

# THE RUDERMAN WHITE PAPER

# ON MEDIA COVERAGE OF THE MURDER OF PEOPLE WITH DISABILITIES BY THEIR CAREGIVERS

**David Perry** 

# With contributions by:

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# THE RUDERMAN FAMILY FOUNDATION

One of our goals at the Ruderman Family Foundation is to change the public's awareness of people with disabilities. More specifically, we make the argument that full inclusion of people with disabilities is not a matter of charity, but of civil rights. We researched this White Paper in order to further the awareness around this civil rights movement. We believe that the results we found will meaningfully contribute to the conversation of media coverage around people with disabilities, specifically the coverage of the murders of people with disabilities at the hands of their caregivers—a topic that needs to be addressed more extensively by media outlets, journalism courses, and the public at large.

#### **Our Mission**

The Ruderman Family Foundation believes that inclusion and understanding of all people is essential to a fair and flourishing community.

Guided by our Jewish values, we support effective programs, innovative partnerships, and a dynamic approach to philanthropy in our core area of interest: advocating for and advancing the inclusion of people with disabilities in our society.

The Foundation provides funding, leadership, expertise and insight in the U.S. and Israel, with offices in both countries. Visit us at: <a href="http://www.rudermanfoundation.org">http://www.rudermanfoundation.org</a>

# **AUTHOR**

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# CONTRIBUTORS

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**Zoe Gross (for the Autistic Self Advocacy Network)**. The Autistic Self Advocacy Network (ASAN) is a 501(c)(3) nonprofit organization run by and for autistic people. ASAN seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy the same access, rights, and opportunities as all other citizens. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us!

**Kristina Kopić** is the Advocacy Content Specialist at the Ruderman Family Foundation. Some of her chief research and pedagogic interests lie in deconstructing social constructs that govern cultural norms and behavior—in particular the constructs of race, gender, and disability. She comes to advocacy from the field of academia where she taught rhetoric and research. She has worked on all the previous Ruderman White Papers in various capacities. In this one, she is responsible for the demographic analysis.

**Vilissa Thompson** Vilissa Thompson, LMSW is a macro social worker and disability rights consultant, writer, and advocate. She is the founder of Ramp Your Voice!, an organization focused on promoting self-advocacy and empowerment among people with disabilities. Vilissa is afforded the opportunity to be a leader and expert in addressing and educating the public about the plight of people with disabilities, particularly women of color.

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Neurodiversity.com, an autism information portal noted for its advocacy writing and coverage of autism research and vaccine-injury litigation; co-author of the 2016 report, A Worldwide Survey of Encryption Products; and curator of the public domain art gallery PortableImagery.com. Seidel is a member of the Board of Directors of CIRCARE, which advocates for the welfare of human research subjects. She lives and works in New England.

**Note:** The views expressed in this document are solely those of the author.

# WARNING

This document contains graphic descriptions of murder and other forms of violence.

# LANGUAGE DISCLAIMER

We at the Ruderman Family Foundation want to acknowledge that language use in the context of disabilities is an important issue that generates both strong discussion and strong feelings. The most frequent point of contention is whether people-first or identity-first language should be used. While it is our policy at the Ruderman Family Foundation to use people-first language (i.e. a person with a disability), we acknowledge that several segments of the disability community prefer identity-first language (i.e. a disabled person). The author of this Ruderman White Paper intends to follow the best practices of the self-advocates within any given community, and will vary usage as seems appropriate when it comes to general descriptions of disability.

The Ruderman Family Foundation and the writers of the Ruderman White Paper denounce the use of any stigmatizing or derogatory language.

# **EXECUTIVE SUMMARY**

# **Overview**

National data repeatedly indicates that people with disabilities are at higher risk for violent crime than people without disabilities. The deaths of people with disabilities at the hands of caregivers, including parents, is a particularly tragic subset of this broader pattern. Moreover, when journalists cover the deaths of this vulnerable segment of the population, the focus is often directed at the murderer. Journalists, consciously or unconsciously, often write stories that build sympathy for the murderer and the circumstances that led them to their crime, while the person with a disability is erased from the story.

We have examined over 200 news reports about cases in North America between 2011-2015 that clearly describe the murder of a victim with a disability by a parent, child, spouse, or unrelated caregiver.

# **Findings**

- At least 219 disabled people were killed by parents and caregivers between 2011-2015—an average of approximately a murder a week. This is a very conservative number due to under-reporting and the fact that a victim's disability is not always made public. The real numbers are likely much higher.
- The killers routinely claim "hardship" as a justification for their acts. The media rarely questions such claims or asks for comment from disability rights organizations, and especially not from people with disabilities themselves.
- In the drive to explain a killing, the lives of the victims get erased resulting in killer-centered, rather than victim-centered reporting.
- Spreading the hardship narrative may lead to more violence, rather than changing policy around supports. In many cases, moreover, the narrative is fundamentally not true.
- Many killers receive little to no prison time. In such cases, perceptions of disability as suffering inform judicial decisions not to punish murder.

# **Best Practices**

- **Tell victim-centered stories**. Don't just report what the killer says about the victim, which will always be dehumanizing. Do the journalism to find out more about the victims' lives, their desires, their agency.
- **Talk to experts in disability**. The disability rights community follows these cases closely and will provide expert commentary. Remember, most caregivers do not kill

- disabled people, so blaming a killing on disability-related hardship is never the full answer.
- **Challenge the claims** of defense attorneys and perpetrators. Investigate whether the claims of defense attorneys and perpetrators are accurate. When prosecutors treat such cases lightly, investigate whether they treat cases involving non-disabled victims the same way.
- **Provide Context**. These cases are rare (there are around 450 cases of parents killing children every year in the United States), but not unique. They need to be put in context so the consequences of dehumanizing disabled people can be made visible to the general public.

# **SECTION ONE: INTRODUCTION**

On December 14, 2016, Dorothy Spourdalakis and Agatha Skrodzka were released from prison after serving three years for the killing of Spourdalakis' son, Alex. In 2013, Spourdalakis and Skrodzka, his godmother, had first tried to poison the 14-year-old boy with sleeping pills, but that didn't work. So they stabbed him repeatedly in his chest with a knife and slashed his wrists. Here's what the local Chicago-area ABC affiliate had to say about their release:

The judge sentenced them to time served. The women got credit for the three years they've spent at the Cook County Jail, which is why they were released. Spourdalakis, who said she struggled to care for her son, walked out of prison a free woman. Despite spending three years at Cook County Jail, she had to come to Logan Correctional Facility in downstate Lincoln, Ill., to be processed for her release. She declined to speak to reporters as she left.

"She is relieved, very anxious and a little scared," said her attorney, Mike Botti. Spourdalakis and her son were featured in a film about the family's struggle by an autism activist group. She said she needed help, but none was available... Initially, they were charged with first-degree murder, but the State's Attorney reduced the charge. Their attorneys said the two women feel an immense amount of guilt they will have to live with.

Everything in this local news report, which is typical of the mainstream media coverage the incident has received over the past three years, is a reportable detail. Almost none of it, though, is necessarily true.

Spourdalakis did struggle to care for her son, obviously, but that says more about her and her choices than the basics of caring for autistic people, even those who have high support needs. Moreover, Spourdalakis received multiple offers of assistance from both state and private bodies. An Illinois Department of Children and Family Services (DCFS) spokesperson, after the murder, told *The Chicago Tribune* that "Family members refused DCFS referrals to community-based services ranging from respite to psychological counseling." Mary Kay Betz, then executive director of the Autism Society of Illinois, told the same paper that after seeing Spourdalakis in a video online, she went to meet the family and promised to do whatever she could to get the mother the support she needed. According to Betz, "Spourdalakis said all she wanted was an attorney."

The death of Alex Spourdalakis, in other words, is complicated. The mainstream media coverage, broadly speaking, simplified it. It involves the many fractures in the autism community, including those who seek to profit from fear of vaccines or misplaced

belief that the disease can be purged with quack cures. It's likely that the Spourdalakis family, due to interactions with disgraced doctor Andrew Wakefield, believed Alex' autism could be cured, and perhaps that failure in part led to the violence. It's hard to know.

What's easy to know is this: **No media report should simply voice the denials and excuses of two killers who murdered an autistic child in their care without, at least, providing some context and counter views**. That's just the basics of good journalism. To do otherwise is to assist in spreading stigma about disabilities, promoting the idea that hardship narratives are both reasons to commit murder and shields against significant criminal penalties, and arguably even enabling the next killing.

