CommunicationFIRST
Because communication is a human right.

ASAN
AUTISTIC SELF ADVOCACY NETWORK

ALLIANCE AGAINST
SECLUSION & RESTRAINT

LISTEN to Us

A Toolkit
About Nonspeaking Autistic People, Meltdowns, and Seclusion and Restraint

February 12, 2021

Introduction: What is This Toolkit?

This toolkit is a joint project by CommunicationFIRST, the Autistic Self Advocacy Network, and the Alliance Against Seclusion and Restraint. It contains resources for writing about nonspeaking autistic people and survivors of restraint and seclusion. While some of the information in this toolkit is meant primarily for journalists and members of the media, it can be used by anyone.

CommunicationFIRST, ASAN, and AASR designed this toolkit as a response to the movie MUSIC, which all three organizations have condemned as a dangerous misrepresentation of nonspeaking autistic people and for its depiction of restraint. A committee of nonspeaking and autistic people organized by CommunicationFIRST watched the film in late January and issued a recommendation that the filmmakers cut scenes that seem to support the use of restraint with autistic people experiencing meltdowns.

This toolkit is designed to be a beginning resource for people who want to learn more about nonspeaking autistic people, methods of communication other than speech, disability representation in media, autistic meltdowns, trauma-informed care for autistic people, restraint and seclusion and their alternatives, and how to best support nonspeaking autistic people and survivors of restraint and seclusion. It is not meant to be a singular resource and we encourage you to view the different resources, especially those written by nonspeaking autistic people, linked in this toolkit.

Here are Some Ways to Support Nonspeaking Autistic People

- Watch LISTEN: a short film made by and with nonspeaking autistics: https://communicationfirst.org/LISTEN
    - A transcript of the film is available on the LISTEN page

- Organize an online watch party with your friends and family
    - Use the Discussion Guide below

- On February 28, watch LISTEN instead of the Golden Globes

- Post about your plans to watch LISTEN on social media
    - "Instead of listening to what someone else has to say about nonspeaking people, tonight I'm listening to them. Please join me. Here's how."
    - Use the hashtags #LISTEN, #ListenToNonspeakers, and #NonSpeakingNotSilent in your posts.
    - Tag CommunicationFIRST, the Autistic Self Advocacy Network, and the Alliance Against Seclusion and Restraint in your posts
    - Twitter: @Communica1st @autselfadvocacy @endseclusion

- Watch any of the movies listed in the section below called "Examples of Movies and Documentaries That Feature or Involved Real Nonspeaking Autistic People in Their Production" with more accurate and sensitive portrayals of nonspeaking autistic people

- Read the blog posts, essays, and articles by nonspeaking autistic people linked in this toolkit. Then keep reading other posts, essays, and articles by those authors.

- Read reviews of MUSIC written by nonspeaking autistic people, including by:
    - Niko Boskovic (2/12/2021): https://www.ocdd.org/february-2021-blog-post/
    - Hari Srinivasan (2/6/2021): https://disabilityvisibilityproject.com/2021/02/06/a-boy-like-me/

ALLIANCE AGAINST
SECLUSION & RESTRAINT

LISTEN Film Discussion Guide

- What did you learn from watching LISTEN?
- Why is it important to listen to nonspeaking autistic people?
- What are different ways people in the film communicated? How did the ways they communicated affect what you learned from them?
- Jordyn talks about presuming competence among nonspeaking autistic people. What does "presuming competence" mean to you?
- Why is it important to consult nonspeaking autistic people for media about nonspeaking autistic people? Why is it important to center the voices of those most affected by a project?
- The phrase "nothing about us without us" is a common rallying cry in disability rights. What does this mean to you? Why is it important for people and organizations working in disability rights to remember this?
- How can you better support nonspeaking autistic people?

Style Guide for How to Write and Talk About Nonspeaking Autistic People (and Disabled People Generally)

- **Autistic people, generally, prefer identity-first language** (autistic people) over person-first language (people with autism). Autism is not a disease and it is not something that can be separated from a person; for many autistic people, being autistic is a core part of their identities. For more information, see: https://autisticadvocacy.org/about-asan/identity-first-language/

- **Avoid terms like "low-functioning," "high-functioning," "severe," "mild," or "moderate" when referring to autistic people and autism.** These terms are undefined and undefinable; there is no standard of what "low-functioning" versus "high-functioning" is. "Low-functioning" is often used as a term to deny an autistic person's right to autonomy, self-determination, and inclusion; "high-functioning" is often used to deny an autistic person's needs for support and accommodations. Many autistic people have periods where their support needs are higher than usual and periods where their support needs are lower than usual. The term "severe" is never positive and generates an automatic negative emotional reaction no matter what it is used to describe. When used to describe a person, the term "severe" can serve to dehumanize that person.

- **Nonspeaking, not nonverbal.** The term "verbal" is derived from the Latin term for "word"; "verbal" thus more accurately refers to the use of language (not speech). Many people who reject the term "nonverbal" believe "nonspeaking" is a more accurate descriptor. The term "nonverbal" can be dangerous because many assume "nonverbal" people are incapable of understanding and using language. Language is different from speech and the two forms of communication are processed and generated in different parts of the brain. Nothing can be assumed about the language-related capacities of people who cannot speak.

- In addition, **most nonspeaking autistic people are still capable of making sounds with their mouth,** like laughing, crying, or "filler" sounds like "uh-huh" and "mmm." Nonspeaking people are still capable of making noises, and those noises often represent a powerful form of communication for someone who cannot speak.

- **There is a difference between speech** (being physically and mentally able to communicate via spoken words) **and language** (an overall system of communication). Non-speaking people are still capable of language (including understanding/communicating in multiple languages). Nonspeaking people have a range of receptive language, just like speaking people. For more information on the nonspeaking/nonverbal distinction, see this interview with DJ Savarese, a nonspeaking autistic poet, at http://www.listen2us.net/nonspeaking-non-verbal

- **Not all autistic people who cannot rely on speech to be understood use the term "nonspeaking" to describe themselves.** Some use the terms semi-speaking, unreliably speaking, minimally speaking, multi-modal communicator, and/or augmentative and alternative communication (AAC) user. And some AAC users reject the term "nonspeaking" in part because they view their AAC-based communication as speech. One way to be fully inclusive is simply to be descriptive (e.g., "person who cannot rely on speech to be understood.")

