

Amy Wall

00:01:22: All right, Amy it's 9am if you want to go ahead and get started.

00:01:28: I think we are good to go.

Amy Whiting

00:01:36: Good morning, everyone, my name is Amy Whiting and I'm the manager of the Regulations Unit at the Department of Developmental Services.

00:01:45: It's 9am on Monday July 18, 2022, and we are gathered here today via Zoom to receive public comments on the proposed rulemaking action by the California State Department of Developmental Services.

00:01:59: Under the rulemaking provision of the California Administrative Procedure Act, this is the time and place set forth for the presentation of statements arguments, and contentions orally or in writing for or against changes to the Department's regulations related to the Community Crisis Homes and Enhanced Behavioral Supports Homes.

00:02:20: On Friday June 3, 2022, the notice of proposed regulatory action was published in the California regulatory notice register sent by email and US mail to interested parties and post it to the Department's website.

00:02:36: We have added the link to the regulations page and the chat for your convenience.

00:02:42: I'm hoping that gets done by one of the staff.

Amy Wall

00:02:46: We will do that don't worry.

Amy Whiting

00:02:48: I will briefly discuss the proposed changes and the rulemaking and then I'll open it up for anyone interested in presenting comments under the rulemaking provisions of the California Administrative Procedure also referred to as the APA.

00:03:02: The purpose of this hearing is... I'm sorry that's.

00:03:06: The purpose of this hearing is only to obtain public comment on the proposed changes, I will not respond to comments during this hearing, nor will I engage in the discussion about the comments other than to seek clarification or answer questions about the rulemaking process if necessary.

00:03:21: All oral and written comments received during this hearing will be considered in accordance with the APA. This entire rulemaking hearing will be recorded via Zoom.

00:03:30: The transcripts of the hearing, including all comments submitted through the chat feature will be made part of the official rulemaking record.

00:03:38: The Department will respond to all comments in the Final Statement of Reasons which will be posted on the Department's website once it is completed. Once again, you can find the link to the regulations website in the chat.

00:03:53: Today we are hearing comments on proposed regulations related to the rules governing the Community Crisis Homes, also referred to as "CCH" and Enhanced Behavioral Support Homes, also, referred to as "EBSH". These regulations are located in the California Code of Regulations, Title 17 commencing with section 59000 for the Community Crisis Homes regulations and 59050 for the Enhanced Behavioral Support Homes regulation.

00:04:26: The Department has also proposed reorganizing the EBSH regulations to mirror the arrangement of the CCH regulations by renumbering several sections. The Department developed a crosswalk which can be found on page four and the Initial Statement of Reasons on our website.

00:04:46: We have added the link to the Initial Statement of Reasons in the chat for your convenience. The crosswalk helps to clearly identify the proposed rearrangement and allows for a side-by-side comparison of the existing regulations.

00:04:59: The proposed regulations clarify the Community Crisis Homes placement duration requirements and capacity limitations as well as the application of emergency intervention techniques regarding seclusion and behavioral restraints in both the community crisis and enhanced behavioral support homes. The proposed regulations add new definitions, to clarify new terms as used in both the CCH and EBSH regulations.

00:05:26: The proposed regulations provide guidance to consumers, regional centers, and consumer advocates in order to better serve consumers with developmental disabilities.

00:05:36: The proposed regulations delineate the specific duration of establishment of the rates for community crisis homes licensed as an adult residential facility or community crisis homes licensed as a group home. The proposed regulations identify specific criteria and requirements for staff training and continuing education requirements.

00:05:59: The proposed regulations prohibit the use of seclusion and prone restraint emergency intervention and both types of homes. Furthermore, the regulations update the admission requirements to include a written functional behavior assessment.

00:06:13: As of today's date, the rulemaking file includes several items, including the notice of proposed action, the express terms of the regulations using underline and strikethrough to indicate changes, the Initial Statement of Reasons, the Standard Form 399 Economic and Fiscal Impact Statement which is required by the State Department of Finance and the notice a public hearing issue July 8, 2022.

00:06:41: Virtual attendees, if you are presenting oral comments today, we would appreciate it if you would also submit your comments in writing, but it is not required.

00:06:50: Please submit your comments, your written comments via our online platform, the link has been provided for you in the chat. This information is also included in the notice of proposed action for this rulemaking and on the Department's website.

00:07:09: If you're not making a comment today but would like to be notified of any changes made during the 15-Day notice, please subscribe to our interested parties' email list which can be done online through our website. We have also added the link to the subscribe in the chat.

00:07:26: This way we'll be sure to have you on our mailing list. The Department will notify you before the final adoption of any changes to this proposal, or about any new material relied upon in proposing these regulations.

00:07:40: If further modifications are made or additional information is added to the record, the notice will be sent to everyone who submits written comments during the written comment period, including those written comments received today.

00:07:52: To everyone who testifies today and to everyone who asks for such notification.

00:07:57: Well, no one may be excluded from participation in these proceedings for failure to identify themselves the names and email addresses or mailing addresses from today's meeting is meetings registration will be used to provide the notice.

00:08:12: To keep things organized I will call on the persons who have raised their hands via the raise hand feature found in Zoom.

00:08:18: You can find the raise hand icon on your Zoom toolbar at the bottom of your screen. It may also be under the reactions icon.

00:08:27: Zoom keeps track of the order that hands are raised, and that is the order I will call on people to share their comments to minimize any background or unintended noise. I currently have all attendees on mute.

00:08:39: When I call on you, I will unmute your microphone so that you can make your comment.

00:08:44: When you are called on to speak, please state your name and the organization you represent, if any, then tell us the section number or numbers of the particular regulation you want to discuss followed by your comments.

00:08:56: Once you have commented, you may stay in the meeting or you may leave. These proceedings are being recorded and will be posted on our website.

00:09:03: After we hear from everyone who has raised their hand and commented, we will continue to stay online until 12 o'clock noon for to capture comments from anyone else who wishes to be heard on the issue.

00:09:16: We will now take oral comments on the proposed regulation. To ensure time for everyone who wishes to speak, please limit your comments to a maximum of three minutes.

00:09:26: If you agree with comments made by a prior speaker, simply state that fact and add any new information you feel is pertinent to the issue.

