Learning and Protecting Our Rights in Commercial Care

An Orientation Guide by Survivors for Survivors

Why This Guide Exists

This guide is made by survivors for survivors of complex trauma. In this guide, the word "we" means ourselves as survivors who remain vulnerable to ongoing harm. This guide is written for us.

We do not recommend sharing this guide with commercial care providers at large. We recommend only sharing this guide with people who we know accept our reality and just want to build more help and more support for us.

This guide is being updated regularly, and a more current version might be available at www.helpexists.org.

For survivors of abusive family systems, family can be the most dangerous people in the world. To avoid further harm, survivors are forced to seek out help on their own – without a safety net and without any advocacy from people who can represent their best interests.

For many survivors, access to care and security is available only through commercial services with therapists, counselors, physicians, case managers, legal professionals, social service agencies, nonprofit organizations, and other service providers.

Providers can underestimate the deliberate systemic cruelty of bureaucracy, while being reliant on systems, frameworks, and practices that directly contribute to our endangerment. As a result, providers may cause serious harm, even when unintended. When providers' frameworks are applied without adaptation for our needs, they can fail us whose life conditions do not fit the assumptions behind those frameworks. A type of

incidental violence occurs when others lack the language, ideas, and understandings needed to make sense of our conditions. Additionally, when providers learn that we experience dissociation, depersonalization, and/or derealization, they often question our credibility even more.

We are building tools that address these problems in the lives of survivors.

Our rights cannot benefit us if we do not know them, cannot assert them, and have no tools with which to protect them. This guide supports us to be in a stronger position to know our rights, build informed allies and supporters, and have more confidence asserting our own framework for protecting ourselves in commercial care settings.

Survivors' Rights

This document is not a legal instrument, even though it reflects rights to which we are legally entitled. Its authority comes from the clarity of our collective voice, clearly articulating those rights and helping to orient us toward them.

Our rights still exist, even when they are being violated. Our rights exist whether we are consciously aware of them, or not. It is also true that society protects power and wealth over vulnerable people. Institutional bias is slated to increase as AI dominates decision-making processes across systems.

Learning our rights is not only learning about laws, policies, and formal protections. It is about practice. Rights are strengthened through use, and we strengthen them when we practice to:

- Ask questions
- Seek clarification

- Express disagreements
- Say no
- Set boundaries
- Request accommodations and modifications
- Learn about our preferences
- Document our concerns

The existence of our rights does not mean they will be upheld. Many survivors were never taught that our rights exist, or how to recognize and have help when our rights are being violated. When our rights are violated, we have the right to disclose what has happened to trusted people and to receive advocacy, support, and help. Learning about and strengthening our rights is a process. Practicing our rights even in small ways builds our agency and protection.

Right to Disability

Survivors have the right to receive accommodations, modifications, and advocacy support as needed due to disability. We should not have to build these supports on our own, though in many situations we may need to. If our efforts to obtain support are not successful right away, that is not our fault. Survivors' disabilities can be invisible, especially when compared to more apparent and more socially accepted types of disabilities. Survivors have the right to be temporarily, permanently, and/or entirely disabled from certain actions.

Abuse-Created Disabilities

An abuse-created disability is a disability resulting from abuse, neglect, and/or exploitation. Abuse-created disabilities can be invisible, often leaving survivors to be misunderstood and be considered as "noncompliant, "difficult," "lazy," "manipulative,"

"attention-seeking," "unmotivated," or "unreliable" based on their disabled presentation. Any such presentations are just symptoms of abuse and neglect symptoms—*not "personality disorders" or character flaws*. Dissociation can look like inattentiveness; freeze responses can look like refusal; memory fragmentation can look like dishonesty; and self-protection can look like defiance. In order to access actual help, survivors need to be understood through a disability lens, not criminalized for adaptations that function to keep them alive.

