



August 26, 2022

Autistic Self Advocacy Network Comments Re: SAFE Initiative Call for Testimony

The Autistic Self Advocacy Network (ASAN)¹ appreciates the opportunity to provide recommendations on the contents of best practice guidelines for health care providers treating children with intellectual and developmental disabilities. We are grateful that the SAFE Initiative seeks to improve the experiences of disabled children in this crucial area of life. We believe guidelines could meaningfully improve the quality of care these children receive by reducing the harms they experience in medical settings. To do so, the guidelines must be centered on the rights, dignity, and humanity of children with disabilities and deliberately designed to protect their rights and reduce their suffering.

Children, like adults, with disabilities have certain legal rights. They are as entitled to safety and bodily autonomy as nondisabled persons. Federal law also establishes their right to freedom from discrimination, effective communication, and reasonable accommodations in medical settings.² However, bias against disabled people is common in the health care system.³ The rights of people with disabilities, including children, are often violated. This frequently results in exposure to traumatic experiences. The risk of these experiences is increased for multiply marginalized disabled people, such as disabled people of color or LGBTQ+ disabled people, because they are often subjected to additional or compounding discrimination and harm in health care settings. For this reason children with disabilities are subjected to preventable harm in the course of medical care. These guidelines must seek to prevent it, to center and prioritize the wellbeing of disabled children receiving medical care, and

Many factors in medical settings can lead to adverse outcomes including escalation, trauma, and restraint. These factors are properly understood as issues of accessibility and bodily

¹ For more information on ASAN, visit <https://autisticadvocacy.org/>.

² See 42 U.S.C. § 12182; 42 U.S.C. § 12132; 29 U.S.C. § 794; 42 U.S.C.S. § 18116; 28 C.F.R. § 36.303(c); 45 C.F.R. § 84.52.

³ See Iezzoni, L. I., Rao, S. R., Ressler, J., Bolcic-Jankovic, D., Agarannik, N. D., Donelan, K., Lagu, T., & Campbell, E. G., *Physicians' perceptions of people with disability and their health care*, 40 Health Affairs 2, 297–306 (2021).

autonomy, not symptoms of autism or other developmental disabilities or “behaviors” to be managed. They have both acute and chronic consequences which must be understood in light of astronomical rates of trauma history among people with intellectual and developmental disabilities.⁴ This trauma causes suffering that is both extreme and preventable. Incidences of trauma, in autistic and developmentally disabled people no less than in the general population, are adverse health events in and of themselves and have long-term effects with other negative consequences for survivors’ physical and mental health. The central goal of any best practice guidelines this process produces must be the prevention of these harms through the reduction or elimination of medical trauma.

Accessibility issues that contribute to restraint and other incidences of medical trauma include sensory inaccessibility, unnecessary time pressure, and poor communication access. Lack of respect for bodily autonomy is also a significant contributing factor in trauma and other adverse outcomes in medical settings for children with disabilities. Ensuring that health care is accessible and that providers do not violate disabled patients’ bodily autonomy can protect children with disabilities from physical and emotional harm that can cause intense suffering and have lasting consequences. The measures health care providers can take to avoid traumatic experiences for children with intellectual and developmental disabilities include sensory accessibility, slowing the pace of appointments, allowing children longer appointments, effective communication, using visual supports, working with caregivers, using medications such as numbing sprays and distractions to help children cope with unpleasant events, using IV sedation and general anesthesia when indicated, working in interdisciplinary teams, and knowing when to postpone a procedure. These measures require prioritizing the wellbeing of children with developmental disabilities. The creation of these guidelines is an opportunity to ensure that providers do so.