00:09:35: Okay.

00:09:37: So I'm going to look in the chat now.

00:09:41: For anyone has raised their hand.

Amy Wall

00:09:44: It's not in the chat, it's in the participant list.

Amy Whiting

00:09:47: Oh yes, thank you.

Amy Wall

00:09:48: And Will Leiner is first up today.

Amy Whiting

00:09:53: Okay Will.

William Leiner (DRC)

00:09:56: Hi Good morning, thank you for the opportunity to speak today um I hope I can get a little bit more than three minutes in a three-hour hearing.

00:10:05: I think this is a really important issue and that it's a partner when phone told me on with going over time.

00:10:13: My name is William Minor I'm an attorney with disability rights California, we are California's protection and advocacy agency.

00:10:22: We have a mandate under state and federal law to protect and advance the rights of disabled Californians.

00:10:28: This work includes advocating for the rights of disabled people to live in inclusive integrated settings and investigating the use of abusive practices, like the inappropriate are excessive use of restraints.

00:10:42: A little bit about me, I had the privilege of working with DDS administrations under directors Del Gadio, Ben Rogers, and then Director Bargeman on a plan.

00:10:53: Institutions for people with intellectual and developmental disabilities and then to create a safety net, so that California would never go back to that model.

00:11:03: I've also had the privilege throughout my career to represent people and institutions who weren't being given a chance at community living.

00:11:11: And, on a personal note my brother is someone who spent his late teenage years at Camarillo State Hospital.

00:11:18: A state operated institution that closed in the late 90s. Throughout his early life, he was deemed inseverable by our system.

00:11:27: And after being kicked out of multiple group homes, he ended up at this institution 300 miles away from our family knowing what I know now about life in institutions I can't even imagine what life was like for him.

00:11:42: But thankfully in 1997 Camarillo closed its doors. He just turned 18 and it was offered a chance to live in his own home with what at the time was a new service called "support and living services".

00:11:53: And, to be honest, my family was skeptical at the time after all we've been told, for years, that he needed to be in the care of a facility.

00:12:00: How could he possibly live on his own even his staff said he'd be back within the week. But it worked and I'm happy to say that my brother has been living on his own for nearly 25 years.

00:12:10: I share this story because supported living services are his safety net.

00:12:15: And to acknowledge DDS's commitment to developing a safety net to support people who are at risk and placement and institutional, incarcerable, or other highly restrictive settings.

00:12:26: And this is why community crisis homes and enhance behavioral support homes exist, right? They're also part of the fabric of the safety net and the regulations that issue govern life in the settings so let's turn there.

00:12:41: Unfortunately, that specific regulations we addressed in our comments today feel like they represent the opposite of safety. There's so much focus on restraint. How and under what circumstances staffer about to exert physical control over another person.

00:12:58: And we are especially concerned about two aspects related to the use of restraint. The use of supine restraints as an acceptable emergency intervention and the permissive use of restraints as an extended procedure in this case for up to two consecutive hours.

00:13:17: I'll address supine restraints first but let me lose the jargon and define supine restraint. Supine means lying down face up.

00:13:28: And supine restraint is a type of physical restraints, where a person is held to the floor in a face up position using physical pressure on their body, and it is unspeakably traumatizing to the people subjected to this practice.

00:13:44: We appreciate DDS's recognition that, and I quote supine restraint is the most restrictive physical restraint permitted and it's misuse poses the greatest threat to the health and safety of the individual being restrained and to their staff.

00:14:02: But while DDS rightfully recognizes the risks associated with supine restraints the regulatory solutions that presents does not adequately address these risks.

00:14:13: For example, the regulations added definition of supine restraints to the regulatory structure.

00:14:20: That this invites permission, and they have the unintended consequence of expanding not reducing their use.

00:14:26: There are training requirements for facility administrators regarding the use of supine restraints this maybe reduce, but it will not eliminate the risks associated with these restraints.

00:14:37: And their new regulations for facility administrators to report supine restraint usage to DDS but they lack clarity about how or in what way DDS more review or act on this information.

00:14:51: For these reasons, we strongly recommend that DDS take the same approach to supine restraint that is taken with other dangerous interventions such as prone restraint where a person is held face, down to the ground and seclusion where a person is confined in alone in a room, they should be banned.

00:15:13: I want to turn to a few points in the use of restraints as an extended procedure.

00:15:18: We know that all restraint positions can be dangerous, lethal even. For this reason, health and safety code section 1180.4 prohibits restraints as an extended procedure.

00:15:31: Which is defined as anything over 15 minutes, and I acknowledge that this same law also gives DDS the authority to adopt regulations, these regulations that authorize exceptions to the 15-minute maximum time limit.

00:15:46: But the regulations in front of us today they authorize the use of restraint as an extended procedure for up to two consecutive hours, this is eight times the statutory maximum.

00:15:59: I can't think of any other word for this, but abuse and question how and under what circumstances a person could pose an imminent danger for two consecutive hours.

00:16:10: Let alone be forcibly restrained by staff for such an extended period of time.

00:16:15: This cannot be read as consistent with the underlying statute or what the legislature intended when it gave DDS this regulatory authority any restraint over 60 or even 30 consecutive minutes should be prohibited.

00:16:30: Now I'm not suggesting that DDS supports the use of restraints, of course, you all don't.

00:16:36: I also recognize DDS is focus on trauma informed care throughout these regulations, we can see considerable effort in these regulations, focused on the prevention and reduction of permissible restraints.

00:16:50: But trauma informed care to do it right, it requires more. Restraints are trauma eliminating restraints is trauma informed care.

00:17:01: These regulations are a start. They require emergency intervention plans to that quote included description of the plan to systematically fade the use of inclusion of supine restraints.

00:17:12: And for facilities to submit those plans to DDS but let's go further. DDS should also require emergency intervention plans to include a plan to systematically fade the use of all restraints.

00:17:29: Zooming out, I have three more points to make.

00:17:33: First regulations like these permitting the use of restraints alongside other regulations not addressed here, allowing these facilities to use locked doors unlocked fences.

00:17:45: They picked these homes at risk of turning into the very type of institutional placements they're designed to prevent.