- **For more information on AAC**, see the section "What is Augmentative and Alternative Communication?"

- **Presume competence when writing or talking about nonspeaking people.** Nonspeaking does not equal non-communicative, or not being able to understand what you are saying to them. Nonspeaking people can also have a variety of other types of disabilities including deafness, intellectual disabilities, or physical disabilities that can change the way they interact with the world-and none of that means that people should treat them as though they are not capable of understanding you.

- **Nonspeaking does not mean not deserving of full respect and autonomy.** Nonspeaking people deserve to be communicated with directly, not spoken over or talked about as if they are not there. Nonspeaking people with intellectual disabilities are full and complete people, and deserve the dignity of being treated as such. Communication looking different is not an excuse for ignoring or disrespecting nonspeaking people.

- **Not all autistic people who cannot rely on speech to be understood are incapable of speech all the time**. Some autistic people are situationally incapable of speech or find their ability to speak fluctuates with their energy levels.

- **Nonspeaking autistic people are experts on nonspeaking autism.** Articles on nonspeaking autism should prominently feature quotes from nonspeaking autistic people and acknowledge that nonspeaking autistic people have lived expertise on nonspeaking autism that speaking non-autistic people do not.

- **For more information on writing about disability**, check out the National Center on Disability and Journalism's Disability Language Style Guide at https://ncdj.org/style-guide/ and the Center for Disability Rights' style guide at https://cdrnys.org/disability-writing-journalism-guidelines/. The website Disabled Writers also maintains a database of disabled journalists and expert sources: https://disabledwriters.com/the-database/

Who to Contact to Interview Autistic People (Speaking and Nonspeaking)

- **Zoe Gross**, Autistic Self Advocacy Network, media@autisticadvocacy.org
- **Sharon daVanport**, Autistic Women and Nonbinary Network, sharon@awnnetwork.org
- **Tauna Szymanski**, CommunicationFIRST, tszymanski@communicationfirst.org

Who to Contact to Interview Victims of Restraint and Experts on Restraint

- **Guy Stephens**, Alliance Against Seclusion and Restraint, guystephens@endseclusion.org
- **Robin Roscigno**, AuTeach, robin@auteach.com
- **Raquel Rosa**, TASH, rrosa@tash.org

ALLIANCE AGAINST

SECLUSION & RESTRAINT

Helpful Articles, Resources, Websites, and Organizations to Learn More About Nonspeaking Autistic People and Their Lived Experiences

- "Language and Communication Differences in Nonspeaking Autistics" by Cadence Elizabeth: https://iamcadence.com/2019/07/27/language-communication-development/
- "Ten Facts About Communicating Non-verbally" by Cadence Elizabeth: https://iamcadence.com/2019/10/21/ten-facts-about-communicating-non-verbally/
- "Autistic, Non-Speaking, and 'Intelligent'" by Amy Sequenzia for Ollibean: https://ollibean.com/autistic-non-speaking-and-intelligent/
- "Communication conundrum: The Person Inside" by Hari Srinivasan for the Daily Californian: https://www.dailycal.org/2018/02/15/communication-conundrum/
- "No Place for Disability in Special Education" by Cole Sorensen for the Disabled Academic Collective: https://disabledacademicco.wixsite.com/mysite/post/no-place-for-disability-in-special-education
- "Well, another poem I guess" by endever* corbin: https://anotherqueerautistic.wordpress.com/2019/12/23/well-another-poem-i-guess/
- "We deserve access to AAC!" by endever* corbin: https://anotherqueerautistic.wordpress.com/2019/01/02/we-deserve-access-to-aac/
- "My AAC isn't for you" by tuttleturtle: http://turtleisaverb.blogspot.com/2019/08/my-aac-isnt-for-you.html
- "Stop locking up our AAC systems in class rooms or in therapy rooms" by Saoirse/Autistic AAC Underground: https://autisticaacunderground.blogspot.com/2019/09/stop-locking-up-our-aac-systems-in.html
- "The First Tendrils of Communication" by Cal Montgomery: https://montgomerycal.wordpress.com/2020/07/15/the-first-tendrils-of-communication/
- "On the Limits Tacitly Imposed By Communication Systems" by Cal Montgomery: https://montgomerycal.wordpress.com/2019/12/28/on-the-limits-tacitly-imposed-by-communication-systems/

Importance of Disability Representation in the Media

Approximately 25% of people in the United States and 15% of people worldwide live with disabilities. Yet far fewer than 15% of characters in media – TV, movies, and books – are disabled, and disabled characters are often created, written, and played by non-disabled writers and actors. Disability representation in the media does not come anywhere close to representing the full diversity of disabled people around the world. For nonspeaking autistic people, there is precious little media representation; most of the media that does exist is either documentaries about nonspeaking autistics or fictional media that casts speaking non-autistic actors to play nonspeaking autistic characters. (See the section "Examples of Movies and Documentaries That Feature or Involved Real Nonspeaking Autistic People in Their Production" for more information.)

Media representation matters because media representation normalizes disability. Books, film, television, and other media have the potential to reach people all over the world in ways that individuals on their own may not. Portrayals of disabled characters that are written and played by disabled people, as well as non-fiction stories that humanize real disabled people, show that disability is a natural part of life and that disabled people exist everywhere and anywhere that non-disabled people do.

This has two main effects. First, it demonstrates to non-disabled people that disability is natural and models interactions with disabled people. We as humans learn from the media as much as any other source. Portrayals of disability that show disabled people as fully human, equal to their non-disabled counterparts, reinforce to audiences that disability is part of the human experience.

Second, this provides positive representation to disabled people. Disabled people, like all other groups of people, deserve to see themselves represented in all media, fiction and nonfiction. Media about disabled people, especially about disabled people from marginalized or underrepresented backgrounds, provides a sense of inclusion and belonging for disabled people.