Sensory accessibility can prevent medical situations from being traumatizing because of the physical pain that arises from sensory issues or escalating to the point that providers consider restraint. These guidelines should promote basic measures like reducing light and noise where possible and encouraging the use of auxiliary aids like sunglasses, headphones, and earplugs. Health care providers should consider providing some of these tools to help patients cope with bright lights and loud noises. Providers should refrain from touching patients more than needed. It will sometimes be beneficial to limit the number of health care workers present with the patient to those who are absolutely necessary. A child who is particularly easily overwhelmed is not the best patient to use for staff or student training purposes.

⁴ See McNally, P., Taggart, L., & Shevlin, M., *Trauma experiences of people with an intellectual disability and their implications: A scoping review*, 34 *Journal of Applied Research in Intellectual Disabilities* 4, 927–949 (2021).

Time pressure can also contribute to medical providers taking coercive measures, such as restraint, that create the risk of physical and psychological harm. Children with intellectual disabilities may require more processing time to follow instructions from a doctor in the course than their neurotypical peers.⁵ Medical appointments often move faster than is manageable for children with developmental disabilities. Some autistic children may “shut down” and become unable to complete a task under pressure to do it too quickly. Children who “shut down” or become overwhelmed are not misbehaving. Allowing adequate time, even if it means a medical appointment takes longer than it normally would, is a necessary and reasonable accommodation for some such children. Providing it can help to prevent children from becoming overwhelmed and reduce the likelihood that health care providers will take actions that may be traumatizing, such as forcing a child into position, in order to complete an examination in the standard amount of time. For this reason, the guidelines should encourage providers to affirmatively offer longer appointments to patients for whom they believe it would be beneficial.

Allowing extra time in the form of postponing procedures can also prevent trauma. It is important to remember that in the vast majority of situations, waiting and trying a procedure again later is an option. While situations such as emergency surgery do not allow for this, most routine procedures can be postponed if a child needs to stop. This is not ideal, but it may be necessary to avoid the inherent trauma and potential physical harms that would be caused by restraining the child. Similarly, if a procedure can be broken into smaller steps and done over a series of appointments, that course of action is the most appropriate one for some patients with intellectual and developmental disabilities if it is the best way to avoid traumatizing, coercive measures such as restraint.

Poor communication access can also contribute to the occurrence of traumatizing events in medical settings. Receiving many forms of medical care is inherently traumatic for any patient who lacks the opportunity to learn what is taking place or express discomfort. That trauma can lead a child to react in ways that increase the likelihood of further traumas, such as restraint. For this reason, it is crucial that these guidelines remind providers of their effective communication obligations. Providing effective communication may necessitate visual aids, simpler language, demonstrations, or an interpreter. The guidelines should promote visual supports that use illustrations or icons to represent a process or set of steps. An example of visual supports would be a step-by-step explanation of how an EEG

⁵ See Erostarbe-Pérez, M., Reparaz-Abaitua, C., Martínez-Pérez, L., & Magallón-Recalde, S. (2022). *Executive functions and their relationship with intellectual capacity and age in schoolchildren with intellectual disability*, 66 *Journal of Intellectual Disability Research* 1–2, 50–67 (2022); see also Catharine Critz, Kiegan Blake, Ellen Nogueira, *Sensory Processing Challenges in Children*, 11 *The Journal for Nurse Practitioners* 7, 710-716 (2015).

works, including pictures to illustrate each step.⁶ These tools should be made available to children and their caregivers in advance of medical appointments and procedures, including on hospital or clinic websites. They are particularly useful for children who have good visual skills but cannot yet read or cannot read at an advanced level, as a caregiver can read the text while the child looks at the images.

Another essential component of effective communication is maintaining access to routinely used communication supports. Many children with developmental disabilities are nonspeaking or unreliably speaking. This is particularly true for autistic children. Disabled children who are nonspeaking or unreliably speaking may rely on alternative and augmentative communication (AAC) systems. These systems can include speech generating devices, picture cards, and letterboards. Providers must ensure that children who use AAC have access to their means of communication throughout a medical visit and take communication through AAC as seriously as they would a child's verbal communication. These guidelines should take the opportunity to promote AAC access as an essential trauma prevention measure.