00:17:52: These are supposed to be people's homes it's right there in the name community crisis homes, enhance behavioral support homes.

00:18:00: How can we call these homes people aren't forcibly held to the floor in their own homes? Homes might have alarms on doors and locked gates surrounding the perimeter but that's for the purpose of keeping people out not keeping them in.

00:18:15: Second, there needs to be better transparency and data reporting about the type, duration, and frequency of restraint use in these settings and all settings really.

00:18:27: But even if the data shows that supine restraints or restraints over 15 minutes or rarely or never used there is still damage in this regulatory structure.

00:18:36: It invites permission. Other states look to California, as an example of how to do things right.

00:18:42: We have a responsibility and an obligation to the people served by our system to get this right. So, we hope that this is the first, not the last opportunity to make these regulations better for the people directly impacted by them.

00:18:58: And lastly, when I shared my story about my brother, I never shared why supported living services works for my brother when everything else around him failed.

00:19:08: The philosophy behind support living services is both deceptively simple in a paradigm shift, at the same time.

00:19:15: At Camarillo State Hospital and every placement before it, my brother is forced to structure has lived around the needs of the program he was in.

00:19:23: All this cause to his frustration and pain, but with support and living services, the support was built around him not to control him but to honor his needs and his preferences and his humanity.

00:19:35: So before we rush to build more and more enhanced behavioral support homes and community crisis homes or more facilities that lock people in with dates and alarms, let's not forget that we have another safety net model that works. His story shows what's possible when you put the person at the center of a real home and developing supports around them.

00:19:57: I thank everyone for the opportunity to share these comments today and go over my time. I'd like to, if possible, turn the Zoom over to my dear colleague Vivian Han who...

Amy Wall

00:20:12: Oops.

00:20:13: Hold on just a minute there.

00:20:17: For some reason it muted.

00:20:25: Alright, alright. Hmm.

00:20:27: We're going to take just a moment. We're at the 20-minute mark. We're going to give Katie or ASL interpreter a little bit of a break and then we'll come back and Dr. Myers is actually next in line so Vivian if you want to raise your hand, I see it is raised in there, so we'll get to you, right after Miss Spiegelman so does that work for everyone?

00:20:57: All right, Katie, let us know when you're ready to come back okay.

Ruth Myers MD

00:21:05: Okay um, am I on?

Amy Wall

00:21:10: No, not yet. We need to give our asl interpreter a break she's been going for 20 minutes and so we're going to take a little bit of time off, we only have our one today so we're going to be respectful of her magic hands and try not to tire her out right in the beginning.

00:21:26: So just a moment I will call on you, Dr. Myers.

00:21:31: Alright, so everyone if you just hold on for about 10 minutes, we're going to take a quick break here and then we'll resume with the comments and Will, I hope that that was the conclusion of yours and it sounded like it was good timing with the technical difficulty. I don't know why everybody went on mute again, all of a sudden.

00:21:51: All right, hold on just a moment.

00:30:00: All right, everyone, thank you for your patience we appreciate you making time for our ASL interpreter to have a bit of a break. Will, you said that you were done so with that I will move on to Dr. Myers, you are the next up for providing comments.

Ruth Myers MD

00:30:21: Hi. Thank you.

00:30:23: For those of you that I haven't had the chance to work with yet, I'm Ruth Myers. I'm a physician. I worked for many years, as a direct support professional for people with IDD until I got through doctor school and I've specialized in people with IDD and complex needs since the late 1980s, which makes me a genuine antique. I have several comments to offer in terms of this discussion about basically increasing the use, of course, of procedures for people with IDD who are thought to be especially complicated from a behavior support standpoint. I should mention that I would like to say that my publications which documented the benefits and the improve safety when those procedures are replaced, I would like to say, those were the first, but they weren't the science supporting the replacement of course of procedures with comfort procedures has actually been in the scientific literature since 1835 so there's a lot of experience, a lot of knowledge, and a lot of procedures that are easier and safer for individuals and the people who support them.

00:31:56: Our articles came out 25 or more years ago and have been repeated and replicated by way better people since then. SAMHSA substance abuse mental health services administration has published numerous guidelines on the benefits to individuals where when course of procedures are replaced with comfort and sanctuary and the benefits are not only observed in the clinical status of individuals, but the benefits are observed in the people, providing the services. There are fewer injuries to everybody.

00:32:39: Workers' compensation costs decline, injuries, preventable deaths and so on, all decline when the model moves away from one of coercion and toward one of sanctuary and comfort. In addition, there are numerous procedures that we developed more than 20 years ago that replace course of procedures and are safer. The other thing I should mention is that since I'm in kind of an unusual specialty, I've had the chance to go a lot of other places to offer training offer consultation and so on, and as I mentioned, my specialty all these years has been the kind of people that that I think you all are talking about and trying so hard to care for.

00:33:32: And, as a result of being in an unusual specialty, I have worked in 50 states in a half a dozen other countries, and one of the things that was always a beacon to me was that California could be relied upon to be on the cutting edge. And, in fact, because I believe that, a little over a year ago I closed my very, very big busy practice in another State to move here permanently.

00:34:03: The personnel, the science and the people are all here to do things, the best way and I would feel very, very sad indeed if California, through these regulations, decided to give up their status of being on the best, most compassionate and most clinically effective cutting edge of services.

Amy Wall

00:34:36: Thank you very much.

Ruth Myers MD

00:34:38: Like to keep it under three minutes.

Amy Wall

00:34:40: No, you did a great job. Thank you very much. Some important points there and we appreciate your comment. Next up, we have Nina Spiegelman who very kindly offered to give her spot to Vivian.

00:34:53: Vivian, if you would like to go ahead with that you're more than welcome to and then we'll do Nina next.

Vivian Haun

00:35:01: Thank you so much and thank you very much Nina. I appreciate it, and thank you to everyone here today for the opportunity to speak.

00:35:12: My name is Vivian Haun. I'm an attorney with Disability Rights California and, like my colleague, I also have a sibling with a disability, who served by the regional center system.

00:35:25: When I first read the proposed regulations, the first thing that stood out to me, aside from the increased focus on and added detail regarding the use of restraints, was how the new language made it easier in many ways to justify the exclusion of the disabled person and our supporters. From the teams and discussions most essential to planning for and making sense of when restraints or actual used.

