Senate Judiciary Committee Constitution Subcommittee
Hearing on Toxic Conservatorships: The Need for Reform
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Senator Blumenthal, Senator Cruz and members of the Subcommittee, it is a great honor to be here today to talk about conservatorship law and options for reform. I am deeply gratified that we have come together to ensure that people with disabilities have the same opportunity to pursue their dreams and freedom as other Americans.

My name is Dr. Clarissa Kripke (she/her). I am Clinical Professor of Family and Community Medicine at the University of California San Francisco. I direct the Office of Developmental Primary Care whose mission is to build the capacity of the healthcare system to serve adults with developmental disabilities.

I provide primary medical care to some of the most medically fragile and behaviorally complex people in the Bay Area. And I have run a consult service that served rural communities throughout Northern California. Most of my patients lived in skilled nursing facilities or state developmental centers before community homes were developed that could support their medical needs. They are all beneficiaries of Medicaid and most are also beneficiaries of Medicare. Almost all are beneficiaries of Social Security Income. Most have complex combinations of medical, developmental, and psychiatric disabilities. Less than half have family members still involved in their lives.

I also have personal experience as the parent of a college-bound, autistic, young adult. She cannot speak and communicates by pointing to letters on a letterboard. My daughter requires care for all of her basic activities of daily living. But she can direct her life and healthcare.

I am also the Vice Chair of the Board of CommunicationFIRST, a national nonprofit whose vision is that every person with a speech-related disability will have what they need at all times to communicate effectively, to be free from abuse, and to be fully included in their community.

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[1] Office of Developmental Primary Care, https://odpc.ucsf.edu
[2] Department of Family and Community Medicine, https://fcm.ucsf.edu/
[3] CommunicationFIRST, https://communicationfirst.org/

One of the most common reasons people cite for pursuing conservatorships is that they fear that their loved one won't be able to access medical care or that family members won't be allowed to provide support.

I am here to testify that in my professional experience as a medical doctor and in my personal experience as a parent of a nonspeaking adult:

1. **Conservatorship is not necessary to deliver high quality medical care. Conservatorship is not even helpful. This is true, even for people with the most complex disabilities.**

2. **Conservatorships do not make people safer or prevent abuse. In fact, they can be harmful by trapping people with disabilities and conservators in bad situations.**

3. **Supported decision-making works better and results in better healthcare decisions.**

Let me go through these points in more detail.

1. <u>Conservatorships Are Not Necessary</u>

Conservatorships are not necessary to deliver high quality healthcare. They are not necessary even for people with the most significant and complex disabilities who cannot speak. If anything, conservatorships encourage healthcare providers to focus on who is authorized to make a medical decision rather than on the patient. The focus should be on engaging the patient, their supports, and the people impacted by a decision. These are the people to engage in a discussion of options, risks, benefits, values, ethics, and practical logistics.

When a conservator has been granted rights to make medical decisions, a doctor is no longer obligated to discuss treatment plans with the patient. The patient may not be present to receive information about their condition. Sometimes the patient may not even be aware that there is an important decision to be made. When there is no conservator, the healthcare provider is obligated to at least try to explain the medical options to the patient. To do so, they have to learn more about how the patient communicates, accommodate their learning style, and to reach out to their support system.

Even if others ultimately have to step in to make a specific decision, this process is important. It educates and prepares the patient to make other decisions in the future. It conveys respect and builds trust. This, in turn, helps patients cooperate with exams, tests, and procedures. When healthcare professionals speak directly to their patients, it reminds them to listen. It helps clinicians avoid confusing the concerns and opinions of supporters with those of the patient. Both are important but are best addressed separately.

> *For example, a patient's mother once told me that my patient didn't want a pap smear. When I checked with the patient, she did want her exam. The mother knew it would take time, and she was late to work. We were able to reschedule when a trusted aide could*

> *accompany her to the appointment. By talking directly to my patient and considering her mother's needs separately, I was able to meet both of their needs.*

2. Conservatorships Do Not Protect Vulnerable People from Abuse

Conservatorships do nothing to protect people with disabilities from abuse. Choice and control over one's life is what makes people safe. Only the person with a disability knows how others treat them. When they have no control and others make their decisions, they are more vulnerable to being abused. Most conservators are people trying to do right by someone they care about to the best of their ability. However, statistics show that most abusers aren't strangers. They are family members, service providers, coaches, and other people in positions of trust—people a judge might select as a conservator.[4] Vulnerable people are often groomed for abuse and may not recognize it as mistreatment. They often depend on the people who abuse them for things they need. It is difficult for a person under conservatorship to contact a judge if a conservator is abusive, tolerates abuse, or accepts untenable situations. Trying to contact a judge in these cases could be dangerous because the conservator has complete control over their life.

I had a patient who we suspected was being abused by their conservator. Because of the conservator's privileged role, Adult Protective Services closed the case quickly due to the lack of proof. Had my patient not been conserved, her distress and our suspicion would have been enough to help her end visits with this person and to help her select someone else to provide her support. The existence of the conservatorship meant we were unable to prevent visitation, but we tried our best to make sure the visits were supervised.

