52</sup> Helene Berman et al., *Sexuality and the Adolescent with a Physical Disability: Understandings and Misunderstandings*, 22 *Issues Compr. Pediatr. Nurs.* 183, 185-89 (1999).

<sup>53</sup> S.M. Brown-Lavoie et al., *Sexual Knowledge and Victimization in Adults with Autism Spectrum Disorders*, 44 *J. Autism & Dev. Disord.* 2185, 2189-93 (2014); Amy Swango-Wilson, *Meaningful Sex Education Programs for Individuals with Intellectual/Developmental Disabilities*, 29 *Sex. Disabil.* 113, 114-18 (2011).

## Maximize your loved one's communication opportunities

Talking about abuse and neglect may not be effective if your loved one has a hard time communicating things that have happened to them. If the person is nonspeaking or inconsistently verbal, one of the most valuable things you can do is help the person learn how to type, read, and express themselves. If the individual uses a picture board or other communication device that has a limited vocabulary, it's important to ensure that the device enables them to communicate refusal, fear, hurt, or dislike of particular people or situations.

## Learn how to recognize the signs of abuse and neglect in an autistic person or other person with a developmental disability.

A person who has been abused and/or neglected tends to behave differently from someone who has not been abused and/or neglected. Learning to recognize the signs<sup>54</sup> will help you prevent abuse and neglect.

### Signs of Abuse

- Unexplained bruises or injuries, such as small cuts or bruises, especially in unusual locations (on face, in vulnerable locations, etc.) or in unusual shapes (in the shape of a ring or a belt, or a human hand, etc.)
- Welts, bite marks, or other markings
- Previously unseen triggers or nervous tics and actions (such as forms of stimming that were not present before)
- Fear of a specific person or place, *especially* repeated attempts by your loved one to not go to that place or be with the person (note that this can be one reason autistic people get lost and leave an area without warning more often than non-autistic people)
- Attempting to alter behavior to conform with what they believe someone else wants. In a nonspeaking person, this can include a sudden, inexplicable change in behavior around someone that they have not given you an explanation for.
- Repeatedly double-checking that they've done something
- Avoidance of tasks they used to enjoy
- Sudden, dramatic onset of depression or anxiety when your loved one has no history of anxiety or depression
- New or dramatically increased nightmares, panic attacks, self-injurious compulsive behavior, or other actions that indicate distress that are out of the ordinary
- Your loved one starts avoiding you and other people who normally support them, and doesn't explain why. This could be a sign that someone else is trying to isolate them from their support network.
- Any sign of post-traumatic stress disorder, such as reliving the same painful memory over and over or repeating phrases that occurred during it
- Seeing someone call your loved one cruel names, belittling them, or convincing them that their experiences aren't real (this is also called "gaslighting")
- Your loved one starts saying bad things about themselves that they never said before. They may be repeating what others have said to them.
- A relative or close friend of your loved one is acting indifferent to your loved one's accomplishments, successes, or actions.
- Someone is trying to convince you that your loved one is a liar and cannot be believed when they talk about their experiences, even though this does not match your experiences with your loved one.
- Sudden bad health, weight gain, or weight loss that is not well explained. Although this may be caused by something other than abuse, it can also be a response to stress.

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<sup>54</sup> The physical signs of abuse and neglect we list were derived from: Angela Bissada et al., *Keeping Our Children Safe: A Booklet for Caregivers and Providers of Children with Developmental Disabilities To Reduce the Risk of Abuse* 13, 14 (2000).

## Signs of Neglect

- Unusually unkempt appearance when such was not the norm for the person previously
- Lack of dental or medical care for a prolonged period of time, leading to untreated ailments
- Sickly or weakened appearance
- Sudden preoccupation with finding food
- Sudden bad health that is not well explained
- Sudden reluctance to allow visitors into the home

## Investigating and Reporting Abuse and Neglect

If you are concerned that your loved one is experiencing abuse or neglect, it is important to investigate. This may include talking to your loved one or finding a means of communication. For more information on how to talk to someone who may be experiencing abuse and how to report abuse and neglect to law enforcement or other agencies, see pages 4-10 of our Guide for Self-Advocates .