00:35:57: Let's start with the process for how the new regulations proposed to make sense of or to debrief incidents where someone is restrained.

00:36:08: The addition of a debriefing process following the use of a physical restraint is appreciated and necessary.

00:36:16: The person who was restrained should be an essential part of the debriefing.

00:36:22: However, our concern is that the regulations, make it far too easy for the person's perspective to not be included in the debriefing if they are experiencing trauma that prevents their ability to attend a debriefing session within the prescribed timelines.

00:36:44: Under the proposed regulations, the facility has to conduct the debriefing within 24 hours after each use of restraint.

00:36:54: And the language says that the that the debriefing shall include the consumer quote "unless the consumer voluntarily declines".

00:37:06: But if the person says that they don't want to participate hours after they've been restrained, because there are too traumatized or because the debriefing is being held in person, and they cannot or will not be in the same room as the staff, where the individual restrain them that is not the same thing as saying that they don't want their story to be told, or that they don't want their version of events to be shared and considered as part of the debriefing.

00:37:39: Often it means that they just are experiencing challenges or barriers to be able to participate in that debriefing and if that's the case if they are unable to participate directly or in person, the facility should be required to make every effort to at least obtain the consumers input in some alternative manner, such as through a separate interview, through a written report, or via Zoom, where possible, before a refusal to participate can be considered truly voluntary and therefore excluded.

00:38:20: The regulations also do not guarantee or require that the person who is restrained can have the people that they want to have at the debriefing there at the debriefing session.

00:38:35: And that's the language on this is vague and unclear, on the one hand, the language says that the debriefing "shall" include individuals requested by the consumer, but on the other hand, goes on to say that such individuals quote "are not required to attend".

00:38:55: When exactly may a debriefing proceed without the participation of people that the disabled person wants to have at that debriefing.

00:39:05: The language of the proposed regulations provide no specifics on that and do not make it clear.

00:39:13: Similarly, the regulations say that the debriefing may also include the clients rights advocate and a regional center representative with approval from the consumer.

00:39:25: But it's not clear at all exactly what triggers an invitation to the debriefing meeting and who holds the authority to make a request. If the disabled person has the right under the regulations to approve such an invitation, are they allowed to make the request? Is it someone else's duty to ask or to make that invitation? The regulations do not make that clear.

00:39:58: Finally and most significantly, the amendment or the language making any individuals deemed necessary by the consumer an optional member instead of required member of the individual behavior supports team is entirely inconsistent with person centered planning and trauma informed care.

00:40:22: Again, currently under the regulations if the disabled person wants to have someone to be part of their behavior support team that person has to be part of that team and under the proposed regulations that would now be optional.

00:40:39: This is troubling because it has the impact of removing essential protections in the aftermath of the use of the restraint.

00:40:49: For the disabled person having a supporter, or another trusted person is part of these discussions, and especially as a witness to to the debriefing.

00:41:02: In the immediate aftermath of an incident is critical, without the presence of individuals deemed necessary by the person. The narrative of what happened will exclusively be told, from the perspective of the facility, or rather staff who did the restraining making individuals deemed necessary by the disabled person an optional rather than a required number means that at a debriefing there may well be no one from outside the facility, who could observe firsthand signs of trauma or potential injury.

00:41:43: People are the experts on their own lives, disabled people are the experts on their own lives and regardless of what supports or interventions we might think are necessary to address moments of crisis, disabled people deserve to have their stories told.

00:42:02: To tell their own stories. They deserve to be able to share what they've experienced in their own words. They deserve to have their family, their loved ones, people they trust, who may know and who know them to be part of their behavioral supports team and to be present to witness discussions that take place about these critical incidents and moments in their lives.

00:42:32: Thank you so much for your time today and for the opportunity to speak.

Amy Wall

00:42:38: Thank you for your comments, Vivian. We appreciate it, and then um just reiterating, if possible, if you could submit comments and writing as well, a copy of comments and writing that is helpful to us on the record keeping end of things.

00:42:53: And with that we will turn it over to Nina Spigelman.

Nina Spigelman

00:43:01: Thank you so much and thank you for the fabulous comments that have already already been made today. Good morning, my name is Nina Spigelman and I'm the policy director for Disability Voices United and, most importantly, the mother of a 26-year-old son with autism who has, over the years, experienced severe behavioral challenges requiring use of residential crisis services and I would say some of those experiences were incredibly helpful and valuable and I would almost say lifesaving, and some were maybe just the opposite. So, you know, I this, this is an issue very, very near and dear to my heart into the hearts of families that, you know across the state that we interact with.

00:43:46: We strongly support the comments under proposed regulations that will the written comments that will be submitted by Disability Rights California and those made today and watch today. I want to highlight some of DRC key points from from the family members perspective. I'm just, I won't, I won't take up too much time, just want to highlight a couple that that Will and Vivian has spoken so you know powerfully on.

00:44:14: As a result of my son's experiences, I appreciate the important part of the safety net provided by community crisis homes and enhanced behavioral support homes and I'm encouraged by the emphasis on the in the proposal on trauma informed, care person centered planning, and positive behavior support. Those are just critically important concepts, however, in stark stark contrast to those concepts, the proposed regulations allow the use of supine restraints as an approved emergency intervention.

00:44:46: As DRC has pointed out, despite DDS's has proposed provisions to minimize risk, and we recognize the efforts to do that, supine restraints and any restraints that prohibit breathing are dangerous and should not be allowed.

00:45:01: Families, in the midst of prolonged crisis due to severe behavioral issues are often hesitant to seek help. I certainly was and it just made matters effort so much worse.

00:45:13: And I worry that families may be deterred from accessing the valuable resource that community crisis and enhanced behavioral support homes offer if they fear that these risky traumatizing restraints can be used there, I know that it just it just compounds and already, you know terribly fraught situation for for families, we also share DRC's concerns so very excellently covered by Vivian's comments just now that the proposed regulations are just not clear about the debriefing process following the use of physical restraint and how the person served as individuals requested by the person to be involved can participate in the process.