For this White Paper, we looked at the media coverage of 260 cases of the killing of disabled people by the parents or other caregivers, ultimately narrowing our sample down to 219 cases in which the circumstances were clear. The cases date from January 2011 to December 2015. The cases range from clearly intentional acts of murder to death through neglect; the victims have a wide range of disabilities, and the legal outcomes vary from acquittal or no charge to lengthy prison sentences.

# Our goals:

- Identify and assess the patterns in coverage. Analyze how those patterns might contribute to stigmatization of disability and disabled people and even intensify the risks of future crimes.
- Provide a comparative framework so that journalists covering such a story in their own community might have easily accessible references.
- Highlight the efforts of the self-advocate community to combat disability stigma, to demand victim-centered stories, and work for change.

# SECTION TWO: OVERVIEW—Filicide in America and the Media

When parents and caregivers murder their disabled children, spouses, siblings or clients, the news media far too often rushes in to explain, justify, and forgive the murderer. They produce "killer-centered" stories that link disability to hardship, hardship to murder, and erase the victim's life and death from the narrative. Judges, prosecutors, and juries tend to go more leniently on murderers whose victims are disabled, and the media tends to report such light sentences as understandable rather than outrageous. Reporters almost never quote experts on disability rights, nor do they ask people with disabilities to comment. Instead, local beat reporters, chasing deadlines, quote neighbors who blithely state that the murderer truly loved his or her victim. Comment threads and social media hashtags proliferate emphasizing empathy for the killers, but rarely seem to ask about the victim.

Overall, such coverage leads to further dehumanization of people with disabilities, spreads the idea that their lives are worth less than non-disabled lives, and contributes to the exclusion of people with disabilities.

While many disabled people have long recognized the prevalence of this issue and the problems with the coverage, awareness intensified thanks to the work of then-college student Zoe Gross in 2012. Gross, who now works for the Autistic Self Advocacy Network (ASAN - see their statement in section 5 of this document), founded the "Disability Day of Mourning" (DDoM) in collaboration with ASAN, Not Dead Yet, and the National Council on Independent Living, as "a nation-wide vigil commemorating the lives of people with disabilities murdered by their parents or caregivers." It's now global. The website for the DDoM, provides a list of names of victims dating back to 1980, from which we drew our initial data set. ASAN also publishes an anti-filicide toolkit. Thanks to the work of these self-advocates and their allies, the disability community is increasingly helping to contextualize filicide and related violence as a systemic problem, rather than regarding each death as a discrete tragedy.

That awareness has not permeated media culture, nor is there a great wealth of cross-disability scholarly analysis (see the resource section for a partial bibliography). We hope that our spreadsheet will provide a useful starting point for journalists or scholars looking for data or context. Most importantly, though, we hope **to fundamentally change how journalists report filicides and related murders by caregivers of people with disabilities**.

To support our research, we compiled data, based on media reports, on 260 deaths from January 2011 to December 2015 and included 219 deaths in our sample. While we are certain this is a significant undercount in the number of deaths of this sort, even this

dataset demonstrates that a person with a disability is killed by their parent or other caregiver approximately every week.

In the following sections, we will present first a quantitative analysis of the whole dataset, followed by a qualitative analysis of the coverage from 2015. Our findings are that the cases are broadly distributed across the country, happen to mostly children and teenagers, but also the elderly (and less often to people in between), and approximately affect both genders evenly (110 male victims, and 109 females victims). We found that most of the news reports focus on white victims, and least on Native American victims. And a plurality of victims have multiple disabilities. On a qualitative basis, far more stories focus on the killers than the victims, while sourcing is usually confined to neighbors speaking about how much the killers loved their victims. Almost no experts in disability are quoted (those who are come from Departments of Children and Family Services). No people with disabilities are quoted.

We in the media can, and must, do better.

# **SECTION THREE: METHODOLOGY**

We drew our data from the Disability Day of Mourning website, further narrowing cases to select only those from 2011-2015 for which the basic facts were broadly accepted by all parties. We wanted to avoid more recent cases in which facts are still emerging, in particular. But there is no question that our 219 cases are a significant undercount of all the people with disabilities killed by those responsible for providing care and support.

**Types of murders**: We have included cases in which the perpetrator was a spouse, parent, child, or any other relative, or an unrelated person who was the victim's caregiver. Based on this definition, we have excluded cases where:

- The person with a disability was murdered by a sibling who cohabited, but could not be determined to be a caregiver.
- The person with a disability was murdered by a friend, lover, or roommate who was not a caregiver.
- The person with a disability died, but the court records and media coverage strongly indicated that the death was an accident, or the cause of death could not be determined as murder or manslaughter.
- The victim could not, based on the available coverage, reliably be identified as a person with a disability.
- The cause of death is unclear or the victim is ruled to have committed suicide.

Due to this strict criteria, as well as the limitations of the legal and press systems, the 219 figure is a definite under-representation of the murders of people with disabilities at the hands of those closest to them. We narrowed the selection criteria in order to analyze media coverage in the most clear cases.

# SECTION FOUR: MEDIA ANALYSIS—Quantitative and Qualitative

# **Demographic Summary**

We analyzed the data for age of the victims, gender of the victims and murderers, types of disabilities, race of the victims, relationship between the victims and perpetrators, and provided a state-by-state breakdown of the data.

Overall, we found that the cases come from across the country and a wide array of ages, races, genders, and relationships. Children are especially vulnerable to this type of crime, parents are the most likely perpetrators, white Americans were most likely to kill or be killed. Of note, while male and female victims (we have no data on whether any were non-binary, in fact) are equal in number, women were slightly more likely to perpetrate such crimes than men. This stands in contrast to the national data on murder, and likely reflects the prominence of women in caregiving roles. More study is needed on all these demographic issues.

All data is published in the accompanying spreadsheet

# **Demographic Analysis**

This section provides a demographic overview of all 219 cases we studied for the 2011-2015 time period.

Figure 1



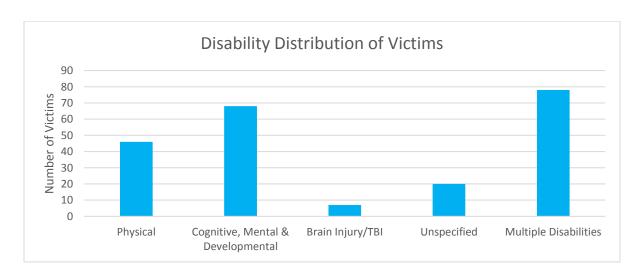
As evident in Figure 1, most victims are children between the ages of 0-18, with the 11-18 category containing the most victims. According to our data, children are sadly the most frequent victims of this type of crime. There is a clear decrease of victims ages 36-45, but from there we can see another rise as the age goes up. The slight dip we see in ages 66 and up can be attributed to the fact that there is a lower percentage of the population in that category.

Figure 2



There is virtually no difference in gender when it comes to the victims. Males and females with disabilities seem to be equally likely to be victims. As noted above, if any of the victims were non-binary gendered, we did not have that evidence.

Figure 3



We divided the victims into rough and basic categories of disability. It appears that people with cognitive and developmental disabilities are among the most victimized, second only to people who have multiple disabilities.

Regarding the race of victims, as shown in Figure 4 below, we see a disproportionately high number of white victims. This statistic is unlikely to be due to white people with disabilities being more likely to be killed by their caregivers. A more likely explanation is that because our data set is solely based on media coverage and not on court or death records, it may be possible that cases that involve white victims are more likely to be covered by the media. With that said, we still believe that this is an area that needs more research to explain the race distribution we see in relation to our population demographics.