Some children who are nonspeaking or unreliably speaking require a supporter or other person to help them communicate. In these situations, the child's communication support person should be able to be with them in the medical facility regardless of any limitations on visitor numbers or visiting hours. Federal guidance for health care providers states that communications support people must be granted access to patients even if there is a no-visitors policy in place.⁷ Health care providers should also consider consulting with a speech-language pathologist (SLP) if they have a patient for whom oral speech is not an effective method of communication. SLPs can assist in finding methods of communication that will work better for a child.

Poor communication access is sometimes a consequence of ableist assumptions. Many children with intellectual and developmental disabilities, especially autistic children, struggle with spoken language, especially in stressful situations. Health care providers sometimes assume that a child not communicating through spoken language is altogether incapable of self-expression or even thought. Nonspeaking and unreliably speaking adults

⁶ See *Autism Behavioral Consult: Visual Supports and Resources*, Children's National <https://childrensnational.org/departments/center-for-neuroscience-and-behavioral-medicine/programs-and-services/center-for-autism-spectrum-disorders/autism-behavioral-consult/visual-supports-and-resources> (last visited Aug. 25, 2022) (*examples of effective visual supports*).

⁷ See Office for Civil Rights (OCR). (2022, February 3). *Faqs for healthcare providers during the covid-19 public health emergency: Federal civil rights protections for individuals with disabilities under section 504 and section 1557* [Text]. HHS.Gov. <https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/disability-faqs/index.html>

report that their concerns are often dismissed or they are seen as incapable of understanding what is going on around them.⁸ This problem is compounded in children, who may also be dismissed because of their youth. These assumptions are dangerous, as they make providers more likely to resort to traumatizing or coercive measures without attempting communication that might help avoid them. These guidelines should require health care providers to presume that communication is possible and make every effort to achieve it, particularly in regard to pain and discomfort, which autistic children may experience and express differently from their neurotypical peers. Pain that is not identified and addressed by medical providers can be inherently traumatizing and often leads to other traumatizing events, like restraint.

Health care providers also should ask for the patient's permission before touching the patient when possible, even when a parent has already provided consent. The guidelines must explicitly address nonspeaking children. Providers treating them should look for signs that the patient does or does not give permission including gesturing yes or no, making facial expressions, or physically moving away from the provider. Health care providers should also always communicate to the patient what is happening and what to expect unless doing so is unwanted. Providers should offer the information a child needs to feel safe and comfortable with the procedure at hand. Questions like "would you like me to tell you what I'm doing as I'm doing it?" or "would you like me to tell you when I am going to vaccinate you?" can help determine whether a patient would appreciate having more information. Allowing children to control access to their bodies as much as possible and explaining what is taking place to the extent desired by the child can reduce the fear children with disabilities experience in the course of treatment, preventing or limiting trauma.

Best practice guidelines should also address the importance of listening to caregivers, who may have valuable insight into what a child with developmental disabilities needs. Caregivers know the child best and may be able to explain the child's behavior or reactions even when the child cannot. Caregivers should be included in discussions of the child's care, including post-appointment or post-hospitalization care. Where it is possible to get the appropriate consent to release medical information, providers should be open to relying on caregivers beyond a parent or guardian, including paid supports. For example, if a child has a personal care attendant or direct support person who assists in their daily care, the guidelines should support informing that person of what kinds of care the child will need after their appointment or hospitalization to the greatest extent consistent with medical privacy law.

⁸ See *Reflections on health care access*. (n.d.). CommunicationFIRST, <https://communicationfirst.org/reflections-on-health-care-access/> (last visited Aug. 22, 2022).