### **Ensure that your loved one is integrated into the community and supported by staff members with whom they feel safe.**

Abuse of people with disabilities often happens in segregated settings and behind closed doors. Isolation can make abuse harder to spot. If you do not live with your loved one, checking up on them regularly is an important way to prevent abuse.

If your loved one cannot do so independently, interview and thoroughly vet any staff person that provides services and supports for them. If your family member shows discomfort around staff or does not want to be around a specific staff person, help them replace that staff person with another one. If the service provider will not adjust which staff members interact with your loved one, help them find another services and supports provider. If you are unsure how to do this, your local Center for Independent Living or Protection and Advocacy (P&A) organization may be helpful. P&As are organizations that help advocate for the rights of people with disabilities. You can find a list of P&As and their contact information on the [National Disability Rights Network's website](#). We also discuss these in more detail on pages 4-5 and 9-10 of the Self-Advocates section of our safety toolkit.

Another thing you can do to prevent abuse and neglect is to try to help your autistic relative build a **broad, coordinated circle of support**. This circle should include friends, family members, and doctors. It is much harder to abuse or neglect someone if many people who love them are involved in their life.

### **Avoid compliance-focused therapies or compliance-focused behavioral interventions**

Therapies that primarily focus on getting an autistic person to do what you want, like Applied Behavioral Analysis (ABA), teaches your autistic loved one that they need to do whatever an authority figure tells them to do. Teaching unconditional compliance makes us extremely vulnerable to exploitation and abuse.

Many of these therapies also involve unwanted touching, such as the therapist grabbing a person's hand and forcing them to perform a particular action. This teaches us that our bodies are not our own.

Instead, insist on services and supports that teach autonomy rather than compliance, and that do not involve force but instead allow your autistic loved one to learn and interact at their own pace.

## Abuse and Neglect In Schools

### Bullying

Bullying is a type of abuse that happens between same-age peers.<sup>55</sup> Autistic people are more likely to be bullied than non-autistic people and we are more likely to suffer significant adverse effects from the bullying.<sup>56</sup> We wrote a summary of the research on bullying and the damage it can cause in our [Research section](#).

Based on our research, we've compiled the following tips on how to reduce the risk your autistic child or loved one will be bullied.

#### *Talk to your loved one about bullying.*

People who are bullied sometimes do not know how to talk to others about it. Because bullying is a form of abuse, it can help to use the same strategies that we discussed in our Signs of Abuse section on page 14. Help your loved one make a list of trusted people at school to talk to if they are bullied.

#### *Report bullying*

##### **1. Report the bullying directly to the school**

It may help to tell the school that your child is being bullied. Public secondary schools (like high school) often have a way for you to tell the school that you are being bullied.

For example, in Maryland, Montgomery County Public Schools has a [Bullying, Harassment, or Intimidation Reporting Form](#). You can give the form to a teacher or the principal.

If your school system does not have a special form, you can also write a letter describing the bullying your child or family member experienced.

Write notes of bullying incidents when you become aware of them and keep any documentation you may have - including notes you receive from the school. Also write detailed notes about what happens in your meetings with school officials about the bullying of your child.

It can help to write your meeting notes into an email (including the things that you said and the information you gave school staff) and send them to school officials after the meeting. This way, the school or organization will have a difficult time claiming that they were unaware of the bullying.

##### **2. Due Process Complaints**

If your child or loved one goes to a public school, you could also file a document called a **due process complaint**, saying that the school broke a law called the **Individuals with Disabilities Education Act (IDEA)**. Under the IDEA, public schools have to give people with disabilities a “free and appropriate public education,” or FAPE. The school may be breaking this law if something is stopping your child or loved one from getting a good education-- like bullying-- and the school is doing nothing about it.

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<sup>55</sup> 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 the Autism and Safety toolkit, we limit our discussion to bullying during K-12 education or college.

<sup>56</sup> 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) (finding that autistic children were substantially more likely to have been bullied than children in the general population); Catherine Cappadocia et al., *Bullying Experiences Among Children and Youth with Autism Spectrum Disorders*, 42 J. Autism Dev. Disord. 266, 270-71 (2011) (describing adverse health effects of bullying).