Figure 4

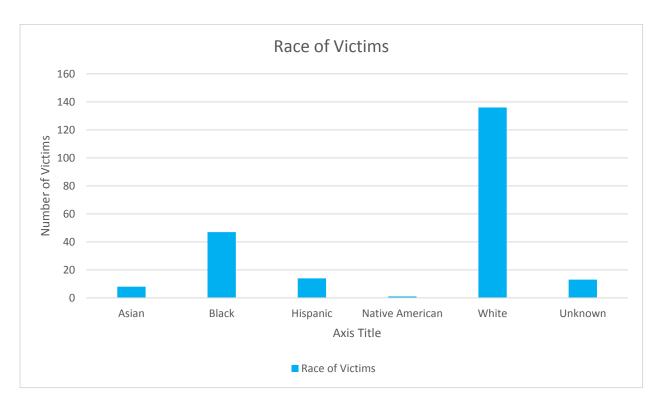


Figure 5

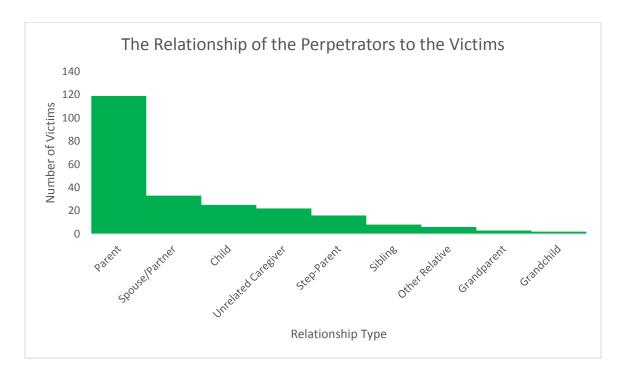
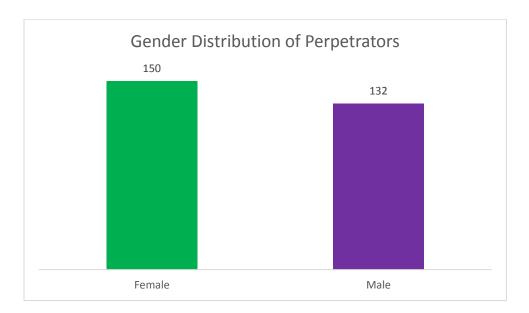


Figure 5 indicates that the most common relationship between a victim and their killer is that of parent to child (119). This finding is consistent with our finding that the majority of victims are children. The second most common relationship is that of spouse or domestic partner, though for this figure we counted reports of "boyfriend" and "girlfriend" in the spouse category. Again, this disproportionate representation of parents among killers may be due to over-reporting rather than an actually greater tendency for filicide among parents. We feel more research is needed on this point.

It's also important to note here that the reason the number of perpetrators is greater than the number of victims in this figure is that more than one person was implicated in several murders.

Figure 6



Out of all the implicated perpetrators, females outnumber males by a little. However, this difference of 18 people is significant because in general males commit approximately 90% of murders according to FBI data. The significant overrepresentation of female perpetrators we see here may be due to two factors: One, women still are responsible for the majority of caretaking in our culture and by virtue of our focus on caretaker murders, they constitute a majority. But the second factors could yet again be ascribed to media coverage itself. Because women murder so rarely, and due to American gender norms about women and mothers, filicide perpetrated by mothers easily becomes sensationalized in the media.

Table 1

State	Number of Cases	Approximate Population of State in Millions
Alabama	2	4.9
Alaska	0	0.7
Arizona	6	6.9
Arkansas	1	3.0
California	15	39.2
Colorado	2	5.5
Connecticut	4	3.6
Delaware	0	1.0
Florida	21	20.6

Georgia	11	10.3
Hawaii	0	1.4
Idaho	0	1.7
Illinois	11	12.8
Indiana	4	6.6
Iowa	0	3.1
Kansas	0	2.9
Kentucky	3	4.4
Louisiana	3	4.7
Maine	0	1.3
Maryland	5	6.0
Massachusetts	2	6.8
Michigan	10	9.9
Minnesota	2	5.5
Mississippi	2	3.0
Missouri	5	6.1
Montana	0	1.0
Nebraska	0	1.9
Nevada	3	2.9
New Hampshire	2	1.3
New Jersey	1	8.9
New Mexico	0	2.1
New York	7	19.7
North Carolina	3	10.1
North Dakota	2	0.8
Ohio	11	11.6
Oklahoma	7	3.9
Oregon	2	4.1
Pennsylvania	11	12.8
Rhode Island	0	1.1
South Carolina	6	5.0
South Dakota	0	0.9
Tennessee	4	6.7
Texas	16	27.9
Utah	2	3.1
Vermont	1	0.6
Virginia	6	8.4
Washington	7	7.3

West Virginia	0	1.8
Wisconsin	8	5.8
Wyoming	0	0.6
Washington, DC	1	0.7
Canada	10	35.1

The source for the population estimates in Table 1 is the <u>US Census Bureau</u>. Looking at the distribution of cases per state, it is evident that murders committed by caregivers happen across the country, but the numbers of cases do not scale with the population in each state. For example, we found eight cases in Wisconsin, which has an approximate population of 5.8 million, and 7 cases in Washington which has 1.5 million more people. This discrepancy can yet again be ascribed to reporting interests, but also to state laws. The accessibility to information for journalists varies in each state. For example, Florida has some of the most permissive laws regarding access to official records and so we see the largest number of cases reported on in Florida (21) even though it is the third-largest state.

# **Qualitative Analysis - 2015**

We closely read 101 media reports on 66 different deaths that took place in 2015 (see the Analysis 2015 tab in the spreadsheet), focusing on early local news coverage rather than later commentary. First, we wanted to know whether the stories focused mostly on the killer, the victim, or were neutral. This was a largely subjective analysis to test the sense that media outlets rarely discuss the victims in these cases, or do so to a much lesser extent than the killers. Second, do media reports blame disability? How often is a killer's claim that a victim was suffering reported without pushback, or do journalists repeat claims about lack of services, the challenges of caring for a disabled person, or disability-related costs? Do reporters raise the possibility that the killers were themselves mentally ill or otherwise disabled? Third, do journalists speak to any disabled people at all or talk to experts in disability (medical or advocacy), some of whom of course may be disabled?

These stories tend to treat the deaths as context-free tragedies, only sometimes engaging governmental officials from Children/Family services, and never talking to other disabled individuals or experts from local or national disability-rights groups. Most stories are neutral. Others, though, portray disability as causing such suffering as to implicitly justify murder.

In this section, we will review some general numbers, then look closely at specific cases and stories. For each article, we examined whether the journalist focused mostly on the

killer, the victim, or whether they tried to stay neutral. This was a qualitative value judgment, but will become clearer as we look at the specifics.

The patterns of problematic language was clear. Most were not explicitly prejudicial, but even neutral cases did nothing to connect one incident with the broader problem. The bad stories offered horrifically biased statements (often from neighbors, but without context). The victim-centered stories that demonstrated competency on disability rights issues were few.

# Breakdown of Focus, Murder Motive, and Article Sources

#### **FOCUS:**

One of the central premises of the anti-filicide movement is that media coverage tends to focus much more heavily on the killers and their motivations than on the victims and their lives, likes and dislikes, and their desire not to be dead. Here are the results:

- 57 articles presented neutral "just-the-facts" reporting, with little speculation as to the motivations of the killers or the experiences of the victims, or with a balance.
- 29 explored the motivations of the killers to some extent.
- 15 provided information on the lives of the victims.

#### **MOTIVATIONS:**

- 16 stories explicitly suggested that the murder was committed to end the victim's suffering, although the victim did not request to die.
- 14 stories cited the difficulty providing caregiving as a justification for murder.
- 10 suggested that the killer might be disabled, usually related to mental health, as a way of explaining the murder.

#### **SOURCES:**

- ZERO stories quoted any person who identified as disabled while reporting on the murder of disabled individuals.
- Zero stories referred to violence against disabled people in any broader context.
- 6 stories quoted experts from the state divisions focused on protecting children's welfare. One story quoted someone who works for The Arc of Illinois.

# **CASE STUDIES**

The problems of reporting become most visible when looking at case studies. This section engages stories of neglect (often covered well), murder-suicide (rarely covered well), filicide, and the murder of spouses. We will also look at social media reactions in a few instances.

The two most common issues were the reporting of testimony from accused killers as simple fact and quoting neighbors, often neighbors in shock, talking about how much the killers loved their victims.

# Stories Covered as Mercy Killing and Suffering

There's a pervasive, society-wide, notion that disability simply equates to suffering. Many people do experience all kinds of difficulties related to all sorts of conditions. Too often, though, the assumption is that to be disabled is to be in distress and that to be in distress is to wish to be dead. In such contexts, murder appears not to be a violent crime, but an act of mercy, stripping agency away from the murder victim.

Journalists continue to explicitly use the phrase "mercy killing." More perniciously, they imply that killings are merciful without using the phrase. Some examples.

# **EVELYN HARVEY**

*RT*, a Russian-backed American news outlet generally staffed by western journalists, often covers on the American criminal and legal system from a critical position. <u>It reported on the murder of Evelyn Harvey</u>, 93, by her husband, 91, suggesting that the murder charge was a sign of America's overly extreme system. The authors wrote:

It may have been an act of mercy when a 91-year-old Texas man shot his wife of 65 years. She was terminally ill, after all. But police have charged the nonagenarian with murder. Evelyn Harvey was 93. She and her husband Nelson, 91, had been living in an El Paso retirement home for nine years as she fought a terminal illness. Then, between 9:00 and 9:30 local time Saturday night, Nelson shot her in the back of the head. He was tired of her suffering, he later told police.

One 90-year-old man murdering his terminally ill spouse is, to be sure, a complex story. This article, though, centers on the husband, tired of his wife's suffering, who then chooses to end it. Her volition gets no attention.