00:45:58: As drafted, it is too easy for the person served, family members, and other people, important to the person to be excluded from that very important debriefing meeting and and other follow ups and the regulations should be clarified to ensure the person has meaningful, non-traumatizing ways to participate along with anyone, including family and supporters, the person deems necessary. Similarly, the proposed regulations overall would benefit from greater clarity on the person's access to family and support circle after admission and during the entirety of their stay. I think that, I guess I want to emphasize the more these homes are actually like homes, as Will noted, a place of and as Dr. Meyers beautifully put it up, there should be a place of sanctuary and comfort. The more they're like that, the more that beleaguered families will actually try to access this very, very potentially lifesaving resource. So I thank you for the opportunity to offer comments at this public hearing. Please consider the excellent detailed comments from DRC and our board President will join later in the hearing to provide further comments on other aspects of of the proposed regulations including law enforcement involvement and we look, finally, we look forward to engaging on these issues as DDS updates the safety net and we very much appreciate the effort put into the regulations and in holding this hearing today, thank you.

Amy Wall

00:47:43: Thank you very much. We appreciate your comments next up, we have Julie Neward.

Julie Neward, The Natalie Project

00:47:52: Good morning, everyone.

00:47:54: Again, my name is Julie Neward. I am a sibling and sister of a woman who has intellectual developmental disabilities. She is also a survivor of sexual assault out in the Community.

00:48:08: I'm project founder of The Natalie Project and our goal is to support families whose loved ones are survivors of sexual abuse as well as their loved one with intellectual and developmental disabilities. I'm here today on the topic of abuse and I wanted to share that restraints are trauma and having experienced a very traumatic experience my sister having experienced that traumatic experience, as well as our family, I wanted to make sure that everybody here keeps in mind that oftentimes behaviors that require restraints may be the result of sexual abuse, given the very high numbers in our Community, and so I do want to keep that on top of everybody's mind. I've been working with Dr. Susan Abend of The Right Care Now Project, and this is information that she has passed along to me.

00:48:59: I want to thank everybody for hosting this hearing today and I do support the comments by DRC and I fully support trauma informed care and person centered planning.

00:49:08: I firmly believe in a debriefing and my sister's case, we never had that that debriefing is so important and having the the person who is restrained there with supports needed on their own account is very important, and having sensitivity towards the incident that happened is also very important, and I want to make sure that all of this also gets placed in writing. Thank you so much.

Amy Wall

00:49:37: Thank you. We appreciate your comments and the time taken to make them. We're going to go ahead and hear from Diana Pastora Carson next and then we're going to take a break for the ASL interpreter again so Diana, you have the floor.

Diana Pastora Carson

00:49:51: Thank you so much.

00:49:52: I'm going to be looking at my other screen to read my comments.

00:49:57: I am the founder of Beyond Awareness which teaches about disability from a social justice perspective in schools. I also teach disability studies at San Diego State University and my biggest thing I'm most excited about always in my life is being a co-advocate with my brother Joaquin Carson.

00:50:20: Joaquin is a 53-year-old man who was a resident at Fairview Developmental Center on two occasions for a total of 15 years.

00:50:35: Joaquin has complex behavior and behavior and communication support needs.

00:50:43: At Fairview he was subjected to restraint during times of extreme dysregulation. At one time these restraints resulted in three fractures in his vertebra. Three weeks, using a wheelchair, and this is a man who loves to run and walk and ride bikes and swim. Not to mention the emotional trauma.

00:51:12: Also, of note this incident triggered a class action lawsuit to find alternatives to restraint and seclusion within developmental centers.

00:51:28: Furthermore, our family, along with Disability Rights California, and many other friends and advocates had to fight our regional center for three years in order to move Joaquin out of the DC into supported living because he was deemed a danger to himself and others.

00:51:54: But now Joaquin has lived in the Community in supported living in his own home near family and friends for more than 10 years.

00:52:08: He has succeeded in living an extraordinary life safely and he is my neighbor. His home is designed in a durable fashion, and he is the only person living in his home, so he and his staff, do not have the stressors of having to meet the needs of other individuals.

00:52:33: His staff who, by the way, are often underpaid and under trained do not have the option of restraint and they do not feel the need to restrain.

00:52:50: They don't have the desire to restrain because his environment is designed to keep him and his team members safe. For example, there are no things hanging on walls that can be thrown. He has murals on his walls. His appliances are bolted, to the floors and to the walls. His toilet tank is embedded within the wall, so that the lid of the tank cannot be removed by him. And his windows are shatterproof. We thought ahead and we designed his home around his individual support needs.

00:53:33: So, my point is this: when we focus on congregate settings as the only safety nets for people and ignore the other options exist, we can't envision and create environments that support people in humane, inclusive, and dignifying ways.

00:53:53: So much more is possible we've seen other options work, and we must do better. I urge DDS to wholeheartedly consider the comments made by Will Leiner, Dr. Ruth Myers, Vivian Haun, Nina Spiegelman, and Julie Neward here and avoid taking backward steps, thank you.

Amy Wall

00:54:19: Thank you very much. We appreciate your comments. All right, we don't have any other hands raised at this moment, so we're going to take a break for the ASL interpreter, and we will start comments up again at 10:05. So, I'll go ahead and put that in the chat, and we'll start again at 10:05. If there's hands raised, we will call on people for their comments. Thank you.

01:05:58: Alright, everyone. The time is now 10:05; we do not currently have anyone in the queue for making comments. If you would like to add your comments or a "me too" to any of the previous comments made, please raise your hand in Zoom and we will call on you, otherwise we will continue to leave this hearing open and accept comments as they come in, so please raise your hand if you would like to comment. Thank you.

01:06:58: All right, Dr. Myers I see that your hand is raised. Please go ahead.

Ruth Myers MD

01:07:04: Yeah, it's actually, not for me my... that the guy I'm married to. He is he won't tell you this because he's a little modest but he's actually the most well trained and experienced board-certified behavior analyst currently in practice in the United States.

01:07:27: He's worked a lot of different places, and I think his viewpoints are important because he was very, very deeply trained and continues to train others in applied behavior analysis and that science has gone through the process of even even the most traditional traditionally trained behavior analysts have come to the point of understanding that course of procedures don't teach people anything we want them to learn.