For more information, check out the following resources:

- "Media and People With Disabilities: Are We Represented Accurately?" by The Lighthouse Chicago: https://chicagolighthouse.org/sandys-view/media-and-people-with-disabilities/

- Episode 62 of the Disability Visibility Project podcast: “Black Disabled Women in Media” (Alice Wong interviewing Kym Oliver and Jay Abdullahi of Triple Cripples): https://disabilityvisibilityproject.com/2019/10/20/ep-62-black-disabled-women-in-media/

- “‘Nothing About Us Without Us’ – Disability Representation in Media” by Vilissa Thompson for Center for Disability Rights: https://cdrnys.org/blog/disability-dialogue/nothing-about-us-without-us-disability-representation-in-media/

- “Disability and the Media: Promoting an accurate image and enhancing the voice of persons with disabilities in the media” by the United Nations Department of Economic and Social Affairs: https://www.un.org/development/desa/disabilities/resources/disability-and-the-media.html

- “Why Disability Representation Matters (And Not Just in the Media)” by Gabe Moses for The Body Is Not An Apology: https://thebodyisnotanapology.com/magazine/why-disability-representation-matters-and-not-just-in-the-media/

- “Road Map for Inclusion: Changing the Face of Disability in the Media” by Judy Heumann for the Ford Foundation: https://www.fordfoundation.org/work/learning/research-reports/road-map-for-inclusion-changing-the-face-of-disability-in-media/

- “Disability Movies Aren’t What They Used To Be. That’s Good!” by Andrew Pulrang for Forbes: https://www.forbes.com/sites/andrewpulrang/2020/02/13/disability-movies-arent-what-they-used-to-be-thats-good/?sh=2f50ddb35efa

- “Media & Disability Resources” collection maintained by Beth Haller of Towson University: https://mediadisability.wordpress.com/

- “Representing Disability in an Ableist World: Essays on Mass Media” by Beth Haller, available from The Avocado Press: https://www.advocadopress.org/representing-disability-in-an-ableist-world/

- “Yes, It *Is* About Disability: Reflections on Disability and Media Criticism After Sundance 2020” by Laura Dorwart for Disability Visibility Project: https://disabilityvisibilityproject.com/2020/03/09/yes-it-is-about-disability-reflections-on-disability-and-media-criticism-after-sundance-2020/

What is Augmentative and Alternative Communication?

Augmentative and alternative communication (AAC) is any method of communication used by people with speech or communication disabilities to supplement or take the place of verbal speech. AAC can use no technology (such as pointing, gesturing, or signing), low-technology aids (such as a paper board with words, letters, and symbols on it), or high-tech aids (such as a computer with text-to-speech software on it).

AAC devices and aids can include (but are not limited to): paper or laminated boards or cards with words, letters, and or symbols; keyboards or typewriters with specialized text-to-speech output; computer, smartphone, or tablet apps that convert words or symbols to speech; and dedicated speech symbol- or text-based speech-output devices.

Some people who use AAC use it all the time. Some people who use AAC use it only sometimes or in certain situations. Many people who use AAC employ multiple AAC methods, such as a person who generally uses an AAC app on a tablet but also uses a paper communication board as a low-tech backup.

AAC, like other kinds of assistive technology, is freeing for the people who use it. AAC empowers people who would otherwise be unable to communicate reliably to talk and express themselves to the world. AAC users are not constrained by their devices; they are freed by them. Similarly, like other assistive technology, AAC devices and aids are part of a person's personal space. Many AAC users see their devices/aids as part of their bodies.

For more information, check out the following resources:

- "Inclusion of AAC Users: Best Practices" from the Pacific Alliance on Disability Self-Advocacy (PADSA): https://pacific-alliance.org/wp-content/uploads/2016/11/PADSA-best-practices-for-inclusion-of-AAC-users.pdf
- "Augmentative and Alternative Communication for Speaking Autistic Adults: Overview and Recommendations" by Zisk and Dalton in the journal Autism in Adulthood: https://www.liebertpub.com/doi/10.1089/aut.2018.0007
- "Respecting privacy in AAC" by Alyssa Hillary for AssistiveWare: https://www.assistiveware.com/blog/respecting-privacy-in-aac

Examples of Movies and Documentaries That Feature or Involved Real Nonspeaking Autistic People in Their Production

- The Reason I Jump (2021): https://kinomarquee.com/film/the-reason-i-jump/5f18b849fc3a940001d483d8
  Based on the novel by Naoki Higashida, who is autistic and nonspeaking, this film explores the lives and inner worlds of nonspeaking autistic people around the world.

- Loop (Pixar, Disney+) (2020): http://www.thinkingautismguide.com/2021/02/welcoming-autism-into-pixars-world.html
  Renee, a nonspeaking autistic girl, makes friends with Marcus, a speaking boy, when the two of them go canoeing together at camp. Renee is voiced by Madison Bandy, a young nonspeaking woman.

- Sisterly (2017): https://www.facebook.com/sisterlyfilm/
  A short film by Nina Vallado about her relationship with her sister Lisa, who is autistic and cannot speak. Nina and Lisa both discuss their story as siblings as well as their challenges and successes.

- Deej (2017): https://www.deejmovie.com/
  David James (DJ or Deej) Savarese is a nonspeaking autistic young poet, writer, and presenter. Deej is about his efforts to be included in mainstream classes and his time studying at Oberlin College.

- Unspoken (2017): https://www.unspokendoc.com/
  A profile of Emma Zurcher-Long, a nonspeaking autistic young person who types to communicate and the author of the blog Emma's Hope Book.

- Jordyn's Rocky Journey (2017): https://youtu.be/q6kPo33zuGU
  Jordyn is a nonspeaking autistic young person with alpha-1 antitrypsin deficiency who communicates via pointing to a letterboard. The film, which shares its name with his blog, shows Jordyn's world and includes many of his own statements via letterboarding.

- Dillan's Voice (2016): https://www.youtube.com/watch?v=mtfeoaUPEhI
  Dillan Barmache is autistic and uses an iPad with a text-to-speech app to communicate. The two short film advertisements profile Dillan and his mother on how he communicates.