# **DUSTIN HICKS - "Possible Mercy Killing"**

In November, 2015, Nina Hicks, 53, of Dawsonville, GA, shot and killed her 14-year-old son, Dustin Hicks, before shooting herself. Dustin was autistic and had Crohn's Disease. 11 Alive

News, a local NBC affiliate, <u>titled their story</u>: "Dawsonville mother kills son, self, in possible mercy killing." They followed that with the lede: "Murder-suicide or mercy killing?" After some outcry on social media, the outlet changed their language to a more neutral. "<u>Police:</u> <u>Dawsonville mother shoots disabled son, self.</u>"

# Joann Canfield JOANN CANFIELD - "Their neighbors say they were very much in love."

Jerry Canfield, a 72-year-old Californian, shot his wife Joann after bringing her home from a nursing home. Joann had dementia. The story itself is nuanced, offering Jerry's claims that he was fulfilling a promise to Joann and quoting lots of neighbors citing their love for each other, but also providing a reference to <a href="The Family Caregiver Alliance">The headline</a>, though, reads: <a href="72-year-old California man Charged with Murder in Wife's 'Mercy Killing.' A followup article from the *Daily Democrat* on his sentencing followed the same pattern, "Alameda: Elderly man sentenced to 3 years in wife's mercy killing." We were unable to locate articles that assessed whether, in fact, Joann had ever expressed a wish to die in any other context. "Mercy" is simply assumed.

# JEAN CAROL ADAMS - "Put her out of her misery"

In Waco, TX, 77-year-old Alvin Adams shot his wife Jean, who was also 77 and had leukemia. Here the word "suffering" is used in a way that immediately presents the murder as understandable. The first three paragraphs read:

Waco police have obtained an arrest warrant for a Waco man who they say ended his 77-year-old wife's suffering by shooting her at their home Monday morning.

Judge Ralph Strother of Waco's 19th State District Court signed an arrest warrant Monday evening charging 77-year-old Alvin Adams with murder in the death of his wife, Jean Carol Adams, who police say was under hospice care and suffering from leukemia.

Waco police spokesman Steve Anderson said officers continue to investigate. He said Adams, apparently "seeing her in so much pain and suffering, put her out of her misery."

She may well have been suffering, but note how immediately the killing is explained as ending suffering, without pausing to consider whether the wife wished her suffering to end or whether there would have been good alternatives to alleviate any real or perceived suffering.

This article did quote a local expert in caregiving, but there too the narrative focused on being overwhelmed, instead of the clearer message - don't kill your spouse! The article reads:

Inez Russell, executive director of Friends for Life, which helps the elderly and those with disabilities, said there are many local resources available for caregivers who feel overwhelmed and need help.

"I think we have people who are dealing with carrying heavy burdens while caring for a spouse and they need to reach out and get help, whether it is somebody to counsel with them or somebody to help provide some of the services the spouse might need that is making it too much for them to deal with," Russell said.

# Stories Focusing on Burdens of Caregiving COURTNEY LILTZ - "Bonnie deserves an award."

Many of the above stories make the link between difficulty caregiving and the decision to commit murder. It was certainly a major trope in the Spourdalakis case, with which this white paper opened, both in the media and in court. In fact, the Spourdalakis defense cited another case from the greater Chicago area, the murder of Courtney Liltz. In June 2015, Bonnie Liltz crushed up medication and put it in her adopted daughter's feeding tube. Courtney, a 28-year-old woman with Cerebral palsy, died as a result. Liltz then took more of the drugs with a glass of wine, but did not die, and so was charged with murder. She pled guilty, was sentenced to four years, but released after a few months and her sentence was suspended.

The details have generated ample press since the incident. The stories often emphasized the difficulty caregiving for a disabled adult and Bonnie's love for Courtney. This piece from the *Chicago Tribune*, from not long after the murder, offered a lot of context, including quotes from other parents and people from The Arc of Illinois. It did not, however, quote any people who identify as disabled, and it offered this quote near the beginning:

"I don't believe in breaking the law, but I do believe there's a desperation point that people reach," Cheever said. "Bonnie deserves an award for the years of sacrifice she gave for her daughter. She is not a murderer."

Obviously that's a genuine quote and a sentiment that a person is entitled to have. A journalist, however, who wants to use that quote, needs to provide broader context about filicide in America before enabling a friend to say that a murderer deserves a medal for the care she once provided.

# **CAROLYN HAGER**

Hager, 78, was killed by her husband William, 86, in 2016, so isn't in our data set. The media - including social media - response to her story was telling. <u>As reported in the New York Times</u>, Hager claimed that he killed his wife because they couldn't afford her medicines anymore, and she was in pain.

The story took place in the context of the presidential election in which health care reform was a major issue, so social media, <u>particularly Twitter</u>, seized on the story. For many, it was a perfect example that our society's healthcare system was broken. The fact that a man murdered his wife, a woman who did not ask to be killed, was largely missed, until the disability rights community began writing and commenting. The story became about healthcare reform, not murder, and Carolyn was erased.

# The Problems with Reporting Testimony

#### **HAKAN ERDEM**

Murder-suicide cases present journalists with significant challenges, especially when the perpetrators are parents or aged spouses. As we will see in the best practices section, self-advocates and self-advocate-led organizations emphasize telling victim-centered stories, and never implying that disability justifies violence. Such practices are not consistently followed.

Hakan Erdem, 12, was murdered by his father in Lawrenceville, GA. Here's how the local paper explained the murder:

The boy had a hard time. With cerebral palsy, Hakan Erdem, a Sweetwater Middle student, was 12-years-old but couldn't care for himself. He screamed uncontrollably, even through the night. He had trouble communicating. He wore a diaper.

Those issues were part of what drove his father, 47-year-old Fikri Erdem, to cut the child's throat with a kitchen knife, killing him on Nov. 16, according to testimony given Wednesday in a courtroom at the Gwinnett County jail.

Note how the article starts by describing Erdem's life in the worst way possible, then finishes by acknowledging it comes from testimony intended to exculpate the murderer. There are, of course, many people with communication challenges and significant care needs who are not murdered by their caregivers or parents.

# The Problems with Quoting Neighbors: Love and Niceness Do Not Negate Murder

When reporters come upon a murder, they frequently turn to family members and neighbors for their initial quotes (along with law enforcement officials). This is an understandable practice, but it leads to highly prejudicial remarks being featured and setting the narrative for an incident. Reporters rarely balance such remarks by engaging local or national disability rights experts and self-advocates. Here are some examples.

# EMILY KAMINSKI - "Act of Love"

Kaminski, 16, was murdered by her grandmother Marshelle Newby. <u>Newby first gave her granddaughter a fatal overdose of medicine, then took pills herself, and died</u>. Before the cause of the deaths were clear, though, neighbors and family members were already reporting this as a case in which a loving grandmother murdered her family member out of love. <u>NBC San Diego reported</u>:

While most questions still remain unanswered in the <u>deaths of a district attorney</u> <u>staffer</u> alongside her 16-year-old granddaughter, a family friend said whatever happened ended years of love and heartache.

A close friend and some-time caretaker added:

"I'm far more inclined to consider it a dual euthanasia, that this was ending years of agony, and suffering and heartache," said Wayne, adding that she is not sure what happened.

She does know, however, what an emotional and physical toll it took on Marshelle to care for Emily.

Whatever happened, she fully believes it had to be an act of love from Marshelle, who Wayne described as a "wonderful person and phenomenal grandmother."

There is, however, no evidence that Kaminski wanted to die, making this murder, not euthanasia, regardless of what the friends say.

# NICHOLAS RICHETT - "He really loved Nicky"

A similar story was reported by Fox 2 Detroit in June of 2015, regarding the murder of Nicholas Richett, 20, an autistic young man. The reporter quoted a neighbor, saying, "You could tell he really loved Nicky...He took care of him. Although Nicky was really tough to handle." We are not arguing about the presence or lack of love in the relationship, but only

that this killer-centered story tells us nothing about Nicholas, his likes and dislikes, hopes, dreams, strengths, weaknesses, or otherwise humanizes the victim. Instead, the emotional content focuses solely on the father's love. This article should, though, be credited with providing resources to other people considered taking their own lives by calling Suicide Prevention lines. There are no resources for murder prevention listed.

# THE STACK FAMILY - "He loved that family very much"

In Elmhurst, Chicago, Francis Stack Sr., then 82, shot and killed his wife, 82-year-old Joan Stack, 48-year-old Francis Stack Jr., his son, and 57-year-old Mary Stack. Joan had cancer and both children were autistic. A neighbor told reporters:

"He loved that family very much and I think the burden got too much for him," he said. "He did mentioned to someone else wouldn't it be nice if they could all go together.