Abuse-Created Developmental Disabilities

A developmental disability is a disability resulting from the interruption of the typical development of the body and mind. Some developmental disabilities are the result of genetics, or exposure to harmful substances, like lead. Some developmental disabilities are caused by abuse, like shaken baby syndrome and Munchausen's by proxy. While many developmental disabilities created by abuse remain unrecognized by governing entities, this does not negate the reality of their existence, their causes, and their effects.

Characteristics of abuse-created disabilities can include:

- They can result from abuse during childhood, including during brain and body development (in utero during gestational growth, in some cases);
- The effects may be lifelong, and may present differently over time or dynamically fluctuate from moment to moment;
- Their presence may be hidden from conscious awareness of the survivor;
- They can make it hard for a survivor to do things most adults and even children take for granted, like:
    - Being able to control the body's actions
    - Speaking at will
    - Self-advocacy

    - Activities of daily living (ADLs): Basic hygiene and self-care, feeding oneself, clothing oneself, moving from place to place, time blindness and missed appointments, etc.
    - Recognizing and avoiding danger
    - Supporting oneself economically
    - A sense of self at all—which effects the ability to form friendships, surround oneself with a supportive social network, and engage self-protection.
- Constant mental and physical pain that cannot be dissociated or compartmentalized
- Amnesia, extreme constant dissociative memory processes, and flashbacks
- Neurological impacts such as traumatic brain injury (TBI), stress-related brain changes, seizures, chronic migraines, or sensory processing differences.
- Nervous system dysregulation, including chronic fight/flight/freeze responses, startle responses, shutdown, collapse, or hypervigilance.
- Cognitive difficulties, such as difficulty concentrating, memory gaps, slowed processing speed, executive functioning challenges, or trouble organizing tasks.
- Speech and communication barriers, including selective mutism, word-finding difficulty, or dissociation while speaking.
- Emotional regulation differences, including overwhelming emotional states, numbness, or rapid shifts between states.
- Relational impacts, including difficulty trusting, forming safe bonds, or recognizing unsafe dynamics.
- Physical health conditions connected to prolonged trauma, including autoimmune conditions, chronic pain, gastrointestinal disorders, cardiovascular strain, and other stress-related illnesses.

- Developmental interruptions, where skills that are typically formed in childhood—such as self-soothing, self-advocacy, and independent living skills—were disrupted or never developed.

Right to Effective Representation and Advocacy

We have the right to build an advocacy body that can function to represent the rights of survivors. Survivors need protection from being prompted to demonstrate our disabilities and their causes; produce evidence of our endangerment; and reveal data about our internal world to unknown/unsafe people who might be acculturated, trained, and sanctioned to disclaim the evidence of abuse.

Because we lack adequate advocacy, we have formed a Survivors' Rights Coalition that is training others to effectively represent and protect survivors from becoming further exploited by the people around us––whether intentionally or otherwise. Effective advocacy adheres to the agreed-upon scope and limits of representing our agency, and not what advocates nor providers perceive is needed.

Right to Privacy

It is our right to decide, in our own time, who we trust, when we trust them, and how that trust is given. Privacy means choosing for ourselves what we choose to share and with whom we choose to share it. A "right to privacy" means:

- We do NOT have to share information that is personal.
- We do NOT have to share information about our internal world, including whether we have dissociated parts of ourselves.
- We do NOT have to share our private things like journals, devices, mail, e-mails, photos, IDs, social media, home address, what state we're from, phone number,

email address, demographics, sexual preference, family genealogy and history, where we work, our disability status, our retirement status, your veteran status, if we have children, etc.

- We have a right to be alone, and we have a right to choose trusted people to accompany us.
- We do NOT have to share our history: who abused us, who was involved, what happened, etc.
- We do NOT have to share our diagnoses.
- We do NOT have to allow people including helpers and providers into our home.

What other privacies do you consider that we might need? If our privacy is not being upheld, we have the right to tell trusted people. We have the right to receive advocacy and help.