01:07:59: So I wanted to mention that on the record, plus he has a kind of a long written piece of material here that also described some of the science from the behavior analysis literature that indicates that really going in this direction, excluding people from having their say, excluding people from feeling like they have a friend in court. Prone restraint any of those procedures are not only a complete violation of trauma informed care and sanctuary they don't teach people things that we want them to learn, and they don't produce the kinds of outcomes, people are hoping for. And of course people can be unpredictable

and and he emphasizes in his written comments which have been submitted, that there are many, many alternative procedures available that are much safer and not coercive.

01:09:02: Stephen Myers PhD.

Amy Wall

01:09:05: Right, thank you, what a nice setup Miss Mr. Myers.

01:09:09: We appreciate you commenting, and we look forward to reviewing your in-depth written comments as well. You have the floor.

01:09:35: I'm sorry did I misunderstand? I thought, Stephen was going to say a few things.

01:09:44: Yes.

Ruth Myers MD

01:10:00: Sorry it's it was just me; he had written his materials earlier for me to offer to the hearing.

Amy Wall

01:10:08: Gotcha all right, thank you.

Ruth Myers MD

01:10:09: Appreciate clear about that.

Amy Wall

01:10:12: I appreciate the clarification and I really appreciate both of you sharing your comments.

Ruth Myers MD

01:10:13: Thank you.

Amy Wall

01:10:28: All right, is there anyone else on the line that would like to comment on the proposed regulations or add a "me too" to any of the previous comments

already given? If so, please raise your hand is you'll find it at the bottom of your Zoom screen, either under reactions or it'll say raise hand just depends on what version of Zoom you have so either spot will work, and we'll wait until.

01:10:56: The next person raises their hand and then call on them.

01:11:00: So, enjoy a few more moments of silence.

01:12:29: All right. Hello Judy and welcome you are next in line. We've had a little pause waiting for folks that wanted to comment so senior hand raised will turn it over to you.

Judy Mark

01:12:39: Thank you, thanks for allowing people to come in and various hours because I just got out of another meeting and really really wanted to make sure that I lend my voice, so my name is Judy Mark, I am the President of Disability Voices United, which is an organization directed by and for people with disabilities and their family members.

01:13:03: I'm also, more importantly, the parent of a 25-year-old son with autism, who has been subjected to abuse and restraint in his life and has left him with trauma and left him with certainly a level of PTSD so that it really affects the rest of his life, even though it happened to him when he was a child.

01:13:31: You know I'm very concerned about these regulations. I think that you know, allowing any kind of restraint, even if you will claim it will be done with training, and you will claim it will be done safely, and you will claim it will be done face up as opposed to face down, you know, is problematic to DVU. I- it's not so much you know we understand that you're trying to do it safely. It for us, it is a matter of stigmatizing the individual with disabilities to say that in some way they are lesser than and can be pulled on the ground, we, number one, number two we know, on the whole, does not work that when, instead of really pushing people down, we should be lifting them up, giving them a voice.

01:14:25: One of the, I would rather us be putting up regulations to ensure that people have a right to communication that if they are non-speaking, that they are given a communication method and that we are doing person centered planning with each person to ensure that, whatever their needs are, are being met. We found with my own son, and I find with many, many other individuals that are part of the DVU network that once you empower people, give them a right to self-determination and I don't mean the self-determination program, even though I think they should have the right to that too, but, but the right to self-determination that, in fact, any sort of behaviors and I put that in quotes

that that the community seeing are certainly reduced and we certainly found that with my son that when we gave him a chance to determine his own life, to decide how he wanted to live his life to give him away to explain to us what was going on that in fact eliminated any kind of aggression or any any concerns that we had almost overnight.

01:15:42: It took us many years to come to that conclusion. Many years of restraints, many years of seclusion, locked away in in in rooms and schools and you know, I was a parent that didn't know what to do, and it really is you all. It's DDS you're supposed to be the experts on understanding alternatives to seclusion and restraint and I would certainly hope that instead of putting out regulations to say here is how you can do it instead we would say there is no way you can do it and here are all the alternatives that you should be trying. And the other thing that I wanted to comment on in the regulations is the sort of roadmap that you lay out for individuals in for the staff in the settings to be able to call on police during a crisis. In my in my additional life it's not really my other life and my additional life I teach classes and in disability studies at UCLA and I have taught in many different areas around police interaction. Actually for many years, I trained thousands of Los Angeles police department officers on how to interact with people with autism and have really come to the conclusion after after last year's shooting by L.A. county sheriff's Department of a regional center client he say yes to run tests in Los Angeles shooting and he he's left paralyzed for the rest of his life. I have come to the conclusion that police should not be called under any circumstances.

01:17:28: There is not a single circumstance, under which someone should dial 911, especially now that we have a 988 system, and so I would implore you to remove that entire section from the regulations. In fact, in one of the things that we're advocating for is to not even have 988 really, really, really, as a last resort, because what you want is to have people that you call in a crisis, who know that individual who that individual trusts to be able to come in, if that person's in a crisis and to be able to have credibility with that individual to to keep them calm and to have them understand that they they can move out of this crisis, you know I'm not saying that there will be no crisis, of course, there will be crises but what we're hoping is that each person has an individual plan to deal with that crisis that includes a list of people that you've been call that does not include ever calling the police.

01:18:31: I honestly in the years that I've been working on this issue, and I also now sit on the statewide governor's advisory committee on the implementation of the Crisis Act. There's never a circumstance, when someone is in a behavioral mental health crisis, where calling the police and you get a good outcome. It just, you never get a good outcome.

01:18:53: And so I really beg you to remove that section from from the regulations and that you make it very, very clear that you shouldn't be dialing 911 and just one more point that I just remember that, with the case of you say you survive this South central, regional center client got a lot of media attention.

01:19:14: It's not like the family was alone and didn't have anyone in the home to help them. There was actually a regional center paid for crisis interventionalist in the home behavior aba provider in the home and nine and the police still came, so we have to figure out a way to get to get better trained people who understand de-escalation techniques, who understand that bringing in police, bringing in any kind of outside individuals that are armed and can kill and hurt people with developmental disabilities is a very bad idea, thank you very much.