While police continue to investigate, Sterchele [a neighbor] believes Saturday night – Stack made that thought a reality.

"We have all come to the same conclusion that we all really admire him for what he did," said Sterchele.

Stack chose to kill three people and then himself. There's no evidence that the people he killed wished to die. Yet, the neighbor is reported admiring the man for committing murder. That may be a genuine sentiment from the neighbor, but the highly prejudicial commentary devaluing the lives of disabled victims requires comment from the self-advocate community.

# BETTY ROWLAND - "They're just awfully nice people."

Donald Rowland, 88, stabbed his wife Betty (86) to death, and then stabbed himself. Again, neighbors were consulted by local reporters for the *Columbia Tribune*.

Polly Reed, who said she has known the Rowlands for nearly the entire 30 years she has lived on Woodrail Terrace, said Betty Rowland was a beautiful dresser and an excellent bridge player. She was saddened by Betty Rowland's death and shocked that her husband was charged with murder.

"They're just awfully nice people," Reed said.

Despite the grim nature of Donald Rowland's alleged offenses, many neighbors expressed sympathy for him.

"They were a lovely couple. I was very fond of both of them," Welliver said. "It's shocking."

# LONDON McCABE (2014) - "The McCabes, they're good people."

This is a story from 2014, but the grizzly murder (a mother throwing her autistic child off a bridge) caught national attention. A reporter for the *L.A. Times* reached out to a friend of the family and another parent of autistic children, but no autistic people. Instead, the narrative presented is one of stress.

"The McCabes, they're good people," Gorski told the Los Angeles Times by phone Tuesday. "This is not something that I would have ever seen happening." Gorski, whose three children are autistic and whose wife suffers from chronic illness, says he is familiar with the stress Jillian McCabe was facing. "You get isolated, you get helpless feeling, you get depressed, and you get desperate...The McCabes are good people and that makes this so difficult to

understand," Gorski wrote, adding, "the Jillian I know is a loving mother/wife."

# KATHRYN BURROUGHS - "Harry was a wonderful guy."

In Barrington, IL, Harry Burroughs (69) killed his 35-year-old disabled daughter, then killed himself. The *Chicago Tribune* coverage was fairly neutral. The suburban paper, *The Daily Herald*, on the other hand, wrote a glowing piece about the murderer, titled, "Barrington Plan Commission mourns longtime member." Harry, an architect, had been on the commission. The piece quotes a former colleague as follows: "Harry was a wonderful guy, a talented architect, a valued member of the plan commission," Anna Markley Bush, plan commission chairwoman, said Thursday. "I will miss him."

We were unable to find coverage in *The Daily Herald* about his daughter, who Harry had killed. Would anyone miss her?

# EMILY JANZEN - "I know he loved his daughter."

Randy Janzen shot his 19 year old daughter, killed his wife, killed his sister, and then killed himself. The story, <u>as reported by the *Vancouver Sun*</u>, brings together a number of the problematic themes we've explored in this section. Emily had migraines, and the article pins the multiple murders on that fact, reading:

Randy Janzen, Emily's father, confessed in a Facebook post to shooting his daughter Emily because she suffered from terrible migraines and depression that caused her great pain.

He goes on to say, he then shot his wife Laurel because "a mother should never have to hear the news her baby has died."

He writes that he has "great remorse" for his actions, and that his family is in heaven and pain free. He also alludes to shooting his sister Shelly because he "did not want her to have to live with this shame" that he "caused all alone."

The article does give a portrait of Emily's life, but even there, reinforces the notion that the migraines caused the murder, by focusing on the killer's Facebook post. It reads:

According to his post, Emily had been plagued with migraines since elementary school, and they caused her to miss two years at the University of B.C., which he writes, "broke her heart." He said he did not want to see his "little girl hurt for one more second."

Emily's experience with her disability, described as "plagued," gets subsumed beneath her father's interpretations. Towards the end of the article, though, we find out that her father's analysis was wrong:

Emily's Twitter account makes frequent references to being in pain and being in the hospital. Many of her posts spoke openly of her despair, but there were occasional moments of joy reflected in her words too.

"I'm so tired of people making me feel guilty for being too sick to hang out. Do you think I want to sit at home or in the hospital all day? NO"

And then days later, an up moment. "Whenever I start to feel sorry for myself, I just thank God I'm still alive," Janzen tweeted April 24. "I complain about all the pain, but at least I'm here to feel it."

Later, the article turns to family friends.

Shane Dwight was a childhood friend of Randy Janzen. The pair were members of a band called Marauder about 15 years ago. Dwight was the drummer and Janzen was lead singer.

Although Dwight hadn't spoken to Janzen in a decade, he was shocked when he read his Facebook post, saying that he always knew Janzen to be a "kind and loving family man," and he wasn't aware of any drug or mental health issues.

"He was a hardworking man, someone who loved his family more than anything," he said, adding when they were in the band, Janzen was seen as a "big brother" figure,

someone who always wanted to help fix problems. "I know he loved his daughter more than anything and was so proud of her."

As always, these are complicated stories, worthy of full analysis. Journalists have to exercise care presenting murderers as loving family members driven by despair over their loved one's disabilities.

# **Good Models of Presenting the Stories**

# **Neglect**

# **ROSEMARY VINCENT**

In general, journalists handle death-by-neglect cases with more nuance than other types of murders, especially in cases where the motivation seems to have been the theft of benefits. Such cases make the reporting simpler, with clear villains and sympathetic victims.

For example, Mary Beth Lane covered the death of Rosemary Vincent for the Columbus Dispatch. Vincent was 85, neglected by her caregivers and left to starve, and died of pneumonia. The story does not tell very much about Vincent, but also makes it clear that the motivation behind the neglect was venal, writing, "Meanwhile, Blackburn said, the couple stole her Social Security checks and used her food stamp card to buy food for themselves, including Monster energy drinks, while she was malnourished." No one could read this story and come away with the impression that disability is a mitigating factor in the crime.

# **Victim's Stories**

# MAX PETERSON - "A beloved student at East High School"

Max Peterson was murdered by his father when he was 16, in Madison Wisconsin. Most of the story, as covered by the *Wisconsin State Journal*, is about Max. His whole personality, including his disability (Angelman syndrome) is described:

Max was a beloved student at East High School, his obituary said. "Like many teenage boys, one of his favorite parts of the day was gym class, where he could be found shooting hoops and sharing his classmates' fun as they scampered about."

He "thoroughly enjoyed" the numerous jobs he held around the school, the obituary said, such as collecting recyclables and helping clean the cafeteria.

Max is survived by his younger brother, Jacob, with whom he loved to [read] books and [play with] blocks. Max could often be found playing outside, spending countless hours on the slide and shooting hoops, the obituary said.

He enjoyed visiting his grandparents' house, where he played memory games, snacked on Teddy Grahams and greeted visitors while looking outside from their large bay window.

The contrast between this kind of victim-centered reporting as opposed to the previous section's examples is stark. The reader gets to experience the victim as a three-dimensional, relatable person who did not ask to die. This angle would seem simple, and obvious, but is sadly too rarely the case.

# **JOHN PEHOTA**

A story doesn't have to be long or a deeply researched feature to tell a victim-centered story. John Pehota, 77, was killed by his wife, Anna. Here the story seems to be about an argument ending in gun violence, but John was disabled, so qualifies for this study. The article offers a brief paragraph on Anna, then quotes a letter that John wrote in his late 60s.

Ten years ago, in a letter to the editor at the News-Journal, John Pehota described himself as "a disabled 68-year-old man living in Flagler County for 16 years, with a debilitating heart condition." He was writing to note that the county commission was ignoring the needs of "handicapped residents of this county. I am physically unable to walk, let alone carry the implements needed to catch a fresh meal from the free ocean that borders our great country," he wrote.

"Since the ban on beach-going vehicles has taken place, I haven't been able to acquire a fresh fish, nor have I been able to partake of the God-given privilege of using the beach that I so enjoyed since I bought my home in The Hammock." He implored commissioners to reopen the beaches to wheeled vehicles. "With all due respect, if the wheels on the turtle vehicles (which have been banned) won't harm the turtles, then neither will mine nor any of the others that respect the county's wishes," he wrote.

# **DAYNE HATHMAN - A lifetime of hugs**

<u>In a similarly short piece on 6-year old Dayne Hathman</u>, a boy with Down syndrome who was shot and killed by a babysitter, the reporter squeezes in lots of detail about the boy and almost nothing about the killer. Details include:

Dayne was born Aug. 14, 2008. He was diagnosed with Down syndrome, although people who knew him have said that he didn't let the disability hold him back. Family and friends have been reminiscing about the hugs Dayne gave.