Counterintuitively, conservatorship can also become unwelcomed from the conservators' perspective. Serving as a conservator is a time consuming, long-term responsibility that is often stressful and overwhelming. Conservators can get trapped in a role they no longer wish to fulfill as they age or their circumstances change. Judges are reluctant to release people from the responsibility if there isn't an alternate person readily available to serve. Conservators who develop disabilities themselves also face difficulty petitioning the court to make a change.

Many conservators are professionals or relatives who are not involved in the person's day-to-day life. Major medical decisions often need to be made quickly, with little notice, and often at inconvenient hours. I have had to try to contact conservators who reside in nursing homes or outside the country; who are only available during business hours; or who are actively avoiding being called, or assuming the responsibility of making a decision. I have also had conservators make decisions that the people who have care and custody of the person feel are unethical or which undermine their relationship of trust.

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[4] Harrell E. (2018) *Crimes Against People with Disabilities, 2009-2015-Statistical Tables*. Bureau of Justice Statistics. Available at https://www.bjs.gov/content/pub/pdf/capd0915st.pdf#page=6.

> *For example, a conservator decided to discharge a patient without a feeding tube. The ability to swallow can take time to recover after a serious illness. The patient was dying of dehydration and weakness from hunger. Food and water are not medical treatment. It is life sustaining. However, the law is clear that patients or their conservators can decline a feeding tube. Neither the group home staffs, nor I felt that allowing someone to starve to death under our care was humane.*

3. <u>Supported Decision-Making Works Well in Practice</u>

Supported Healthcare Decision-Making works better than conservatorship. Supported Healthcare Decision-Making is a process where people with disabilities can name trusted supporters to assist them with communicating, accessing healthcare services, making decisions, and implementing their healthcare plan.

Maximizing Potential

Supported Healthcare Decision-Making allows people to maximize their potential. As with most things in life, people learn to make better decisions by getting practice. If people are given opportunities to make choices and accept responsibility for the consequences, they learn to make better decisions. They also learn whose advice to trust. Not all healthcare decisions are the same. Just because someone doesn’t have the capacity to make a specific decision at a specific moment in time doesn’t mean they will never be able to make a similar type of decision in the future. It doesn’t mean that they are unable to make other decisions. Supported Healthcare Decision-Making allows people to learn and grow from their experiences.

Better Communication Leads to More Efficient and Accurate Diagnosis

Everybody communicates. Communication is the foundation of patient care. Eighty percent of making an accurate diagnosis is based on the patient’s clinical history. Only patients know their internal sensations, experiences, and values. It is critical that healthcare providers communicate directly with their patients, and work to support and listen to them. Sometimes communication barriers cannot be overcome or can only partially be overcome. Sometimes we don’t get a clear history, but often we get a crucial hint about what is going on. Those hints can tell us where to look for the problem. That can be lifesaving. While communication may not always be easy, the success rate is a lot higher when we try.

> *For example, a patient came to me with her sister who had recently assumed her care. She didn’t know her very well. She insisted my patient was incapable of giving me a history. Since the sister thought something was wrong, but didn’t know what, I suggested we try. I put her in front of a keyboard to see if she would type. I asked her to show me how she says, “yes” and observed carefully. I asked her to show me how she says, “no.” I offered choices. I got out anatomy charts to see if she would point. Finally, I said, “Touch hurt.” She took my hand and put it on her upper, right stomach. I got an ultrasound based on that communication and diagnosed gall stones. That would have been a very hard diagnosis to make without her help.*

Improved Adherence

People adhere to the treatment plan more readily when they are empowered and supported to understand their condition and share decision-making with their healthcare provider. The patient is likely to be aware of barriers to implementing the plan for their health that the healthcare provider didn't consider such as when staff are available to assist or how the plan might impact roommates. Healthcare providers engaged with Supported Healthcare Decision-Making processes learn how to accommodate their patients. Direct communication empowers patients to report side effects and complications of treatments that may not be apparent to caregivers.

Flexibility

In Supported Healthcare Decision-Making, the person can name new supporters at any time. This ensures that the person can rely on support from people whose knowledge, skills, and availability are best matched to the situation. Flexibility to name multiple supporters or to easily replace supporters temporarily can provide relief to overwhelmed caregivers and can smooth transitions when family can no longer provide the same level of support.

Engagement in the Process of Making Decisions

A decision is understanding the options, the risks and benefits of each one, weighing them against each other, and communicating a choice. I see two main situations where others substitute decisions for the patient. The first is where the patient has the ability to make a decision, but their ability is overlooked because of their diagnosis, appearance, or method of communication. In this situation, the problem is usually that their disability, learning style, or communication has not been accommodated. For example, they may not be able to decide if they want dialysis or a brain scan until they watch a video or take a field trip to see what those procedures are like. In this situation it is not appropriate for others to make a substituted decision for the patient. Supported Healthcare Decision-Making allows patients to work with trusted supporters to ensure their abilities and communication attempts are not overlooked.