- Hear Me Now (2015): https://youtu.be/W_IiOLrSsKU
  Chammi Rajapatirana is austistic and types to communicate. The short film features his poetry and his thoughts on life.

- Wretches and Jabberers (2011): https://www.wretchesandjabberers.org/about/
  Tracy Thresher and Larry Bissonnette, two nonspeaking disability rights advocates, travel the world meeting other nonspeaking people and talking about what it is like to exist in a world that denies people rights based on how they communicate.

- Autism is a World (2004): https://www.imdb.com/title/tt0443434/
  A profile of Sue Rubin, a nonspeaking autistic woman, and her relationship to autism.

What is a Meltdown?

Meltdowns are a common autistic experience. They are an involuntary reaction to sensory overload, stress, frustration, and other emotions or stimuli. The physical signs of a meltdown can vary greatly between autistic people but can include:

- Screaming
- Kicking
- Punching
- Being unable to move
- Being unable to speak or use language
- Being unable to stop speaking
- Rocking
- Crying
- Being unresponsive

Sensory overload happens when an autistic person reaches their sensory input threshold – essentially, how much stimuli like light, sound, touch, taste, smell, interactions with people, or bodily sensations like hunger one can take. When a person reaches sensory overload, every stimulus they face is magnified to the point where stimuli that are ordinarily unremarkable become painful.

If an autistic person is unable to escape their sensory overload, they may have a meltdown. Although every autistic person experiences meltdowns differently, meltdowns are generally marked by strong reactions and emotions and loss of control of one's body. This reaction can be so strong that it is difficult for a person to remember parts of their meltdowns.

Meltdowns are physically exhausting. Amethyst Schaber, in their YouTube video on meltdowns, compares it to feeling like having run a marathon, being sick with the flu, and being hit by a truck, all at the same time. After a meltdown, a person may want to be alone, take a nap, or move somewhere quiet. They may also want access to sensory aids like fidget toys or a weighted blanket.

Because meltdowns are an involuntary reaction to stress and sensory overload, reducing stressors and opportunities for sensory overload can help reduce meltdowns. For autistic people, "small" issues can be incredibly stressful – for example, an appointment being rescheduled or a space being reorganized. Giving autistic people advance notice of changes and, when possible, the ability to negotiate or reject those changes can reduce stress immensely.

Reducing sensory overload means two things: a) reducing “bad” sensory input and b) allowing for “good” sensory input and regulation. Reducing “bad” sensory input could mean letting someone who is light-sensitive wear sunglasses inside or changing the kind of lightbulbs a space uses. It could also mean letting someone who is sensitive to certain textures pick clothes that will not trigger their sensory issues. Allowing for “good” sensory input and regulation could mean letting someone who likes the feel of a certain fabric always carry a piece of that fabric with them. It could also mean letting someone listen to their favorite music to help them calm down. For many autistic people, sensory regulation involves stimming, or moving their body or objects around in repetitive ways. Stimming is a natural part of being autistic and is often essential to avoiding meltdowns.

For nonspeaking and unreliably speaking autistic people, meltdowns often happen because they are the only way someone has of communicating how they feel. A person who has no reliable form of communication other than their movements and emotions may have a meltdown simply because they cannot express themselves in any other way. Giving nonspeaking and unreliably speaking autistic people other ways of communicating is essentially to reducing meltdowns. These methods can include AAC tools and devices (see the section Augmentative and Alternative Communication for more information).

How to Support Someone Who is Having a Meltdown

The first and best way to support an autistic person dealing with meltdowns is to work on preventing and minimizing meltdowns. Meltdowns are a response to stress and sensory overload, so minimizing stress and sensory overload can help immensely in preventing meltdowns. Giving autistic people sufficient time and space to prepare for events and the ability to respond to sensory input through fidgeting and moving their bodies is essential to reducing the likelihood of meltdowns.

It is also important to remember that no two autistic people have the exact same meltdown triggers or responses. Asking someone ahead of time what kind of support they would like during a meltdown will help you ensure you provide the right support for them in the moment.

During a meltdown, it is essential not to put more demands on the person in meltdown than absolutely necessary. There are times when it may be necessary for their own safety to try and move them because of an immediate threat to their life; for example, someone standing in the middle of heavy traffic. If a person in meltdown is at risk of harming other people, move the other people, not the person in meltdown. But, assuming that someone is in a safe location, try to minimize their sensory input. Don’t yell at them, ask them questions quickly, or touch them unless they request it. Stay calm and reassure them that they will be okay.

As the person is coming out of a meltdown, offer them assistance. Meltdowns are physically exhausting; a person may be hungry, thirsty, or tired afterward. They may want to be in a low-sensory environment – if there is a quiet, dark space available where they can be alone or with a trusted person, offer it to them. Some autistic people, on the other hand, find certain types of sensory input essential after meltdowns. Someone who finds pressure calming may want a hug or to find a small space to squeeze into.

Autistic people, regardless of their typical ability to speak, may be less able to communicate during or after a meltdown. Someone who is typically able to speak, for example, may not be able to but may be able to type. Someone who is typically unable to speak but can type, similarly, may not be able to type at all. If possible, provide someone with alternative ways to communicate. These can include methods such as typing on a phone or computer, writing in a notebook, answering yes/no questions, pointing to objects or a communication aid, and signing or gesturing.