Amy Wall

01:19:54: Thank you. We appreciate your testimony and that's now part of the record. We have anyone else who wants to make comments at this time, please raise your hand and Zoom you can find the raise hand button at the bottom of your screen in the Zoom toolbar or it could be in the reactions button on the Zoom toolbar just depends on what version of Zoom you have.

01:20:21: Currently, we have no one in the queue for comments.

01:20:26: So, we will wait until somebody raises their hand.

01:33:26: Hello Judy, I see that your hand is raised go ahead, you can make your comments now.

Judy Mark

01:33:32: Thanks, this is actually a statement that I'm reading from someone else's that's Okay, who wanted to be here this morning, but it's not feeling well today, so this is a statement from Connie Lapin, member of the Disability Services Task Force and a longtime parent a long-time parent advocate. She has a 54-year-old son with autism, who has been subjected to restraint and abuse for many parts of his life, so this is just a very brief statement to me. Not only does restraining people diminish the person who's being restrained, but it also diminishes the staff doing the train restraining. It removes the trust between the staff and the person. It also backfires because it actually leads to more aggressive behaviors as opposed to less let's learn from history.

01:34:27: Thank you.

Amy Wall

01:34:30: Thank you very much for sharing Connie's comments; they are now part of the record for this hearing. Is there anyone else who would like to make comments at this time, please raise your hand via Zoom.

01:34:43: If you can't find the raise hand button it's usually at the bottom of the screen or under the reactions tab at the bottom of the screen, You can put a note in the chat and we can call on you from the chat as well. So, the floor is open for anyone who wants to make comments, just raise your hand and we'll call on you in the order that they come in.

John Knight

01:37:05: Looks like we have a raised hand by Gilda; want to take yourself off from you go to make your comments, please.

Gilda Panales

01:37:14: Hi everybody. I'm I'm a BCBA and I'm a CPI trainer as well and I'm listening to everybody, and I think that for us, the bcb aide it is really important that we observe and then give immediate feedback and really work as a multi multi disciplinary team with other service providers, such as MFT.

01:37:43: In my experience, working with one of my teams, we do you use it as a last resort and historically we haven't used CPI because we provide intensive training, working together with MFTs because I understand how traumatic the event, it is and I think it's important to understand as well that the training, the hours of location for the staff it's very, very important, and the follow up in that home so it's um but at the same time we have to keep in mind that we want to make sure that both the client and staff are safe and what I have seen in the past, not in the current placements, where I am providing services, but in other placements it's that stuff don't know how to restraint correctly and I think that the CPI trainers, they will have to really constantly follow up giving feedback when as just a practice because the the incident that happened in the past, is because of the lack of training in not use them, the proper CPI training. One of the feedbacks that I have received in one of the audits, it said, we need to specify what each individual CPI procedure has to be used for individual or client and that it's very important because I'm hearing different procedures that we don't use.

01:39:27: But we have to make in consideration the medical, the physical you know disadvantages of our clients, so what we're doing right now it's I'm training my staff based on medical and physical disadvantages of our clients, what will

be the procedure that's the last resort, they have to use, and these will really limited a lot of the any injuries and my result, but while we're doing a lot it's a lot of making the safe an environment that is safety and care for our clients, but it takes a lot of training and a lot of the time to as well, to be able to do it that's kind of like what I wanted to add is if BCBA and CPI trainer.

Amy Wall

01:40:17: Thank you. We appreciate you sharing your experience and your comments with us. Is there anyone else who would like to make comments at this time, please raise your hand.

01:40:34: Alright, not hearing from anyone, we will continue to keep this hearing open and accept comments as they come in.

01:42:21: Alright. Hello Mary. Looks like you want to make some comments, please go ahead and unmute yourself, you have the floor.

Mary Watson

01:42:31: Hey. I'm an administrator of EBSH for children and and I just like to comment regarding the discussion about the debriefing. I feel that it's very important but sometimes with our children they need the time to settle down and we have a philosophy that every day is a new day so sometimes, if you bring them into a debriefing and pretty much there, they don't want anything to do with it with the you know, but it's really important and so I'm asking my MFT and my BCBA, even if they don't participate in the full debriefing within 24 hours that they do it afterwards, at least. At some point when the youth is is at a state where they're ready to talk about it because I agree it's very important to get their information and so I would just like to comment that you know, maybe there should be a certain allowance on time and that it's still be required to have the consumers information and debriefing done with someone on the team that makes sense even if it's not within the 24 hours.

Amy Wall

01:44:16: Yes, thank you, we appreciate your comments.

Unknown Speaker

01:44:19: Okay.

Amy Wall

01:44:24: Do we have anyone else who would like to make comments at this time or second any comments they heard earlier in today's hearing.

01:44:40: All right, see no hand raised. I will again remind everyone you're welcome to comment anytime from now until 12 noon.

01:44:49: Simply raise your hand via Zoom you'll find the raise hand button at the bottom of the screen or under reactions it varies depending on what version of Zoom you have, and once your hand is raised will call on you in the order that the hands pop up in Zoom.

01:45:10: And if you'd like to skip the verbal comments and just submit written comments the link to submit written comments, is in the chat and we'll post it again shortly it doesn't look like we've had any new participants join us but, just in case we'll post it in the chat again as well.

01:45:29: Thank you.

01:55:05: Right just another prompt if anyone would like to make comments, please raise your hand via Zoom I just put the instructions in the chat in case anyone has just joined us.

01:55:20: For our next public hearing we will figure out how to put background music on during the silent part to make it more interesting, but we appreciate you all being here, we appreciate the comments made so far and welcome any additional comments that people would like to provide, so please raise your hand if you have comments to make.

01:59:48: Alright Gilda, looks like you have your hand raised and would like to make a comment, please go ahead.

Gilda Panales

01:59:58: Yes, I'm. Just a clarification.

02:00:01: For the incidence of the 15 minutes, for each of the CPI hold, as a CPA trainer they change it to 10 minutes as the most of the time that they can be unfold, so it contradicts that to the 15 minutes, so I will like to have that because when I train people I told him 10 minutes, and then they have to disengage. Let them go and then restart again because I do agree, for the two hours consecutive, it is very hard and for the 10-minute period that's the something that the guidelines have changed for the CPI so it's something that it's not consistent, so I will like to have a further discussion about that.