Some survivors have no agency in being forced out to reveal private information when asked and are saddled to report or disclose without any regard for their own personal security or safety. We have the right to refuse disclosure when it is unsafe, and the sections that follow include cue cards to support what can be said in these situations.

Even More Rights

This document does not contain every right we have, only a few rights that are essential to our protection in commercial care settings. The majority of our rights are left unnamed and obscured from public understanding. We may have more rights than we have ever been shown, encouraged to exercise, or believed possible.

We develop the knowledge and skills of our rights gradually, through repeated experiences of being listened to, respected, and supported in exercising choices. We benefit from learning and practicing our rights with safe-enough people in low-risk environments before navigating higher-stakes commercial care settings.

Building Protection from Harm in Commercial Care

For many of us, the capacity to say no was systematically destroyed. Such patterns do not disappear as we form new relationships with providers. We may comply with requests – for disclosure, for access to our internal world, for information that we do not wish to share — not because we consent, but because compliance is what we were engineered to do. Providers who do not understand this may interpret our compliance as consent where it is not. In order to protect ourselves against unnecessary exposure within commercial care systems that collect, store, and share our sensitive data – this guide is focused to help us build skills for exercising greater control over personal information sharing while still representing our unmet needs.

Beginning Care with a New Provider

We can review our rights stated in this guide, in advance of attending a first session with a new provider. We can write down information that we intend to share and make cue-cards for what we can say if we need privacy around certain matters or wish to decline answering certain questions.

We can ask an advocate or another provider to establish contact with new providers before our first session and communicate our specific needs for trauma-informed care. In doing so, we can choose how much information we would like to share, i.e. what types of accommodations and modifications we may need throughout the course of care; how our abuse history may affect our ability to self-advocate; our needs for providers to refrain from AI notetaking and charting of personal historical details; etc.

With vetted, safe-enough providers, we can request to share educational materials about trauma-informed care in an initial meeting, and request that they review documentation

about our rights, reflect on it, and confirm their understanding of our rights and preferences before clinical work begins.

A provider who dismisses or minimizes any of these needs and requests is telling us something important about whether they are safe for us.

Warning Signs that a New Provider May Not Be Safe

Warning signs that a provider may not be safe, or at least not well-suited to work with us may include behaviors such as:

- Pressuring us to disclose trauma history
- Minimizing the impact of trauma or disability on our lives
- Encouraging us to "move on" from traumatic experiences
- Showing discomfort when we request trauma-informed accommodations
- Reacting negatively or defensively when we set limits
- Failing to recognize triggers, distress responses, or coping strategies as valid
- Making us feel "difficult" or unreasonable for advocating for ourselves
- Ignoring or dismissing visible distress or emotional reactions
- Dismissing concerns about prior harmful experiences with providers and systems
- Repeatedly dismissing, overriding, or undermining our instincts and perceptions
- Failing to acknowledge the importance of our choice, autonomy, and control in care
- Treating consent as implied or assumed, rather than ongoing and explicit
- Ignoring, dismissing, or forgetting stated preferences
- Making us feel that we "must" disclose data in order to receive care

- Failing to respect our right to decline questions, interventions, or topics of discussion
- Refusing to collaborate on how care, communication, or treatment will be structured
- Rushing the pace of intake, assessment, or treatment
- Beginning assessments or interventions without clearly explaining what will happen first
- Using fear, urgency, intimidation, or pressure to influence decisions
- Using language that feels judgmental, stigmatizing, or pathologizing
- Discouraging us from bringing a support person, advocate, or trusted contact
- Being unclear or evasive about documentation, reporting obligations, or records
- Failing to invite questions, feedback, or collaborative discussion
- Positioning themselves as an authority on our lived experiences
- Creating dynamics in which we feel responsible for managing the provider's emotions rather than focusing on our own care

Taken together, these behaviors may indicate that a provider is not well-suited to work with us, particularly if they are unable or unwilling to center our agency, respect our boundaries, and support our ongoing consent and control in care, including our ability to pause, decline, redirect conversations, and set the pace and direction of our time together.