The guidelines must also address pain management. Preventing or reducing pain can make medical procedures significantly less traumatic for children with intellectual and developmental disabilities. Blood draws, vaccines, IVs, and other procedures involving needles may be daunting for autistic children. Fear of pain — especially if one does not have a good way to communicate discomfort — may lead to extreme reactions on the part of the child. This, in turn, can lead to adverse experiences, such as a child being physically restrained in order to get a vaccine. Aids such as numbing sprays, short-term anti-anxiety medications, and distractions can help in making these procedures less painful and anxiety-provoking for children. The guidelines must stress the difference between using a short-term anti-anxiety medication to induce calm and chemical restraint for the purpose of immobilizing the child.

There may be some instances where autistic children need IV sedation and general anesthesia for procedures that would not ordinarily require sedation. For example, many autistic children cannot tolerate routine dental cleanings while awake and must be asleep in order to complete these procedures. While sedation and anesthesia have risks, they are the best option for many children who cannot tolerate procedures while awake and would otherwise be subjected to physical or chemical restraint. Anesthesia has the potential to cause harm, while restraint's harm is inevitable. However, these measures should also be weighed against less intrusive options. If, for example, a child can tolerate a procedure after taking a short-term anti-anxiety medication, that is likely preferable to anesthesia.

Hospitals and medical practices should also have interdisciplinary teams that work on issues related to the care of children with intellectual and developmental disabilities, including policy, staff training, and general accommodations. For example, Children's National Hospital in Washington, D.C., has an Autism Behavioral Consult team that assists in helping autistic children prepare for their medical appointments. Such teams can help providers who are not trained in working with autistic children make their practices more accessible. Similarly, Child Life Specialists are providers trained in childhood development and the effects of illness, injury, and medical trauma on said development. While having providers trained in working with autistic children as part of an interdisciplinary team is important, Child Life Specialists can also be helpful in preparing autistic children for appointments or procedures.

By promoting these solutions to common problems for autistic people and others with developmental disabilities in medical settings, best practice guidelines could prevent some of the trauma that is a routine part of health care for too many disabled children and adults. Sensory inaccessibility can be traumatizing if exposure to such an environment is severe, lengthy, or repeated. Coercive measures providers take instead of communicating or

addressing pain causes trauma as well. Children, like adults, need security in their own bodies and freedom from unwanted incursions on bodily autonomy. They need others around them, including medical providers, to treat their suffering as significant and avoid causing any more than is absolutely necessary. Failure to meet these needs causes medical trauma.

The trauma autistic people experience in health care is an immediate and harmful health event. It can impact children in many ways.⁹ It can cause PTSD symptoms such as “flashbacks” or nightmares. Children may also experience hyperarousal, meaning their “fight or flight” response from the event does not go away. Children experiencing hyperarousal may “act out” or exhibit “challenging behaviors” because their brains interpret even safe situations as potentially dangerous. It is estimated that between 12 and 20 percent of children who experience medical trauma will go on to develop post-traumatic stress disorder (PTSD). Children with intellectual and developmental disabilities feel this psychic torment no less keenly than their neurotypical peers. For autistic children, these trauma responses may be complicated by alexithymia (decreased ability to tell what one’s emotions are) or being nonspeaking.

Medical trauma also has long-term health impacts. People with medical trauma may be reluctant to seek care when they need it. Autistic children experience worse health outcomes and health disparities than both non-disabled children and non-autistic disabled children.¹⁰ A childhood filled with medical traumas, whether in the form of overt abuse or repeated incidences of suffering due to overlooked pain or sensory inaccessibility, may lead to a person avoiding health care as an adult. Autistic adults are less likely to seek care for a number of reasons, including fear or anxiety around medical appointments.¹¹ Experiences

⁹ See Kassam-Adams, N., & Butler, L., *What do clinicians caring for children need to know about pediatric medical traumatic stress and the ethics of trauma-informed approaches?*, 19 *AMA Journal of Ethics* 8, 793–801 (2017); see also Peterson, S., *Effects*, The National Child Traumatic Stress Network (2018, February 1), <https://www.nctsn.org/what-is-child-trauma/trauma-types/medical-trauma/effects>.