"Everybody got hugs," Dayne's next door neighbor Misha Gallatin said. "You didn't have to know him to get hugs."

Dayne didn't limit his affection to people. When he would stay with Gallatin, he'd share his love with the two stuffed deer heads inside her house.

"He loved his deer heads," Gallatin said. "He'd hug them tight and we'd have to say bye to them every time he left. He was pretty awesome."

When he stayed with his grandmother Mary Hathman, he found other targets for his affection. Like a particular tree.

"From the time he could walk, every time we'd get home, he'd walk up to the big tree and say hello and hug it," she said. "And he'd just pet this tree ... If he would have been able to have grown up, I bet he would have gone into some field involving trees."

This writing does play into stereotypes about people with Down syndrome being extra loving, yet is a significant improvement on the kinds of articles that blame disability as suffering or excuse killers on the grounds of difficulty caregiving.

# **Longform Journalism**

Here's one final example from 2015. In late December of that year, Jeff Himmelman of the New York Times Magazine wrote "Four Bodies in Elmhurst," on the Stack murders, referenced above, where the mother had cancer and both children were autistic. It's an exemplary piece of longform journalism, researched and careful, and written under vastly different circumstances than the short-form, breaking news, pieces on which we've been focusing here. Still, its successes suggest a level of nuance and care that other journalists might consider when confronting one of these stories, especially when Himmelman warns against assumptions.

Hearing the story of the Stacks after the fact, it's easy to assume that the parents faced, or believed they faced, an imminent crisis around continuing care for Frankie and Mary. There are waiting lists in many states of up to 10 years for the kinds of group homes that they were living in. If parents or caregivers of children with these types of disabilities die without having arranged for the care of their child, the child's future is left to the state — which may mean an emergency placement at a group home, or at a nursing home or some other kind of bare-bones facility that might not meet the person's needs.

But the Stacks had gotten out ahead of all of that. The financial mechanics of planning for the future of a son or daughter with disabilities are daunting and complex, but in many cases they can be managed with effort and help. There are special-needs trusts, Medicaid waiver services and second-to-die insurance policies that can be set up. The important thing is to plan, and the Stacks had: While Frankie and Mary were still living at home, they attended day programs through Ray Graham, and as Frank and Joan got older, Frank found a way through Medicaid, Medicare, his private health insurance and Supplemental Security Income (S.S.I.) to secure funding for permanent residential placement for both of them in perpetuity.

"They did all the right things," Zoeller said. "They very deliberately planned to make sure that Frankie and Mary had a safe and secure future."

The piece talks to experts in disability and aging, cites ASAN and the Disability Day of Mourning, links this death to the Liltz death, describes the reactions of other disabled (non-verbal) individuals, and otherwise follows all the different kinds of best practices that we will discuss in the following section. It warns us not to make easy assumptions about motives, demonstrates how to engage context, and doesn't erase the stories of the victims or the killers. It's balanced journalism, not prejudicial, and shows the possible - given enough resources and time.

But most journalists don't have that kind of time before they have to file. In the next section, self-advocates will offer their advice to journalists seeking to understand filicide and related murders.

# SECTION FIVE: BEST PRACTICES and SELF-ADVOCATE STATEMENTS

# Statement by Autistic Self Advocate Network written by Zoe Gross

# Say "murder," not "mercy killing"

When a disabled person is killed by a relative or caregiver, don't call it a "mercy killing" - by using that term, you are saying that the murder was a good thing. Use the terms "murder" or "homicide" as you would in other cases. In cases where the killer claims that the victim wanted to die, or asked to die, but there is no evidence of this, you should likewise report the case as a homicide, not an "assisted suicide" or "suicide pact."

# Center the victim

Use the victim's name. Talk to people who knew and cared about the victim, and can describe their personality, likes and dislikes. Include details, and don't limit them to the clinical. What did the victim enjoy doing? What were they struggling with? What are some fond memories from the people in their life? The reader should get the sense that the victim was a real human being.

# Don't give the murderer a platform

Follow established journalistic best practices which are used to avoid encouraging copycat crimes. Focusing on the victim is one of these best practices. Additionally, avoid grisly sensationalism and in-depth descriptions of the method of murder. If possible, avoid using the full name of the murderer in news coverage. Crucially, do not use coverage of a murder to give the murderer a platform. If they have left notes, blog posts, or other writings which describe their life or their intention to commit murder, avoid printing direct quotes from these, and especially do not reproduce them in full. Make sure that your coverage does not focus on communicating the worldview of the murderer.

# Don't take the murderer's word for it

In disability-motivated filicide cases, statements from the murderer about the life of the victim, or about the murderer's motivations, are often reported uncritically. This can include arguments that the victim wanted (or "would have wanted") to die, that the murderer killed out of love or concern for the victim's future, or even details about what level of disability services a family was receiving. When covering a murder, the murderer should not be the sole source of information for any fact that you report.

# Don't present murder as a natural outcome of the situation

In the wake of these murders, we often see articles with headlines such as "Tragic Incident Highlights Struggles of Parents Caring For Children with Autism" or "Killing Draws Attention to Lack of Services for Family Caregivers." These articles first describe the

murder and then include quotes from other family caregivers, or people working with caregivers, in the same local area. These people detail the struggles of family members trying to care for disabled relatives with inadequate services to help them. They often explicitly excuse the murder ("I understand why he did it.") or normalize homicidal urges toward disabled relatives ("Any parent caring for an autistic child has had those dark moments."). Without meaning to, journalists writing these stories portray murder as the inevitable result of caring for a disabled person.

It's absolutely true that people with disabilities and our families don't get enough services, and this is worthy of news coverage in its own right. But there are thousands of families across the country with insufficient or nonexistent services who refrain from murdering their disabled family members. In addition, most high-profile cases have occurred in upper-middle-class communities and have been committed by parents who either refused services, or had more family services than is typical - and the same "lack of services" articles were written about those cases in spite of the facts.

# Other people to interview & other questions to ask

Again, make sure to talk to people who can speak to who the victim was as a person. These people may be the victim's friends, teachers, coworkers, faith leaders, or other relatives.

Local or national disability rights advocates, or representatives of your state's Protection & Advocacy agency, can provide context on the issue of violence against people with disabilities.

If it appears that the victim may have been killed because of their disability, and your state has hate crime laws that include disability, find out if this will be prosecuted as a hate crime. Report the answer either way.

# **Statement by Timotheus Gordon**

While murdering loved ones with disabilities out of fear and ignorance is morally unacceptable, reporting those stories to support the murderers (e.g., the victims' caregivers), recycle stereotypes about certain disabilities, or sanctifying people with disabilities are just as damaging to the disability community as the murders themselves. Stories from the media are just snapshots of one's life; therefore the public only gets to know a small part of a person. If the story about the victim is saturated with negative stereotypes on disability or the story promotes sympathy towards the perpetrators (i.e., the caregivers), then the audience will assume that not only disability is scary and burdensome, but also disabled people deserve to die when the caregivers cannot 'control' them anymore. The disability community will not stand for such portrayals. We already face stigma from our families, peers, communities, and institutions we're a part of (e.g., churches, schools, day care centers, workplace). We also have government officials, including President Donald Trump, who openly attacks people with disabilities through mocking them, taking away (or proposing to take away) essential services & accessibility features, and combating them by suggesting false cures or links to certain disabilities (i.e., the link between autism and vaccines). Reports from various media outlets add to the stigma when they demonize victims of murders by caregivers and sanctify caregivers for 'ending their misery'.

It is imperative for reporters to cover stories of caregivers killing people with disabilities in a way that doesn't stigmatize the disability community. They should use the stories to bring awareness to this act and spark conservations on how to bring more resources to families who need help with caring for loved ones with disabilities. Those stories are also opportunities for audiences to get exposed to preferred means of addressing of a person with a disability and meet people from PWD-led organizations who speak on the issue of media representation/depiction of the disability community.

One of the first things journalists should do when covering stories on homicides by caregivers is to speak with people with disabilities who follow those reports or are affected by neglect or pity from their caregivers. They are the experts because they have disabilities and experience stigma firsthand; they can provide to journalists views on why "mercy killings" is not beneficial and the importance of treating people with disabilities with dignity and respect. Journalists can also refer to disability self-advocacy organizations, such as Autistic Self Advocacy Network or People First. Those organizations can also provide insight to why caregivers killing their loved ones with disabilities is harmful to the disability community.