The second situation is where the person's will and preference truly can't be determined. The first situation is a lot more common than the second. But even if others have to step in and make a decision on behalf of a person, the patient can still participate in the process to the best of their ability.

> *For example, I had a patient with diabetes who did not like insulin shots. He was clear he did not like the shots but was not able to weigh his fear of needles against the benefit of controlling complications from his diabetes. Taking his preferences into account, the team decided to accept the level of sugar control that could be achieved with one shot of insulin per day, instead of the four shots that were recommended.*

4. Supported Healthcare Decision-Making Works Even When Will and Preferences Can't be Determined

Despite our best efforts, there are times when we can't clearly determine a patient's will and preference. In those situations, we make decisions as a team. Interdisciplinary team-based care with patients and their supporters in the center of the team achieves consensus. We schedule a meeting and invite the patient and the trusted people in their life such as friends, disability service representatives, social workers, caregivers, family, day services providers, job coaches, advocates, and clinicians. If the situation raises ethical issues or strongly differing opinions, a Client's Rights Advocate or ethicist can be invited to attend. Anybody who provides or funds care may have competing or conflicting interests, even if they do so without compensation. Those interests need to be acknowledged and managed.

At the meeting, we address the patient directly, regardless of whether we think they can understand, and even if they aren't responding. This is important because patients often surprise us with their understanding and insight when we don't expect it. Also, groups behave differently when they are speaking to someone rather than about them. They are also more likely to behave respectfully when the person is in the room.

For many of my patients, we use this same process for all of their major healthcare decisions regardless of whether the patient has a conservator. I can only think of a few times in my career when a team was unable to reach a timely consensus. The cases where there is conflict typically involve conservators. Conservators can make unilateral decisions so they are not obligated to work towards consensus with the people who will be most impacted. The most common situation where we run into difficulty is when the conservator is overwhelmed, confused, or doesn't want to make a decision. No decision is still a decision. Failing to decide can lead to care that is delayed or denied. Decisions typically have to be made before a court gets involved in oversight. Court oversight is more likely to delay care than it is to facilitate it. With Supported Healthcare Decision-Making, trusted people who are willing and available to help can be invited to support the decision-making process to ensure timely care for the patient.

No single decision-making process can guarantee a perfect outcome. One can always find unfortunate anecdotes. However, in my twenty years of experience providing healthcare to people with complex disabilities, I can attest that Supported Healthcare Decision-Making works. It works better than conservatorship for ensuring good healthcare. It avoids the expense, effort and delay of having a court get involved in private healthcare decisions. Involving the courts does not add value to the process of delivering healthcare. Resources are better spent on educating people with disabilities, supporters, and healthcare professionals on how to partner effectively. They are also better spent on funding reliable support. Supported Healthcare Decision-Making respects the rights and freedoms of people with disabilities. And it gives people with disabilities and their supporters the flexibility they need to expediently solve complex problems so patients can get the best care.

5. Resources

More information on how Supported Healthcare Decision-Making works in practice can be found in the consensus guide, *Partners in Health: Implementing Supported Healthcare Decision-Making for User of Augmentative and Alternative Communication*.[5]

Self-determination requires access to an effective form of communication. Information on access to support for communication can be found in *Everybody Communicates: Toolkit for Accessing Communication Assessments, Funding, and Accommodations*.[6]

Preparing youth to make decisions should start during childhood. Tips for parents to assist them with raising children with disabilities who are prepared to direct their lives and their supports can be found in *What's Next?: A Self-Advocates Guided Tour through Transition for Parents and Other Supporters*.[7]

Guidance for patients, social workers, and hospital personnel on how to hold effective team meetings to empower patients with disabilities can be found on the Office of Developmental Primary Care's Website.[8]

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[5] Kripke CC, Crisp-Cooper M, Doherty B. (2021) *Partners in Health: Implementing Supported Healthcare Decision-Making for User of Augmentative and Alternative Communication.* Regents of the University of California. Available at:https://odpc.ucsf.edu/advocacy/supported-health-care-decision-making/partners-in-health-implementing-supported-healthcare.

[6] Office of Developmental Primary Care. (2018) *Everybody Communicates: Toolkit for Accessing Communication Assessments, Funding and Accommodations*. Regents of the University of California. Available at https://odpc.ucsf.edu/communications-paper.[6]

[7] Crisp-Cooper M. Francisco S. (2016) *What's Next?: A Self-Advocates Guided Tour through Transition for Parents and Other Supporters.* Regents of the University of California. Available at https://odpc.ucsf.edu/advocacy/transition-successful-community-living/whats-next-a-self-advocates-guided-tour-through.

[8] Office of Developmental Primary Care. *Patient Centered Care (2018*) The Regents of the University of California. https://odpc.ucsf.edu/clinical/patient-centered-care