Resources on Meltdowns

- “Preventing Meltdowns: Outsmarting the Explosive Behavior of Individuals with Autism Spectrum Disorders” by Judy Endow for Thinking Person’s Guide to Autism: http://www.thinkingautismguide.com/2010/07/preventing-meltdowns-outsmarting.html
- “About Autistic Escalation and Meltdown” by Dean R. Kelble, Jr. for Autism EMS: http://www.autismems.net/57801/82012.html
- “Understanding Autism, Aggression, and Self-Injury: Medical Approaches and Best Support Practices” by Clarissa Kripke for Thinking Person’s Guide to Autism: http://www.thinkingautismguide.com/2016/08/when-autistic-children-are-aggressive.html
- “Autistic Insights on Meltdowns, Aggression, and Self-Injury” by Brent White and Lindsey Anderson for Thinking Person’s Guide to Autism: http://www.thinkingautismguide.com/2016/11/autistic-insights-on-meltdowns.html
- “Meltdowns: How Autistic Humans Experience Crises” by Sonny Hallet for Thinking Person’s Guide to Autism: http://www.thinkingautismguide.com/2019/03/meltdowns-how-autistic-humans.html
- “Autism and Self-Injurious Behaviors” by Bridget Allen for Thinking Person’s Guide to Autism: http://www.thinkingautismguide.com/2012/10/autism-and-self-injurious-behaviors.html
- “What Is Sensory Processing Like For Autistic People?” by Reid Caplan for Thinking Person’s Guide to Autism: http://www.thinkingautismguide.com/2019/10/what-is-sensory-processing-like-for.html
- “The Protective Gift of Meltdowns” by Maxfield Sparrow for Thinking Person’s Guide to Autism: http://www.thinkingautismguide.com/2018/07/the-protective-gift-of-meltdowns.html
- “An Open Letter from an Autistic Child in Meltdown, Written by an Autistic Adult Who Still Melts Down From Time to Time” by Maxfield Sparrow for Thinking Person’s Guide to Autism: http://www.thinkingautismguide.com/2016/10/an-open-letter-from-autistic-child-in.html

- “How it feels to have an autistic meltdown and how you can help” by Sarinah O’Donoghue for BBC The Social: https://www.bbc.co.uk/programmes/articles/38f5MsC2mB5fnmCr5v77zDn/how-it-feels-to-have-an-autistic-meltdown-and-how-you-can-help
- “It’s Still Not a Tantrum: The Ever-Elusive Adult Meltdown” by Becca Lory Hector: https://beccalory.com/still-not-tantrum-ever-elusive-adult-meltdown/
- “The M Word: We need to talk about adult autistic meltdowns” by Ashlea McKay: https://medium.com/@AshleaMcKay/the-m-word-we-need-to-talk-about-adult-autistic-meltdowns-fec98f60157b
- “Welcome to the Autistic Community” from the Autistic Self Advocacy Network: https://autisticadvocacy.org/book/welcome-to-the-autistic-community/

Resources on Trauma-Informed Practices

Autistic people, like other people with intellectual and developmental disabilities (I/DD), are at higher risk for experiencing abuse and trauma. This risk increases for nonspeaking autistic people. Autistic children with a history of adverse childhood experiences (ACEs) are also more likely to have unmet health care or therapeutic needs. It is also important to remember that the experience of just living in a world that is unaccommodating and often hostile to autistic people, especially nonspeaking autistic people, can be traumatizing in and of itself.

A trauma-informed care approach is often necessary with autistic people because of this. Trauma-informed care assumes that people are more likely than not to have experienced trauma. Through the principles of safety, choice, collaboration, trustworthiness, and empowerment, trauma-informed care provides services in a way that acknowledges a person's trauma and seeks to reduce the risk of retraumatization.

Below is a list of resources on autism, trauma-informed care, and best practices for trauma-informed care for autistic people and other people with I/DD.

- "Resource List - Trauma Informed Approaches and Autism Spectrum and Other Developmental Disabilities" from ACES in Education: https://www.acesconnection.com/g/aces-in-education/blog/resource-list-trauma-informed-approaches-and-autism-spectrum-and-other-developmental-disabilities-1
- "10 Things to Keep in Mind When Writing About Autism, Violence, and Services" by Cal Montgomery: https://montgomerycal.wordpress.com/2020/08/07/10-things-to-keep-in-mind-when-writing-about-autism-violence-and-services/
- "Dear Parents Who Want to Keep Their Nonspeaking Children Safe as They Go Out Into the World" by Cal Montgomery for CommunicationFIRST: https://communicationfirst.org/dear-parents-who-want-to-keep-their-nonspeaking-children-safe-as-they-go-out-into-the-world/
- "What is Trauma Informed Care" from the University at Buffalo: http://socialwork.buffalo.edu/social-research/institutes-centers/institute-on-trauma-and-trauma-informed-care/what-is-trauma-informed-care.html
- "Trauma-Informed Care, and Intellectual and Developmental Disabilities" from the Hogg Foundation for Mental Health: http://hogg.utexas.edu/trauma-and-idd

- “Adverse Childhood Experiences Are Associated with Unmet Healthcare Needs among Children with Autism Spectrum Disorder” by Berg et al. in Journal of Pediatrics): https://www.jpeds.com/article/S0022-3476(18)30914-4/fulltext
- “Trauma And Autism Spectrum Disorder: A Reference Guide” by Earl et al. at the University of Washington: https://depts.washington.edu/uwhatc/PDF/TF-%20CBT/pages/1%20Therapist%20Resources/Bernier-Lab-UW-Trauma-and-ASD-Reference-Guide-2017.pdf
- “Trauma and Developmental Disabilities” from the Traumatic Stress Institute: https://traumaticstressinstitute.org/trauma-and-developmental-disabilities/
- “Facts on Traumatic Stress and Children with Developmental Disabilities” from the National Child Traumatic Stress Network: https://www.nctsn.org/sites/default/files/resources//traumatic_stress_and_children_with_developmental_disabilities.pdf
- “The Road to Recovery: Supporting Children with Intellectual and Developmental Disabilities Who Have Experienced Trauma” from the National Child Traumatic Stress Network: https://www.nctsn.org/resources/road-recovery-supporting-children-intellectual-and-developmental-disabilities-who-have
- “When Disability is a Disguise: Addressing the mental health needs of people with intellectual and developmental disabilities” from the Hogg Foundation for Mental Health: https://utw10282.utweb.utexas.edu/wp-content/uploads/2015/09/disguise_full_4_27_V2.pdf
- “Abuse and Exploitation of People with Developmental Disabilities” from the Disability Justice Resource Center: https://disabilityjustice.org/justice-denied/abuse-and-exploitation/

Resources on Restraint

Restraint is an outdated crisis management technique that is commonly used in schools across the nation and beyond, and is disproportionately used on disabled and minority children. These interventions are dangerous and can lead to significant trauma and injuries to students, teachers, and staff. Some children have even died as a result of the use of restraint and seclusion. There are far better ways to work with children that avoid the need for crisis management. Our schools should be moving towards neurodevelopmentally informed, trauma-sensitive, biologically respectful, relationship-based ways of understanding, and supporting students.