Amy Wall

02:00:53: Right, thank you for that clarification we've made note of it.

02:06:19: Right, as you may have noticed, we've put the instructions up on the screen so that everyone can see them regardless of when they join the meeting that's one of the disadvantages of the chat feature is you only get what's in the chat from when you sign on and later so we've got the instructions here. We will continue to keep the line open and anyone who wants to make comments should raise their hand and we will call on you in order received. Thank you.

02:30:33: It is now 11:30, just wanted to prompt folks we have about a half hour left in this public hearing.

02:30:41: The instructions are shared on the screen, if anyone would like to comment, please raise your hand the Zoom and we will continue to keep the line open until 12 noon to accept all comments from any parties that want to make them, thank you.

02:34:30: Alright, it looks like Tami, you have your hand raised you're welcome to make your comments now.

Tami Barmache

02:34:41: Okay, can you hear me now.

Amy Wall

02:34:42: Yes, I can.

Tami Barmache

02:34:43: Okay, thank you.

02:34:45: Okay, so please forgive me I'm a little nervous. This is not something I normally do but I just felt very compelled to call in and speak with you today, so I made a few notes and I'll try to be brief.

02:34:58: So, my name is Tami. I have a son who's 22 years old and he's autistic and non-speaking; he types and spells to communicate. My son is a tall young man, but he's struggling right now to manage a lot of neurological movement difficulties and he can sometimes become highly dysregulated. This can be difficult for him to manage his state of frustration, his impulsivity. His body, it can

sometimes lead to some unsafe situations for him and for those around him. So, this speaks very personally to me.

02:35:35: I have serious concerns about any restraints being used to support this sort of situation. In using those restraints to me feels analogous to using a saw or something that needs a scalpel. I think that these situations are so nuanced these individuals are complex that the reasons that they're doing what they're doing are complex and when restraints are used, you're never really getting to the true reason that it's happening and supporting them in a respectful way.

02:36:05: So, it does nothing to address that true need in the moment. I think there's a danger of becoming a default strategy. With little else done to find out why they've become distressed and work with them to come up with a plan for supporting them.

02:36:21: During these really difficult times I think sometimes when we have a tool, like a restraint we don't really look for other things, even though people may not feel great doing it, they just sort of turn to it because it's easier than trying to find more complicated nuanced and respectful solutions.

02:36:38: And working together with the person who they're supporting it requires access to communication and I think that that is often not it's not ignored, but it's not given the type of attention that it really needs. Communication is often at the root of why a lot of these this dysregulation happens, and then they need to be able to communicate their distress and what they need to be supported in those situations. I fear that if my son were to need the support of this sort of facility, which I hope would be there to help us all in a crisis, that these practices would be used regularly you know, for safety reasons, but they'll just manage the situation and do nothing to really ensure his safety and wellbeing in the long run.

02:37:27: Of, from my experience a lot of these systems that are created with the proper intentions and the desire to do right by individuals like my son, they're created to educate and support people like him, but often end up really just managing them and lead to a lot of daily traumatic experiences and worsening, unfortunately of outcomes for everyone involved, so the thing that you're trying to help support like maybe a an outburst you know something that feels unsafe, it ends up being exacerbated and worse, the next time. It's not it's not leading to solutions that ultimately really make everyone's life better.

02:38:13: Unfortunately, the difficulties always are usually blamed on the individual who's struggling and is often helpless to do anything about what's going on. They're not usually given the support to communicate their needs and they're rarely included in their their plans for support.

02:38:32: So, I do ask that DDS consider what I'm saying and prohibit any restraints and look to these amazing organizations that have found alternative ways to support people like my son in a person-centered way to include them in the conversations about why they're distressed what supports they might need. I know there are organizations who I believe have spoken to today that work work to support people like my son and who have very difficult situations and never use restraints they found alternative ways.

02:39:07: So that asked that you please turn to the disabled community themselves and the professionals who support their most difficult situations without using restraints. Please turn to them for input and for guidance regarding ways to keep everyone safe without using this type of force and power over another human being.

02:39:27: So, in closing, I ask that you please extend these incredible human beings who live in a world where they are misunderstood and marginalized almost every day of their lives the common decency to presume that they want to lead productive and connected lives, supported by people who respect them and honor who they are. That would be the most powerful intervention that you could ever provide. So, thank you for your time.

Amy Wall

02:39:58: Thank you for your comments, Tami and you have nothing to be nervous about; that was very well said, and we appreciate you adding to the meaningful comments that we're gathering here today.

02:40:11: Is there anyone else that would like to share their comments on the proposed regulations?

02:40:24: Right not seeing any hands. Again, we will keep the line open until 12 noon. Please raise your hand or indicate in the chat that you'd like to make a comment, thank you.

03:00:12: Alright, everyone. The time is now 12 noon. I'm going to turn things back over to our hearing officer Amy Whiting to close out today's public hearing.

Amy Whiting

03:00:23: All right, thank you Amy. Is there anyone else that was just to speak concerning the Department's proposed regulations on the Children's CCH and EBSH? If so, please raise your hand.

03:00:42: Seeing no requests, I hereby close this virtual hearing and the opportunity for verbal comments, however, please note that you can still submit comments before 5pm today through the link found on the regular website in the chat feature of this meeting or via hardcopy to our office at 1215 "O" Street, Sacramento, California.

03:01:04: Actually, you can submit written comments, all the way up till midnight today's date. Just our office will be closed after 5pm so you're going to submit them in person you'll need to get to our office before 5pm, but of course the online link will be there through the end of the day, today, thank you.

03:01:27: And I just want to thank everyone who's attended today's hearing and for their comments that you've provided and thank you also to our Spanish and ASL interpreters who assisted today.

03:01:38: All oral and written comments received during this hearing will be considered in accordance with the APA, this entire rulemaking, oops sorry I messed up here.

03:01:54: This entire rulemaking hearing was recorded in Zoom. The transcript of the hearing, including all comments submitted through the chat feature will be made a part of the official rulemaking record.

03:02:04: The Department will respond to all comments in the Final Statement of Reasons which will be posted on the Department's one website once it's completed. We appreciate the community's assistance in developing these regulations and have a good rest of your day, thank you.