You must file the document with the county agency and state agency that runs your school. Here is an example of the form you must file, for the schools in the District of Columbia: <https://osse.dc.gov/publication/due-process-complaint-form>

### 3. Filing an ADA Complaint

You might also be able to say that the bullying is so bad that it counts as discrimination on the basis of disability - especially if the bullying is based on your child or loved one's disability. This would break a law known as the **Americans with Disabilities Act (ADA)**. Both public schools and universities (under Title II) and most private schools, high schools, colleges and universities (under Title III) must follow the ADA. Religious schools are exempt from the ADA, but privately run group homes, institutions, and residential treatment centers are covered by the ADA. For more information on what the Americans with Disabilities Act does, see page 12 of our Self-Advocates section.

Where to file an ADA complaint depends on what kind of school your child or loved one goes to.

If your child goes to a **public school**, you can send a complaint to the Department of Education Office of Civil Rights (OCR). For more information on how to file such a complaint, go to OCR's website at <https://www2.ed.gov/about/offices/list/ocr/complaintintro.html>.

Regardless of where your child goes to school, if it is covered by the ADA then you can also send the complaint to the Department of Justice (DOJ). You can file the complaint at [https://www.ada.gov/filing\\_complaint.htm](https://www.ada.gov/filing_complaint.htm).

OCR and the Department of Justice talk to each other. That means that if they think you sent your complaint to the wrong place, they will send it to the right place. So if you send your complaint to the Department of Justice, you may hear from an investigator from OCR.

#### **A note on filing IDEA and ADA complaints**

Both filing an IDEA due process complaint and an OCR complaint might put you in a position where you have to fight against your school or school district. This means that you should file a complaint only if you have already tried to report the bullying to the school, or if you are sure that the school will not otherwise do anything about your complaint.

There are also **time limits** when filing complaints under the IDEA or ADA. For more information on how these time limits affect your ability to file a complaint, see page 12 of the Self-Advocates section of our toolkit.

You can also file an IDEA or ADA complaint through a **private lawyer**. A lawyer could help you file a lawsuit in court. It may be hard to find an affordable lawyer. However, in special cases, some lawyers are willing to represent people *pro bono* (for free) or *on contingency* (which means they are only paid if they win you money). Note that before going to court under the IDEA, the lawyer would usually have to start by filing a due process complaint.

#### **If your child is in elementary or secondary school, advocate for strict policies against bullying of children with disabilities.**

Parents of underage children with disabilities can proactively speak to the school about their child and ask the school what it does to reduce the risk of bullying. As we discuss in our Research section, bullying greatly harms autistic students and limits our ability to participate in school. Nonetheless, parents who immediately reported that their child had been bullied found that many schools were inattentive. For one parent who filled out our survey, even though the students were "physically and mentally abusive," the school "did little to nothing." In another case, despite the severity of the bullying involved, the parent had to "hold a conference with all of [sic] the student's teachers" to make them aware the student was being bullied.

In order for school districts to better address the bullying of children with disabilities, they *must* receive complaints from multiple concerned parents invested in their child’s safety. The following resources may help you advocate for your autistic child’s right to be free from bullying in school:

- The United States Department of Education’s Office of Civil Rights (OCR) provides a [fact sheet to parents](#) explaining what they should do if they believe that their child with a disability has been bullied at school.
- The Department also issued a [Dear Colleague letter](#) that provides guidance explaining what a secondary school must do legally when a student with a disability has been bullied. You can use this document to explain to the school what your child’s rights are.
- [Stopbullying.gov](#) contains an excellent list of resources and descriptions of which bullying prevention methods in schools actually reduce bullying.
- PACER’s National Bullying Prevention Center offers sample letters that you can send school officials when you have a child with a disability that has either an Individualized Education Plan (IEP) or Section 504 plan at the school: <http://www.pacer.org/publications/bullypdf/BP-19.pdf>. They also provide a resource, [What Parents Should Know About Bullying](#), that describes steps parents can take to reduce bullying in their schools.
- Join up with other parents, such as parent information centers and advocacy organizations that focus on disability, in order to collectively advocate for the needs of your children.