Invoking Our Rights

Survivors' rights can be invoked at any point with safe-enough people in safe-enough environments. If a safe-enough provider asks you for something – you can exercise your right to decline. You can name that right in the moment; or ask for time; or ask for an advocate to speak on your behalf later on. You do not have to explain or justify your limits. We have rights to:

- Ask an advocate to review a document before signing
- Ask a provider to explain a procedure in a way that a child can understand
- Tell a provider stop, even in the middle of a procedure (when safe)
- Tell a provider that something is not helpful
- Request the presence of a nurse, tech, or a support person of our choosing
- Choose to pause, refuse, or reconsider a recommendation
- Request a second opinion
- Ask to view our own file
- Request our medical notes
- Correct misinformation in a file

Consent is not permanent and can be withdrawn or changed as your needs shift. You are allowed to pause or stop a conversation at any time, even if it has already started. If something feels confusing or overwhelming, we can ask for information to be repeated, simplified, or provided in writing so that we can revisit it later either by ourselves or with a trusted person. We may also communicate that, based on the information that we are learning, we would prefer to return at another time with a trusted person, or prefer to schedule a hybrid or remote appointment in which a trusted person can be present by phone or video.

If we are unsure about what we need in the moment, we can ask for options, or communicate that we will seek support from trusted people to consider next steps that

are best for us, without committing to anything immediately. Uncertainty, hesitation, and changing capacity are just normal human responses.

Cue Cards for Protecting Our Privacy and Agency

We can set boundaries with providers about topics that we are willing to engage in. We can refuse to answer certain questions or limit what information we choose to share. Examples may include:

- “I prefer not discussing that in detail on my medical record.”
- “I would like more information about why that question is being asked.”
- “I would like to understand how this information will be documented and used.”
- “I am only comfortable sharing information that is necessary for my care today.”
- “I would prefer to focus on my immediate concerns and symptoms.”
- “I need time to think before answering that question.”
- “I would like to pause this conversation for now.”
- “I would like a trusted person present before continuing.”
- “I am willing to revisit this topic if trust and safety are established over time.”
- “I prefer not to discuss any matter related to trauma history in this appointment.”
- “I would like clarification before responding further.”
- “I am exercising my right to decline answering that question.”
- “I would like to end or pause this appointment if my boundaries cannot be respected.”

In advance of commercial care appointments, we can prepare cue cards written on paper, printed, or available on a device. Sometimes reading a prepared statement to the provider helps us maintain more control over what personal information becomes disclosed.

Exit Planning for Unsafe Care Dynamics

When a provider behaves in mentally, emotionally, physically, sexually, or otherwise abusive ways, direct confrontation with the provider about our rights can increase danger and harm – especially when an abusive provider controls access to essential care, medications, referrals, benefits, insurance approvals, disability documentation, workplace or school accommodations, and other necessities that affect our stability and survival.

Those who are able to safely transition to a new provider without facing significant barriers or increasing non-safety can reduce harm by doing so. Some survivors may experience disability-related barriers that make it difficult to transition to new care without support, which can result in continued reliance on an abusive provider.

Harm Reduction in Relationship with Abusive Providers

When reliance on an abusive provider must continue, the safest and most effective harm reduction can be to limit contact, communicate in writing, bring a support person, document interactions, seek outside advocacy, and identify alternative providers before attempting to challenge unsafe behavior directly. Whenever possible, bring a support person to appointments. Even if they do not speak at all during the appointment, the presence of a witness can decrease abusive behavior and increase a provider's accountability.

Mutual aid in survivor-led community is a tool that can be utilized to document what happened and what is happening. Documentation can include keeping dated notes of what was said and done, saving text messages and emails, taking screen shots, requesting copies of records, and writing down our recollection of visits as soon as it is safe to do so.