Types of Restraint

Physical Restraint: A personal restriction that immobilizes or reduces the ability of a student to move his or her torso, arms, legs, or head freely. The term physical restraint does not include a physical escort. Physical escort means a temporary touching or holding of the hand, wrist, arm, shoulder, or back for the purpose of inducing a student who is acting out to walk to a safe location. (2012 U.S. Department of Education Restraint and Seclusion: Resource Document)

- Standing restraints are meant to restrict a child's arms. A school worker can cross the student's arms over his chest from behind or grasp the arms while standing beside the child.
- In seated restraints, adults use their lower bodies to hold the child still and secure the student's arms across their bodies.
- Supine restraints begin with a "takedown," and staff members then secure the student's arms and legs. Care should be taken not to put pressure on the child's joints. Typically, at least three staff members participate.
- Prone, or facedown, restraints begin like supine restraints. Employees then turn the student onto his front and secure his arms and legs. Workers are told to avoid putting pressure on the student's back, which can inhibit breathing.

Mechanical Restraint: The use of any device or equipment to restrict a student's freedom of movement. This term does not include devices implemented by trained school personnel, or utilized by a student that have been prescribed by an appropriate medical or related services professional and are used for the specific and approved purposes for which such devices were designed. (2012 U.S. Department of Education Restraint and Seclusion: Resource Document)

Chemical Restraint: Chemical restraints include drugs that restrict the child's ability to move or control his behavior which were not prescribed by a physical as a standard treatment for the child's condition and or that are not administered as prescribed (e.g., a much larger dose is given). The dangers of chemical restraint were documented by the Hartford Courant in 1989. (Jessica Butler, 2019 How Safe is the Schoolhouse)

Why is restraint dangerous?

While restraint is intended as a crisis management procedure, it involves significant risks. Even with proper training, there is no such thing as a "safe restraint." Anytime children and adults enter into a fight or flight response there is the danger of significant injuries and even death. Autistic children and adults have suffered broken bones, head trauma, scratches, bruises, seizures, brain injuries, amputations and more.

Many individuals who are being restrained have a trauma history and the use of restraint is itself traumatic. Trauma can change the brain. Brain areas implicated in the stress response include the amygdala, hippocampus, and prefrontal cortex. Traumatic stress can be associated with lasting changes in these brain areas. The amygdala detects threats in the environment and activates the "fight or flight" response. Those who have been traumatized may feel unsafe and may enter into a hyper-vigilant state. This can lead to distress related behaviors causing an individual to become overwhelmed or triggered. When demands are placed on anyone that they are unable to meet the situation may escalate. This may lead to fight, flight, or freeze behavior, which may lead to the use of restraint and re-traumatization.

During lunch on April 29, 2020, Cornelius Frederick, a student at the Lakeside Academy in Kalamazoo, Michigan, threw a sandwich at another boy in the Lakeside Academy cafeteria. A staff member responded by tackling Cornelius to the ground. Over the next 12 minutes, as Cornelius struggled and gradually grew still, seven men who worked for Lakeside held him down, some putting their weight on his legs and torso. Cornelius died in a hospital two days later. The medical examiner ruled his death a homicide.

On November 28, 2018, 13-year-old autistic boy Max Benson died as a result of being held in a prone physical restraint by the staff at his now-defunct K-12 private school, Guiding Hands School in El Dorado County, California.

Michael Renner-Lewis III, a 15-year-old autistic student, was killed on his first day of high school in 2003 when he was restrained face-down by several staff members at Parchment High School in Michigan after he became agitated following a seizure. His mother, Elizabeth Johnson, sued the school district and settled the case.

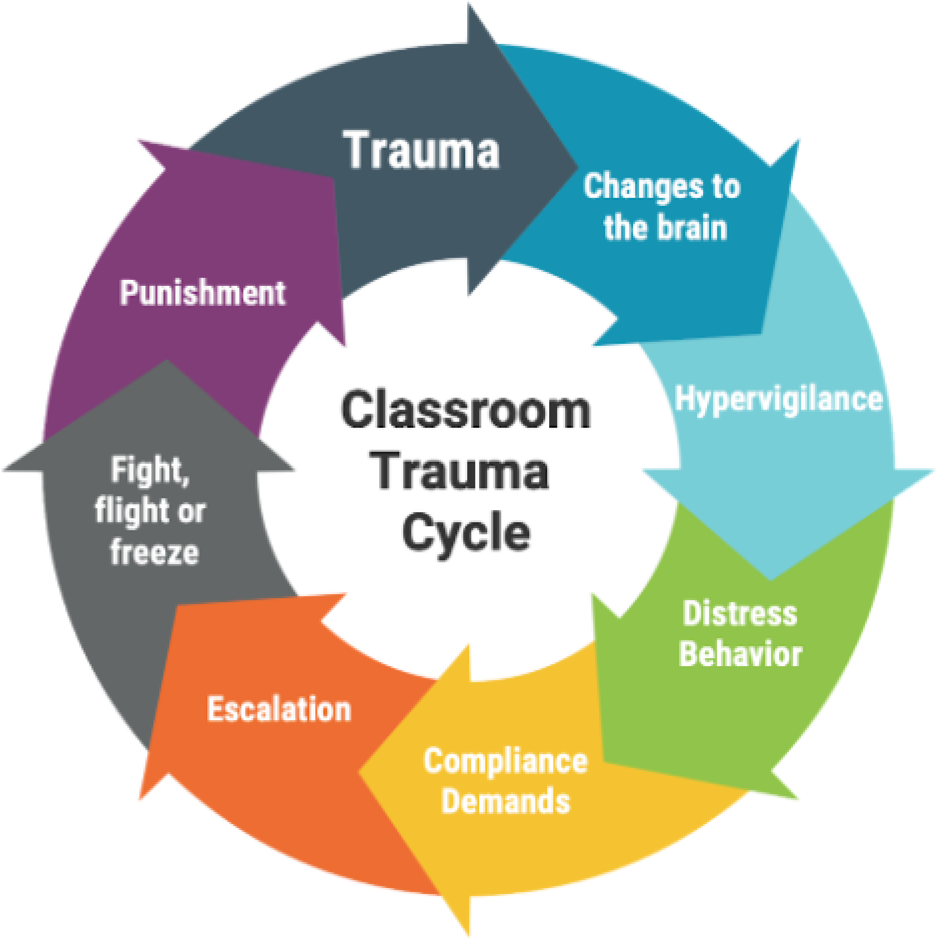
Seven-year-old Angelika Arndt died in 2006 after being suffocated while in a face-down restraint hold performed by staff members at the Rice Lake Day Treatment Center in Wisconsin.