## **Restraint and Seclusion**

Restraint is when a child or other person is held down, either by mechanical means such as handcuffs or straps (called “mechanical restraint”) or with a person’s body (called physical restraint). Seclusion is when a group of people, usually staff members, isolate and trap another person alone in a locked room. These two forms of abuse are most often used on children and adults with disabilities, especially in institutions and schools as a form of behavior control. These practices are dehumanizing, traumatizing, and ineffective. They can cause great harm to your loved one. For more information on the harm associated with restraint and seclusion, see the Research section of our safety toolkit. The following suggestions are things you can do to prevent the use of restraint and seclusion on your loved one.

### **Know the Law**

In many states, there are no laws specifically saying that restraint and seclusion is illegal. In other states, there are laws against restraint and seclusion but only in some situations. For example, staff may be able to use some restraints (like using their hands or body to hold down your loved one’s arms) but not others (like tying your loved one to a chair or locking them in a room). Staff may only be allowed to use restraint and seclusion when your loved one is doing something that would be dangerous for your loved one or someone else. In some states, schools have to notify parents each time they use seclusion or restraint. You should check the applicable laws in your state. The Department of Education has a [summary of these laws](#) on its website.

Even if there are no laws in your state specifically about seclusion and restraint, it still may be illegal. For example, seclusion or restraint may violate laws against assault, abuse, or disability discrimination. If the school is a public high school, you can say that seclusion and restraint violate the IDEA, as described in the “Bullying” section of this guide.

Seclusion and restraint may be covered by the ADA or Rehabilitation Act. The ADA bans disability discrimination by state agencies (including public schools and universities) and public businesses (including non-religious private schools). The Rehabilitation Act bans disability discrimination by any program that gets money from the federal government - which also includes public schools, universities, and most group homes and institutions. Seclusion or restraint may be considered discrimination under the ADA. If you want to file a complaint under the ADA, see instructions in our Bullying section above.

### **Advocate for your child to be safe from seclusion and restraint**

One way to prevent the use of any restraint or seclusion on your child is by sending the school a “No Restraint” letter. You can find an example of such a letter at the end of TASH’s booklet for parents, “[Shouldn’t School Be Safe? Working Together to Keep Every Child Safe from Restraint and Seclusion In School](#).”<sup>57</sup> TASH’s booklet also contains a comprehensive list of steps that parents can take to prevent the restraint and seclusion of their child. Although these letters are not always followed, they can make it harder for school officials to claim that they thought their actions were acceptable.

Another way to prevent seclusion and restraint is by keeping your child in integrated settings. This may seem counter-intuitive, because schools often argue that staff segregated, “structured” settings, residential schools, or other institutional environments are more knowledgeable about how to teach children with disabilities. However, these settings are often far more likely to use restraint, seclusion, or other abusive practices. For example, the Judge Rotenberg Center in Massachusetts, a residential school, infamously uses electric shocks and both physical and mechanical restraints on its students.

Note that many residential schools, centers, and homes may not explicitly mention that they use restraint and seclusion. We also advise parents to carefully check the language in their child’s 504 plan, behavior intervention plan (BIP), Individualized Education Plan (IEP), and other documentation related to their child’s education to make sure that none of these plans allow the use of restraint and seclusion. Note that these documents may refer to specific types of restraints by name or call seclusion something else, rather than use the exact phrase “restraint and seclusion.”

Segregated settings are especially dangerous when all students are non-speaking or have communication challenges. Because these settings do not include children without disabilities, there are fewer possible witnesses who can report abusive behavior. In settings that serve many children with emotional disabilities, like the Judge Rotenberg Center, students who report abuse often are not believed.

### **Advocate for the use of conflict resolution alternatives that do not involve the use of restraint and seclusion**

Many school districts and schools use restraint and seclusion solely because they see no other alternative. Introduce your school or school district to conflict resolution alternatives. The Department of Education released a [resource document](#)<sup>58</sup> on restraint and seclusion which promotes the use of Positive Behavioral Interventions and Supports (PBIS), or nonviolent behavior modification, by teachers. PBIS addresses the behaviors most likely to precipitate a use of restraint and seclusion (i.e. behaviors that are an imminent threat to self or others) by changing the child’s environment in order to teach non-aggressive behavior in school, while reducing the characteristics in the environment that heighten the likelihood of aggressive behavior.<sup>59</sup>

The best way to prevent restraint and seclusion is to use techniques that de-escalate aggression, such as using accepting, calm, and direct language. Even in situations that are very dangerous, seclusion and restraint are not necessary. One example of a possible alternative are defense pads. Instead of restraining a person who is behaving aggressively or has lost control of their body, staff members use pads as shields to protect themselves. An example of these defense pads are [those used by the company Ukeru Systems](#).