Audio Recording

Notably, recording laws do not account for the rights of survivors with TBIs, amnesia, and related causes that medically indicate the necessity for recording at all times. Audio recording during abuse is a necessary tool for self-protection that is also illegal in some states. Recording laws vary by state: 38 states in the US are “one-party” consent states, meaning that you can legally record any conversation for which you yourself are present. The other 12 states are “all-party” consent states (California, Connecticut, Delaware, Florida, Illinois, Maryland, Massachusetts, Montana, Nevada, New Hampshire, Pennsylvania, and Washington) meaning that every person involved in the conversation must agree to be recorded.

Realistic Next Steps

If a provider violates our rights, ignores our stated preferences and advanced directives, causes us harm, or abuses their power – we do not have to handle it alone. We have the right to access advocates, survivor-led networks, legal resources, regulatory bodies, and community organizations that may be able to offer assistance for assessing next steps and helping us make the transition to safer care alternatives.

While legal action may be a needed pathway towards accountability and restitution after abuse has occurred, survivors and advocacy organizations often lack the financial, material, and human resources necessary to pursue formal legal actions.

Due to the reality of organized abuse members exacting influence within institutional bodies, legal action is frequently not safe for survivors. Sometimes the best that we can plan for is safely transitioning to a new provider without losing stability.

If Harm Follows Disclosure

Disclosures made to peers, advocates, and even other providers may unintendedly get back to the abusive provider. This can happen through misplaced trust, informal conversations, institutional communication, shared professional networks, or because

someone minimizes the abuse and believes they are “helping” the victim by informing the provider. If disclosure reaches the abusive provider, their response may be intimidating, retaliatory, dismissive, manipulative, or otherwise unsafe.

Disclosures may unintentionally reach people who are close to the abusive provider who act to minimize our experience, side with the provider, portray the victim as mentally unstable or in psychosis, accuse the victim of being the perpetrator, or otherwise initiate retaliatory rumors about the victim.

When disclosure harms our stabilization and survival, we can immediately stop sharing updates, plans, and vulnerabilities with anyone who has acted to harm us. Instead, we can delay all further disclosure and focus exclusively on securing alternative care.

> “I reassure and validate that I am doing my best and I am not the one doing the crime. I have the right to try my best. I have the right to prioritize my safety. My silence in a dangerous moment is not my consent. My fear, hesitation, and caution do not make me guilty. I am not responsible for another person’s unethical or abusive behavior. I am a person deserving of care, fairness, and protection even when I cannot safely advocate for myself directly. I can remind myself abuse and neglect are reflections of the other person’s bad choices, not my value. I do not have to carry shame for adapting to unsafe circumstances. The harm done to me is not evidence that I deserve it. I do not have to prove my worthiness to deserve respect. My dignity is not harmed when someone else abuses power. I can recognize unfairness without forcing myself into danger to correct it immediately. I can learn about my rights inside, even if openly asserting them outside is still dangerous. Power imbalances do not erase my humanity or my rights. I deserve compassion for how difficult this moment is. My experience matters even if others minimize it. I can seek witnesses, allies, records, advocacy, legal support, and safer channels when the time is right. I can survive this moment. Picking survival and

> stability today does not mean I have given up on future freedom." - anonymous victim-survivor

Continuing and Expanding Inner Rights

This guide remains open and evolving. The rights collected in this document are only an initial attempt to name some of the ways that victims and survivors can protect ourselves during conditions of abuse, neglect, and internalized harm.

Survivors are encouraged to adapt these rights, expand them, and add to them based on our own needs and experiences. We utilize a secured document share site where survivors can share their reflections, name more rights, and help grow these documents together. That site can be found at www.helpexists.org/toolkit.

We are building these tools because the systems we navigate were not built for us. We are building tools together, from what we know about what we need and what has been missing. Our tools will get better as we use them, learn from them, and develop them further.

What these tools represent is our collective insistence that we are the authorities on our own experience, that our needs matters and will be stated, and that we will look out for each other in spaces where no one else has.