Additionally, journalists should be mindful of which terms they use to describe people with

disabilities. Certain words or phrases could be view as socially acceptable words to mainstream audiences, but those same terms are not acceptable to the disability community. For instance, autistic people wouldn't like it if a journalist refer to them as "people touched by autism", "people stricken by autism", "people living with autism", etc. Those allude to autism being a burden to the person who has it AND those around them. "Autistic people", "people with autism", or "\_\_\_\_\_ has autism" are more acceptable, but it's still wise to ask someone in the disability community first which term(s) to use in an upcoming story.

When covering stories on "mercy killings", any media professional should ask the disability community which terms are acceptable to use in the story and what should they refer the person with a disability as (e.g., "autistic person", "They have cerebral palsy", "person with Down's Syndrome"). They are the primary sources that journalists to turn to for figuring out appropriate terms to use to describe the disability community. People can also refer to guides that provide examples of appropriate words and phrases to use, such as the National Center on Disability and Journalism and Alabama Department of Mental Health guides.

If one has the desire to respond to the main story on caregivers murdering people with disabilities, or "mercy killings", then I recommend journalists to cover stories on how "mercy killings" and their coverage effects the disability community, disability acceptance and culture, and movements and/or legislature that would prevent such things to continue to happen. Currently, stories that are tied to the main coverage of "mercy killings" either tend to praise the caregivers for killing people with disabilities, eulogize people with disabilities, or demonize people with disabilities. All three points of view severely harm to the disability community and could even drown out voices of people speaking out against those acts of violence.

Reforming how the news outlets depict people with disabilities may take time, and it may take longer periods of time for those who have never been exposed to the disability community before or have been accustomed to accepting mythical stereotypes of people with disabilities. However, those steps can help begin to promote disability acceptance, addressing "mercy killings" in more perspectives, and ultimately ending "mercy killings". If done with care and diligence, then the tools will help journalists connect with the disability community more and spread the message of the dangers of "mercy killings" to the public.

# Statement by Vilissa Thompson, LMSW

The Irresponsibility of the Media Means Life and Death to Disabled People

As a disabled woman of color, when I learn of stories of disabled people who are murdered by caregivers, my heart breaks. These individuals were unique, beautiful, and deserved a fair chance of life as any of us. What angers me when I discover these tragic incidences is the media's gross display of sympathy towards their murderers. This misdirected sympathy paints the perpetrators as "victims" when they acted as judge, prosecutor, and executor in determining that a disabled person was unworthy of living because they became "too much" to care for.

As a social worker and disability rights advocate, I am deeply troubled at the level of irresponsibility on the behalf of the media in the consistent, erroneous depictions of these hideous crimes committed on my people. The media has a long history of representing disability and the disabled experience from an angle that allows ignorance and misperceptions to thrive, which harms our ability to be seen and treated equally in society. These portrayals affords ableism (the social prejudice of disability) to continue, which not only affects disabled people, but also our families.

Due to ableism, many of us and our families are isolated within our own communities. This isolation can create barriers to our ability to access necessary supports and services we need to survive, as well as be fully integrated and included in our communities. For those of us and our families who are within the intersections of race, poverty, living in rural areas, etc., such factors can impact and exacerbate the isolation and inability to access resources that exists. For many families and caregiving relationships, these stressors can become a deadly trigger when we are looked upon as a "burden" or the "source" of the problem that must be eliminated. That distorted thinking and ill "rationalization" by those who care for us can mean deadly outcomes, as we have witnessed time and time again in news stories about the deaths of disabled people at the hands of loved ones and caregivers.

It is the responsibility of the media to end the way it reports the murders of disabled people and validate that these crimes are atrocious acts committed on our community. There are several ways the media can step up for disabled people who are killed, in danger of being harmed, and to become better allies to the community:

• Cease the sympathetic tones given to perpetrators when they commit such acts against members of our community. The misplaced sympathy on the murderers and not the murdered normalizes the actions that occurred. Call these incidences what they actually are - reprehensible murders. Disabled people are being killed by family members and caregivers because they are viewed as

"burdens" or stressors. The disturbing sympathy relied in the coverages of these incidences projects the idea that the slaughtering of disabled people is justified and forgivable. No other deaths committed on individuals based on their identities would be given this kind of leeway; what makes the murders of disabled people different? Absolutely nothing.

- Reach out to disabled advocates whose work cover filicide and the murders of disabled people by their caregivers. This is a passionate topic in our community because we understand how our very existence is devalued, and the history of disabled bodies being stripped of its humanness. The fact that we are still being killed and harmed in society because of simply being disabled is a sickening reality we all live with. It is imperative of those in the media to connect with advocates who can discuss the factors that places our lives in danger, and give them a platform to put pressure on our criminal system to seek justice in these cases. The murders of disabled people cannot and should not go unpunished.
- The term "mercy killings" when it relates to these kind of murders is oxymoronic; there is nothing merciful about what happens to these victims. In fact, these persons suffered the most when they were being killed by their loved ones or caregivers. Labeling these acts as anything but abhorrent occurrences is an utter disgrace to the lives lost. The media has the duty to report the truth, not soften or weaken the impact to make it less jarring for society to digest.
- Finally, stop protecting the characters of murderers by stating how loving they appeared to outside family members, neighbors, and so forth. We do not see those same sentiments dominate when crimes are enacted on non-disabled adults and children. These offenders committed these acts out of sheer selfishness and self-centeredness, not out of love. There is no excuse to be rendered when someone kills another person because they are disabled; to attempt to frame these stories where the characters of murderers are upheld in good esteem is downright vulgar.

Disabled people deserve to live. Disabled people should live in spaces where they are free from having their very lives jeopardized. Disabled people are worthy of being loved and valued. Our lives are not inferior because we are disabled. We are not burdens to our families, caregivers, communities, or society. It is long overdue for the media to understand these truths, and to stop the perpetuation that killing disabled people is warranted and not remain steadfast in demanding that the full extent of the law be sought after and enforced. Cushioning the effects of filicide and caregiving murders increases the pity expressed towards the guilty and fewer convictions seen, both of which can no longer continue or be defended.

# **Conclusions**

The self-advocate statements in this document, like those of so many from the disability community over the years, are simply asking for disabled murder victims to be treated as if their lives mattered. The way forward is clear.

- Place killings in context
- Tell the victim's story
- Speak to disabled people about disability-related violence
- Don't blame disability for the murder of disabled people.

These are simple steps, rooted in the best practices for how we report on many marginalized communities. They should become the norm, rather than the exception.

# **SECTION SIX: RESOURCES FOR CITIZENS and JOURNALISTS**

# **Homicide & Disability Resources**

# **Anti-Filicide Toolkit**

http://autisticadvocacy.org/home/projects/disability-community-day-of-mourning/antifilicide

The Anti-Filicide Toolkit is intended to provide advocates and allies with concrete tools and resources to use in their own communities, including in response to local incidents. The toolkit includes information about how to understand and respond to filicide, frequently asked questions about filicide, and a guidebook for Day of Mourning vigil site coordinators.

# **Disability Community Day of Mourning**

http://autisticadvocacy.org/home/projects/disability-community-day-of-mourning Since 2012, the Autistic Self Advocacy Network, ADAPT, American Association of People with Disabilities, Not Dead Yet, the National Council on Independent Living, the Disability Rights Education & Defense Fund, and other disability rights organizations, have held local vigils across the country to remember disabled people murdered by their family members or caregivers, to bring awareness to these tragedies, and to demand justice and equal protection under the law for all people with disabilities. This year's observance will fall on Wednesday, March 1, 2017.

# **National Center on Disability & Journalism**

# http://ncdi.org

Offers a disability style guide with suggestions on appropriate language and short descriptions of disability-related terms; tip sheets on interviewing people with disabilities and specific disability topics; a library with news stories about people with disabilities; and a roster of disability-related organizations, experts, advocates and people with disabilities who are willing sources for journalists.

# Research on Abuse & Murder of People with Disabilities (General)

Richard Lucardie (2005), "Intrafamilial homicide of people with developmental disabilities," Developmental Disabilities Bulletin 33, no. 1/2.

# https://archive.org/details/ERIC\_EI844473

This paper provides a preliminary description of intrafamilial homicides as they affect PWDD. Content analysis of media accounts of intrafamilial homicides of PWDD describes the characteristics of those involved and the circumstances of the homicides.

Agata Debowska, Daniel Boduszek and Katie Dhingra (March-April 2015), "Victim, perpetrator, and offense characteristics in filicide and filicide-suicide," Aggression & Violent Behavior 21.

http://www.sciencedirect.com/science/article/pii/S1359178915000221

The purpose of this paper is to provide a critical review of most recent studies of parental and step-parental filicide. A detailed review of the literature revealed the importance of certain demographic, environmental, and psychosocial factors in the commission of child homicide.