Parents can advocate for the use of strict “no restraint and seclusion” policies in the school. The Department of Education resource document establishes fifteen principles<sup>60</sup> around which schools, State Educational Agencies, school administrators, special education aides, teachers and other officials should structure their education policies. One of these principles is that every effort should be made to avoid the use of restraint and seclusion, through the use of positive behavioral alternatives and other conflict de-escalation techniques.<sup>61</sup>

<sup>57</sup> TASH, *Shouldn’t School Be Safe? Working Together to Keep Every Child Safe from Restraint and Seclusion in School* 1 (2008), [http://stophurtingkids.com/wp-content/uploads/2013/05/TASH\\_Shouldnt-School-Be-Safe.pdf](http://stophurtingkids.com/wp-content/uploads/2013/05/TASH_Shouldnt-School-Be-Safe.pdf).

<sup>58</sup> U.S. Dep’t of Educ., No. ED-OSE-09-O-0058, *Restraint and Seclusion: Resource Document 1-3* (2012) <https://www2.ed.gov/policy/seclusion/restraints-and-seclusion-resources.pdf> [hereinafter referred to as “Resource Document”].

<sup>59</sup> Resource Document at 13.

<sup>60</sup> Resource Document at 11.

<sup>61</sup> Resource Document at 14-23.

Finally, you can join the nationwide fight against restraint and seclusion in schools. Stop Hurting Kids, a nationwide campaign against restraint and seclusion developed by TASH and the Alliance to Prevent Restraint, Aversive Interventions and Seclusion (APRAIS), has a website<sup>62</sup> that has many helpful resources and links to get you started.

**Note on autistic meltdowns:** Sometimes, we lose control over our bodies and emotions. This usually happens when we are extremely stressed out, frightened, or overstimulated. Many autistic people experience this as being a lot like a panic attack. We recommend describing these to the school and explaining that they are not temper tantrums. Restraining someone during a meltdown or attempting to shame the person into stopping will only make the meltdown worse. You may want to explain this to any services and supports provider, anyone else working with your loved one as well.

If you have a good relationship with your loved one, it may help to ask them during a calm moment what they would like you to do if you witness one of their meltdowns. Many of us change behavior and/or have different sensory sensitivities when we are extremely stressed. If you don't have a good relationship with your loved one, it may help to share notes with others or to talk to other autistic adults. This information may help ensure that, in the future, you are prepared to react in the way that best helps your autistic loved one.

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62 Stop Hurting Kids, <http://stophurtingkids.com/> (last visited Aug. 24, 2017).

## Suicide Prevention

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Autistic people are more likely to die from suicide than non-autistic people.<sup>63</sup> Many parents and family members are not aware of this risk or may not know how to address it. Nevertheless, learning to support autistic people who are feeling suicidal is an important part of helping us keep ourselves safe. Here are some strategies that may help.

### **Talk to your loved one about how they are feeling and learn to recognize signs that they might be considering suicide**

Talking about suicidal thoughts with someone else reduces, rather than increases, the likelihood that someone will attempt suicide.<sup>64</sup> However, many people who are thinking about suicide do not know how to reach out. Pay attention to signs that someone may be having thoughts of suicide, and talk to them if you are concerned. Warning signs can include:

- Signs of extreme depression, such as decreased motivation, “flat” speech or facial expressions, or inability to enjoy the things the person previously enjoyed
- Feelings of hopelessness or helplessness
- Extreme anxiety and stress more persistent and common than any anxiety the person has expressed in the past
- Says things like “I wish I could die” or “I don’t deserve to live”
- Drastically increased use of a known coping mechanism, such as alcohol, drugs, or social withdrawal
- An unusual fixation with death, if no such fixation existed before
- Any actions that suggest they are planning ahead for death, such as the giving away of possessions, drafting of a will, or no longer seeming interested in long-term plans or consequences
- Any sudden increase in positive emotions after a period of having been extremely miserable; this may mean that your loved one has a suicide plan

If your autistic relative is showing any of these signs, talk to them about how they are feeling. Remember to:

- Avoid sounding judgmental or telling them that they shouldn’t feel the way they feel
- Listen carefully to what they have to say
- Show empathy
- Take any concerns they have seriously
- Recommend local resources, such as suicide hotlines and support groups
- Ask how you can help
- Alert other trusted people if the person seems to be at a very high risk of suicide, such as if they have the method prepared already and appear intent on carrying out their plan

Involuntary hospitalization is not always the appropriate response when a person expresses suicidal thoughts. If a person is not an active, imminent threat to self or others, hospitalization may actually be unduly disruptive and traumatizing. Autistic people who have been involuntarily hospitalized may be reluctant to seek help afterwards for fear of re-hospitalization, and may even make another attempt after being discharged. On average, people are at the highest risk of dying from suicide just after discharge from a psychiatric inpatient hospital.<sup>65</sup>

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<sup>63</sup> Br. J. Psychiatry, *supra* note 3.

<sup>64</sup> Annette Erlangsen et al., *Short-Term and Long-Term Effects of Psychosocial Therapy for People After Deliberate Self-Harm: A Region-Based, Multicentre Study Using Propensity Score Matching*, 2 *Lancet Psychiatry* 49, 49-58 (2015) (finding that talk therapy, called psychosocial therapy in this study, reduced the risk of suicide).

<sup>65</sup> Harriet Bickley et al., *Suicide Within Two Weeks of Discharge from Psychiatric Inpatient Care: A Case-Control Study*, 64 *Psychiatr. Serv.* 653, 656-57 (2013) (finding that the suicide rate within a week of discharge and before the first appointment was greatly elevated); Daniel T. Chung et al., *Suicide Rates After Discharge from Psychiatric Facilities: A Systematic Review and Meta-Analysis*, 74 *JAMA Psychiatry* 1119, 1119-26 (2017) (finding that the suicide rate during the first three months after psychiatric discharge was far greater than the global suicide rate).

Where appropriate, you may wish to explore less restrictive options first - including removing a person's access to weapons or other items that could be used for self-harm, arranging for the person to be supervised by close friends or relatives during a period of crisis, creating a [safety plan](#), and/or using a drop-in crisis center. Sometimes, a person may simply be expressing suicidal thoughts that they do not plan on acting on. In these situations it may be sufficient to simply talk things through and help set up appointments with someone who can help, such as a doctor, therapist, or clergy member.

We advise carefully evaluating whether you should call the police, if your autistic loved one is a threat to either themselves, you, or someone else. Often, when someone calls 911 to take someone to the hospital, it is the police - not health care workers - who arrive to take them there. Most officers are not trained to interact with a person who is in the midst of a mental health crisis, particularly a person who also has a developmental disability and/or is a person of color. When evaluating whether you or not you should call the police, consider all factors related to the call, including the degree of danger facing your loved one, the availability of other alternatives (such as driving your loved one to the hospital directly), how your loved one might react to the police, what the police's relationship is to your community, and how the police might react to seeing your loved one in distress.

### **Help your autistic family member manage their co-occurring mental health disabilities, if any, and connect them with autism-inclusive peer support groups**

Mental health disabilities are common in autistic people and increase our suicide risk, just as they do in non-autistic people. We may need more support in order to do what is necessary to manage a mental health disability, such as arranging to see a therapist or psychiatrist. If your loved one is struggling with their mental health, it may help to offer (but not impose) your help with setting up and following through on appointments. Supporting your autistic relative's mental health needs without judgment can reduce their risk of suicide.

Although many parents may want to be deeply involved with their loved one's mental health care, it is important to only attend psychologist or psychiatrist appointments, and view your loved one's medical records, when they ask you to. Most people prefer to have privacy when they are dealing with highly sensitive and personal issues, such as their mental health. It can be hard to talk freely when someone else is in the room. This does not mean that they do not want your help in other ways.

Autistic people often benefit from peer support groups for mental health disabilities, but many such groups may not be autism-inclusive. You could propose to your autistic relative that they try out having one meeting with different peer support groups until they find one that best fits their needs. If they do decide to visit a mental health peer support group, advise them to be prepared to advocate for the accommodations that they need. Keep in mind that, because mental health concerns are so common among autistic people, local social groups for autistic self-advocates may also be good places to find support for mental health concerns.