¹⁰ See Bishop-Fitzpatrick, L., & Kind, A. J. H., *A scoping review of health disparities in autism spectrum disorder*, 47 *Journal of Autism and Developmental Disorders* 11, 3380–3391 (2017); see also Karpur, A., Lello, A., Frazier, T., Dixon, P. J., & Shih, A. J., *Health disparities among children with autism spectrum disorders: Analysis of the national survey of children’s health 2016*, 49 *Journal of Autism and Developmental Disorders* 4, 1652–1664 (2019); Tregnago, M. K., & Cheak-Zamora, N. C., *Systematic review of disparities in health care for individuals with autism spectrum disorders in the United States*, 6 *Research in Autism Spectrum Disorders* 3, 1023–1031 (2012).

¹¹ See Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., & Baggs, A., *Comparison of healthcare experiences in autistic and non-autistic adults: A cross-sectional online survey facilitated by an academic-community partnership*, 28 *Journal of General Internal Medicine* 6, 761–769 (2013); see also Raymaker, D. M., McDonald, K. E., Ashkenazy, E., Gerrity, M., Baggs, A. M., Kripke, C., Hourston, S., & Nicolaidis, C., *Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities*, 21 *Autism* 8, 972–984 (2017).

with medical trauma are likely one of the reasons for this phenomenon. Avoidance of and delays in seeking medical care can worsen individual health outcomes and deepen health disparities for marginalized groups. For this reason, medical trauma has effects that can last, and truncate, a lifetime.

It is crucial that the guidelines lead medical providers to consider trauma prevention in light of their patients' experiences outside of medical facilities. Many children with intellectual and developmental disabilities they find themselves treating will have already experienced traumatic events. Past medical trauma, such as being restrained, can make new traumatic experiences worse, such as a later experience with restraint, worse. New traumatic experiences can trigger established trauma, leading to stronger trauma reactions going forward. A trauma history from within our outside of the medical setting can also make some experiences triggering, and potentially traumatic, that might not have been in the absence of a trauma history. For example, getting an MRI might terrify a child who has been subjected to seclusion in a confined space at school. Because of the trauma they experience in daily life, children with disabilities are particularly vulnerable to the compounding effects of additional trauma they experience in medical settings.

The subjective experiences of people, including children, with intellectual and developmental disabilities matter. Because the immediate and life-long suffering brought about by medical trauma is avoidable, these guidelines must regard it as unacceptable. Consequently, the guidance should center the rights and full humanity of children with intellectual and developmental disabilities. To that end, they should seek to eliminate the causes of medical trauma, including accessible environments and violations of bodily autonomy. They should promote measures that prevent medical trauma, including effective communication, allowing extra time for examinations and procedures when a child's disability necessitates it, respect for bodily autonomy, and a trauma-informed approach to disabled children. Incorporating these practices into best practice guidelines for health care providers serving children with disabilities would make the health care experience better for disabled children, alleviate needless suffering, and promote the provision of quality care. It would ultimately prevent children from being so traumatized by their experiences in medical settings that they avoid care as adults, experiencing worse health outcomes as a result.

It is critical that these guidelines reflect the rights and full humanity of autistic people and instruct medical personnel on how to accommodate and support us. These guidelines must instruct medical personnel to use measures like the ones we have recommended to avoid escalation, restraint, seclusion, coercion, and medical trauma for autistic children. Autistic children, like all children, have the right to be safe in their own bodies, including during

medical appointments. Any guidelines written about providing care for autistic children must, at their core, account for the safety and well-being of these children.

ASAN is likely to attend the public forum on October 6-7 and continue to take every opportunity to contribute to the crafting of these guidelines. We thank the SAFE Initiative and its organizers for the opportunity to submit comments on this important issue. For more information on ASAN's positions on providing safe and accessible medical care to children with intellectual and developmental disabilities, please contact R. Larkin Taylor-Parker at rtaylorparker@autisticadvocacy.org.