Corey Foster of New York City, 16, died after being restrained by school staff members for allegedly refusing to leave the basketball court at the Leake & Watts school for students with special needs in Yonkers, N.Y. The autopsy report ruled Corey's death an accident due to "cardiac arrest during excited state while being subdued." The Foster family is suing the school.

There are those that provide misinformation and those that even indicate that prone restraint is safe and therapeutic. It is not. Prone restraint is neither safe nor is it therapeutic.

A 2014 United States Senate report states:

"There is no evidence that physically restraining or putting children in unsupervised seclusion in the K-12 school system provides any educational or therapeutic benefit to a child. In fact, use of either seclusion or restraints in non-emergency situations poses a significant physical and psychological danger to students." - Senator Tom Harkin



One of the reasons restraint is so dangerous is that humans have strong survival instincts when they are in danger. The “fight or flight” response is the body’s response to distress or threat. A part of the brain, the amygdala, is our threat detection system. When we are threatened the amygdala sends a distress signal to the hypothalamus which in turn activates the sympathetic nervous system by sending signals through the autonomic nerves to the adrenal glands. These glands respond by pumping adrenaline into the bloodstream which brings about several physiological changes.

When we are threatened our heart beats faster, pushing blood to the muscles, heart, and vital organs. Our pulse and blood pressure increase and we start to breathe more rapidly. This increase in oxygen being sent to the brain increases alertness. The result is our sight, hearing, and other senses become sharper. Adrenaline triggers the release of blood glucose and fats from temporary storage sites in the body which supplies energy to all parts of the body. Our body is ready to fight or flee, we no longer have the ability to access the frontal cortex that might help us to make logical and rational decisions, we are in survival mode. Why is this important? Because when you put hands on a child to restrain the child you will put them into a fight or flight mode. The person restraining the child will also likely enter into a fight or flight response mode. This is one of the reasons that the use of restraint is never without risks.

Many have come to realize the dangers of prone restraint. To date, over 30 states have banned the use of prone restraints in schools. There are far better ways to work with children, even children whose behavior may at times escalate.

Restraint is NEVER without risks. This is not just a matter of opinion. Even the companies that provide training in the use of restraint acknowledge the risks involved.

Here is a short excerpt from documentation produced by the Crisis Prevention Institute (CPI):

“In circumstances where it has been identified that physical interventions are an appropriate response to manage a prevailing risk associated with an individual’s behavior, it is important that staff fully understand the adverse impact physical interventions may have.”

CPI lists potential restraint-related injuries or harm, may include:

- Psychosocial Injury: Including post-traumatic stress disorder and damage to therapeutic relationships.
- Soft-Tissue Injury: Including injury to skin, muscles, ligaments, and tendons.
- Articular or Bony Injury: Including injury to joints and bones.
- Respiratory Restriction: Including compromise to the airway, bellows mechanism, and gaseous exchange, which results in respiratory crisis or failure.
- Cardiovascular Compromise: Including compromise to the heart and the peripheral vascular system.

The Crisis Prevention Institute provides training to school districts in the use of de-escalation techniques and hold (restraint) techniques. They clearly articulate the risks involved in using restraint, yet people trained in these practices sometimes begin to believe that training equates to safety. It is not uncommon for school staff and leadership to say things like “we are trained in safe restraint techniques.” Restraint is NEVER without risks, the greatest of which is death.

Restraint from an Autistic Perspective

Interview with Alex Campbell: When he was in elementary school, he was subjected to multiple counts of restraint and seclusion for disciplinary reasons. In 2014, Alex began advocating for the need to regulate the use of restraint and seclusion. Alex has inspired the creation and passage of three laws in Virginia and hopes to continue inspiring others. He has been invited to provide testimony to the Commission on Youth, the Virginia House of Delegates Subcommittee #1 under the House Committee on Education, the Virginia Senate Subcommittee on Public Education, the U.S. House Subcommittee on Early Childhood, Elementary, and Secondary Education, and the Virginia Department of Education In 2018, Alex was invited to a Congressional briefing and asked to re-introduce the Keeping All Students Safe Act to the United States House of Representatives. Alex has inspired the creation and passage of three laws in Virginia and hopes to continue inspiring others. https://youtu.be/10_TvoD6-bY

Interview with Sam Maloney: Sam Maloney is a 20 year photographer from Rochester, NY. Sam started his photography journey at 10 years old. Sam is a restraint and seclusion survivor from the age of 5 to 14 years old. Sam is continuing his photography education through his person centered plan through New York State. Sam is also working to support autism acceptance. Autism on US Routes 11 and 20 is a journey to inspire others to see the best in themselves. Sam will be traveling the country to spread his campaign to change Autism Awareness to Autism Acceptance. https://youtu.be/SVCtLcKC1FE

First-person description of what prone restraint is like from Cal Montgomery: Okay, let's talk about prone restraint. Not what it looks like when it happens in front of you or how it feels to do it, or what it is like to find out it happened to your kid, but one person's experience of having it done, informed by watching it happen to others and then trained to do it. https://www.facebook.com/story.php?story_fbid=10217980898057532&id=1337764352

There are Better Ways

There are far better ways to work with indivduals and avoid the need for crisis management. We should be moving towards neurodevelopmentally informed, trauma-sensitive, biologically respectful, relationship-based ways of understanding, and supporting everyone.