### **Identifying other sources of social support for your autistic relative**

We encourage you to identify as many sources of social support and encouragement for your autistic relative as possible. Suicide is less likely when a person has multiple, significant connections to their community that bolster their sense of purpose and self-worth. Some of these sources could include friends, other family members, school peers and support groups, community organizations, and churches, synagogues, mosques and other religious organizations.

## Resources

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For more information on any of the subjects we talked about in this guide, you can go to the websites and read the documents we list below.

### On Police Violence and Law Enforcement

- The Depression and Bipolar Support Alliance’s “How to Help Someone in Crisis” page: [http://www.dbsalliance.org/site/PageServer?pagename=help\\_crisis](http://www.dbsalliance.org/site/PageServer?pagename=help_crisis)
- The American Psychological Association’s “How to Help Someone In an Emotional Crisis”: <http://www.apa.org/helpcenter/emotional-crisis.aspx>.
- Law for Black Lives, “Freedom to Thrive”:
- <https://static1.squarespace.com/static/5500a55ae4b05a69b3350e23/t/595cf69b1b631b031e0542a5/1499264677929/Freedom+to+Thrive+Web.pdf>
- Participatory Budgeting Project: <https://www.participatorybudgeting.org/participate/>.
- National Alliance on Mental Illness’ page on Crisis Intervention Training: [https://www.nami.org/Law-Enforcement-and-Mental-Health/What-Is-CIT#\\_edn1](https://www.nami.org/Law-Enforcement-and-Mental-Health/What-Is-CIT#_edn1)

### On Safety In the Community

- Federal Communications Commission Information on Text-to-911: <https://www.fcc.gov/consumers/guides/what-you-need-know-about-text-911>
- National Autism Association’s List of YMCA Centers that Offer Autism-Friendly Swimming Courses for Children: <http://nationalautismassociation.org/resources/autism-safety-facts/swimming-instructions/>
- Organization for Autism Research’s Life Journey Through Autism: A Guide to Safety: <https://researchautism.org/resources/a-guide-to-safety/>

### On Abuse and Neglect in Schools, Residential Treatment Centers, and Institutions

- Department of Education’s Parent Fact Sheet, “What Are Public Schools Required to Do When Students with Disabilities Are Bullied?”: <https://www2.ed.gov/about/offices/list/ocr/docs/dcl-factsheet-bullying-201410.pdf>.
- Department of Education’s Dear Colleague Letter, “Responding to Bullying of Students with Disabilities”:
- <https://www2.ed.gov/about/offices/list/ocr/letters/colleague-bullying-201410.pdf>
- Stopbullying.gov: <https://www.stopbullying.gov/>.
- PACER’s National Bullying Prevention Center: <http://www.pacer.org/bullying/resources/parents/definition-impact-roles.asp>
- Department of Education’s Restraint and Seclusion Resource Document: <https://www2.ed.gov/policy/seclusion/restraints-and-seclusion-resources.pdf>
- TASH’s “Shouldn’t School Be Safe? Working Together to Keep Every Child Safe from Restraint and Seclusion at School” booklet: [http://stophurtingkids.com/wp-content/uploads/2013/05/TASH\\_Shouldnt-School-Be-Safe.pdf](http://stophurtingkids.com/wp-content/uploads/2013/05/TASH_Shouldnt-School-Be-Safe.pdf)
- Stophurtingkids.com: <http://stophurtingkids.com/>

## **On Autism and Suicide**

- Safety Plan Template:
- [https://suicidepreventionlifeline.org/wp-content/uploads/2016/08/Brown\\_St StanleySafetyPlanTemplate.pdf](https://suicidepreventionlifeline.org/wp-content/uploads/2016/08/Brown_St StanleySafetyPlanTemplate.pdf)
- PleaseLive's list of abuse hotlines: <http://www.pleaselive.org/hotlines/>
- Crisis Text Line: <https://www.crisistextline.org/faq/>.
- Healthy Children.org's "Ten Things Parents Can Do To Prevent Suicide": <https://www.healthychildren.org/English/health-issues/conditions/emotional-problems/Pages/Ten-Things-Parents-Can-Do-to-Prevent-Suicide.aspx>