# Research on Abuse & Murder of Children with Disabilities

Dick Sobsey, Wade Randall, and Rauno K. Parrilla (Augusat 1997), "Gender differences in abused children with and without disabilities," Child Abuse & Neglect 21, no. 8.

http://www.sciencedirect.com/science/article/pii/S0145213497000331

Objective: Two questions were posed: (1) What are the proportions of boys and girls in various categories of substantiated child abuse? (2) Do the gender proportions differ for children with and without disabilities?

Rohini Coorg, MD1 and Anne Tournay (May 22, 2012), "Filicide-suicide involving children with disabilities," Journal of Child Neurology 28, no. 6. <a href="http://journals.sagepub.com/doi/abs/10.1177/0883073812451777">http://journals.sagepub.com/doi/abs/10.1177/0883073812451777</a>

Filicide-suicide, or murder of a child by a parent followed by suicide, has an unknown incidence in both the general and disabled population. As there is no national database, the authors examined known associated factors and newspaper reports to characterize filicide-suicide victims and perpetrators involving children with disabilities.

Rebecca D. Pfeffer (2012), "Autistic and at-risk: The public and personal safety of children with autism spectrum disorders," dissertation, Northeastern University. https://repository.library.northeastern.edu/files/neu:1024

The purpose of this study was to investigate the victimization experiences of children with autism spectrum disorders in the U.S. This study found patterns of victimization that children with autism may be uniquely vulnerable to, including manipulation by peers, physical assault by teachers, the application of traditional methods of punishment that are inappropriate for children with Autism Spectrum Disorders, and academic neglect.

Mark T. Palermo (February 1, 2003), "Preventing filicide in families with autistic children," International Journal of Offender Therapy and Comparative Criminology 47, no. 1.

http://journals.sagepub.com/doi/abs/10.1177/0306624X02239274

Autism has been associated with an increased risk of social victimization, and a recent rise in number of acts of filicide of developmentally disabled children has included several cases of autism. In this article, possible risk factors for filicidal behavior in families with autistic children and prevention strategies are reviewed.

F. Declercq, R.Megarick and K. Audenaert (2017), "A case study of paternal filicidesuicide: Personality disorder, motives, and victim choice," Journal of Psychology Interdisciplinary and Applied 151.

http://www.tandfonline.com/doi/abs/10.1080/00223980.2016.1211983

Although evidence with respect to its prevalence is mixed, it is clear that fathers perpetrate a serious proportion of filicide. This paper presents a fully documented case of a paternal filicide. Noteworthy is that two motives were present: spousal revenge as well as altruism.

# Research on Abuse & Murder of Disabled Adults by their Caretakers

Lori Post, et al. (April 20, 2010), "Elder abuse in long-term care: Types, patterns, and risk factors," Research on Aging 32, no. 3.

http://journals.sagepub.com/doi/abs/10.1177/0164027509357705

The authors investigated types and patterns of elder abuse by paid caregivers in long-term care and assessed the role of several risk factors for different abuses and for multiple abuse types. Among older adults who have experienced at least one type of abuse, more than half (51.4%) have experienced another type of abuse. The findings have implications for those monitoring the well-being of older adults in long-term care as well as those responsible for developing public health interventions.

Debra Karch and Kelly Cole Nunn (January 2011), "Characteristics of elderly and other vulnerable adult victims of homicide by a caregiver: National Violent Death Reporting System—17 U.S. States, 2003-2007," Journal of Interpersonal Violence 26, no. 1.

http://journals.sagepub.com/doi/abs/10.1177/0886260510362890

Homicides of dependent elderly and nonelderly adults by their caregivers violate trust and have long-term consequences for families. Many homicides by caregiver incidents are precipitated by physical illness of the victim or caregiver, opportunity for perpetrator financial gain, mental illness of the caregiver, substance use by the caregiver, or an impending crisis in the life of the caregiver not related to illness. Understanding the vulnerabilities of victims, the characteristics of suspects, and the multiple types of motivations is key to developing effective prevention efforts.

Sofia Lalanda Frazão, et al. (November 2014), "Domestic violence against elderly with disability," Journal of Forensic and Legal Medicine 28.

http://www.sciencedirect.com/science/article/pii/S1752928X14001632

Abuse against elders with disabilities is a growing problem as the world population ages. Though they require mandatory reporting, these cases are most frequently not detected or not reported by health professionals for a variety of reasons, including the difficulty of making an accurate diagnosis. By performing a retrospective analysis of alleged domestic violence cases against elders with moderate or severe disability, presented to medical forensic examination at the North Branch of the National Institute of Legal Medicine and Forensic Sciences of Portugal, in Porto, between 2005 and 2013 (n = 70), we aimed to improve our knowledge of some demographic and forensic characteristics of these cases as well as improve their detection and prevention.

# Research on Representation & Weighing of Disability

Melanie Rock (August 2000), "Discounted lives? Weighing disability when measuring health and ruling on "compassionate" murder," Social Science & Medicine 51, no. 3. <a href="http://www.sciencedirect.com/science/article/pii/S0277953699004736">http://www.sciencedirect.com/science/article/pii/S0277953699004736</a>

This paper examines the politics of "suffering" by considering the Disability-Adjusted Life Year (DALY) alongside a controversial Canadian murder case, involving the killing of a child with disabilities by her father. By examining the politics of "suffering" in the DALY and the Latimer affair, this paper underlines a valorization of the "normal" body in much of the social science literature on health, medicine and suffering.

Richard Lucardie and Dick Sobsey (2005), "Portrayals of people with cerebral palsy in homicide news," Developmental Disabilities Bulletin 33, no. 1/2.

http://files.eric.ed.gov/fulltext/EJ844472.pdf

Through content analysis, employing qualitative and quantitative methods, Canadian media representation of people with cerebral palsy (PWCP) in public life was examined. Stigmatizing language was significantly more frequently used within the context of homicide and cerebral palsy. In 94.74% of media stories, the terms mercy killing or euthanasia were used within the context of Tracy Latimer's homicide. While the Latimer case provided an extreme example of the media associating stigmatizing terms with the killing of PWCP, the same association was made in other cases. Results from this study are discussed in terms of self-categorization theory, media effect, and factors associated with discrimination against PWCP.

Richard Lucardie and Dick Sobsey (2005), "Homicides of people with developmental disabilities: An analysis of news stories," Developmental Disabilities Bulletin 33, no. 1/2.

http://files.eric.ed.gov/fulltext/EI844471.pdf

Over the past decade, there has been increased interest in crimes against people with developmental disabilities (PWDD). While national and international information has been available on homicides of people in general, little attention has been given to homicides of

PWDD specifically. This paper provides a preliminary description of homicides as they affect PWDD. The deaths of PWDD primarily resulted from neglect, burns, beatings, shootings, and asphyxia. Discussion examines media presentation of homicides, research on homicide, models of violence and aggression, and prevention.

Mitzi Waltz (April 1, 2008), "Autism = death: the social and medical impact of a catastrophic medical model of autistic spectrum disorders," Popular Narrative Media 1, no. 1.

http://www.portico.org/Portico/#!searchView/?rft.spage=13?v=1?url ver=Z39.88-2004?rft.genre=article?i=1?cs=1754-3819

This discussion interrogates the continuing impact of the pervasive and persistent usage of debilitating metaphors perpetuating 'historical' superstitions, myths and beliefs surrounding disability. This article examines the real-life consequences of the power exercised through the deployment of derogatory metaphors and their very real effects on care and treatment decisions. The article illuminates how diagnostic categories and their associative metaphors work to situate boundaries of normality with pathologising difference. It concludes by demonstrating the catastrophic effect of the metaphoric dehumanization of autistics that has recently culminated in murder being euphemistically referred to and condoned as 'mercy killing'.

Bette Bottoms, et al. (February 2011), "Gender differences in jurors' perceptions of infanticide involving disabled and non-disabled infant victims," Child Abuse & Neglect 35, no. 2.

http://www.sciencedirect.com/science/article/pii/S0145213411000160

There were pervasive gender differences such that compared to men, women mock jurors rendered more guilty verdicts, perceived the father/defendant as having greater intent to kill his infant, and felt less similar to the defendant. Compared to men, women also believed the father was more responsible and the pneumonia was less responsible for the infant's death, had less sympathy and empathy for the defendant, endorsed more negative beliefs about the father, and were more likely to believe the infant was a unique person. Mediational analyses revealed that these statistically significant effects were explained, in part, by gender differences in attitudes toward the defendant. Further, whether the infant victim was portrayed as severely disabled (versus developmentally normal) had little effect on central case judgments such as verdict, but jurors who believed the infant was severely disabled gave significantly shorter sentences to the defendant, were less likely to perceive the defendant as mentally ill, and felt significantly less empathy for and similarity to the infant victim.