What can schools and others do to eliminate the need for restraint? Schools and other settings use a number of effective approaches to support children and adults who are nonspeaking, intellectual or developmentally disabled, or have complex medical needs.

Ukeru

Ukeru is a trauma-informed crisis management alternative to restraint and seclusion. Developed by Grafton Integrated Health in Virginia. Ukeru centers on a philosophy of comfort vs. control:

- Using a trauma-informed approach to create a supportive, caregiving environment sensitive to clients' past experiences of violence and victimization.
- Helping individuals thrive in the least restrictive environment consistent with achieving the best outcome.
- Achieving the greatest impact with the least amount of disruption to an individual's routine.

Collaborative and Proactive Solutions

Collaborative & Proactive Solutions (CPS) is the non-punitive, non-adversarial, trauma-informed model of care Dr. Greene originated and describes in his various books, including The Explosive Child, Lost at School, Lost & Found, and Raising Human Beings.

The Collaborative & Proactive Solutions model believes that children sometimes exhibit challenging behavior because they're lacking the skills or have unsolved problems. If they had the skills, they wouldn't be challenging. That's because – and here is perhaps the key theme of the model — Kids do well if they can.

Low Arousal

The term 'low arousal' was first used in 1994 (McDonnell, McEvoy & Dearden, 1994). McDonnell (2010) identified four key components considered central to low arousal approaches. These include both cognitive and behavioral elements:

- Decreasing staff to client demands and requests to reduce potential points of conflict around that individual.
- Avoidance of potentially arousing triggers (e.g. direct eye contact, touch, and removal of spectators to the incident).
- Avoidance of staff's non-verbal behaviors that may lead to conflict (e.g. aggressive postures and stances).
- Challenging staff beliefs about the short-term management of challenging behaviors.

Restorative Practices

A growing body of research shows that schools and districts that have implemented restorative strategies report a range of impressive outcomes.

These include reductions in student misbehavior and classroom disruptions and dramatic decreases in suspensions, improved academic outcomes, improved school climate indicators, and reduced absenteeism.

Trauma-informed Practices

As we've discussed, the majority of children and youth will be exposed to at least one potentially traumatic event before graduating from high school. Children with disabilities are perhaps more likely to have experienced adverse childhood experiences.

In a trauma-sensitive school, all staff share a common understanding of trauma and its impact on students, families, and staff and a mission to create learning environments that acknowledge and address trauma's impact on school success.

Children that have experienced trauma need to feel seen, safe, soothed, and secure. Relationships are critical to helping children succeed.

Keeping All Students Safe Act

The Keeping All Students Safe Act would make it illegal for any school receiving federal taxpayer money to seclude children and would ban dangerous restraint practices that restrict children's breathing, such as prone or supine restraint. The bill would also prohibit schools from physically restraining children, except when necessary to protect students and staff. The bill would better equip school personnel with the training they need to address school-expected behavior with evidence-based proactive strategies, require states to monitor the law's implementation, and increase transparency and oversight to prevent future abuse of students.

Here are voices of supporters of the Keeping All Students Safe Act, including the autistic perspective: https://endseclusion.org/2020/12/20/tell-us-why-you-support-the-keeping-all-students-safe-act/

More information about the Keeping All Students Safe Act: https://endseclusion.org/2020/11/24/supporting-the-keeping-all-students-safe-act/

The Kids We Lose

The Kids We Lose is a 90-minute documentary film about the human side of being a child or student with behavioral challenges, and the struggles faced by parents, educators, staff in facilities, mental health clinicians, and judicial and law enforcement professionals in trying to ensure that these kids receive the help they need. https://www.thekidswelose.com

More Information on Restraint:

- “Restraint and Seclusion: Resource Document” from the U.S. Department of Education https://www2.ed.gov/policy/seclusion/restraints-and-seclusion-resources.pdf
- “How Safe Is the Schoolhouse? An Analysis of State Seclusion and Restraint Laws and Policies” by Jessica Butler for the Autism National Committee: https://www.autcom.org/pdf/HowSafeSchoolhouse.pdf
- Information on different types of restraint from the Alliance Against Seclusion and Restraint: https://docs.google.com/presentation/d/1syh8HUnWmnpmt6_NgLrlPxy3igMA4mddXjhnYAHE1-c/edit#slide=id.g76a38ec40b_0_27
- “Prone restraint is neither safe nor is it therapeutic” by Guy Stephens for the Alliance Against Seclusion and Restraint: https://endseclusion.org/2021/02/01/prone-restraint-is-neither-safe-nor-is-it-therapeutic/
- Information on Ukeru: https://www.ukerusystems.com
- Information on Collaborative and Proactive Solutions: https://www.livesinthebalance.org/about-cps
- Information on the low arousal approach: https://www.studio3.org/low-arousal-training
- “Understanding the Risks of Physical Restraints” from the Crisis Prevention Institute: https://www.crisisprevention.com/CPI/media/Media/elearning/flex/PDF_NCI-Risk-of-Restraints.pdf

ALLIANCE
AGAINST
SECLUSION
&
RESTRAINT

CommunicationFIRST *is the only national, nonprofit, 501(c)(3) organization dedicated to protecting and advancing the civil rights of the more than five million people of all ages in the United States who, due to disability or other condition, are unable to rely on speech alone to communicate. Run by and for people with expressive communication disabilities, CommunicationFIRST advances its mission by educating and engaging the public, advocating for policy and practice reform, and engaging the justice system to ensure access to effective communication, to end prejudice and discrimination, and to promote equity, justice, inclusion, and opportunity for our historically marginalized community.* *https://CommunicationFIRST.org*

The Autistic Self Advocacy Network (ASAN) *is a disability rights organization run by and for autistic people. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. For more information about the organization, please visit:* *https://autisticadvocacy.org*

The Alliance Against Seclusion and Restraint *is a highly diverse grassroots coalition comprised of neurodivergent and neurotypical parents, grandparents, autistic self-advocates, attorneys, educators, and others. The group is dedicated to changing minds, laws, policies, and practices so that restraint and seclusion are reduced and eliminated in all settings. For more information about the organization, please visit:*
https://www.endseclusion.org