**Email conversation re: resources on use of restraint to administer COVID-19 vaccine**

**From:** Dawn Rudolph
**Sent:** Wednesday, January 20, 2021 6:00 PM
**To:** Ayers, Kara <Kara.Ayers@cchmc.org>
**Cc:** Smith, Leah <Leah.Smith@cchmc.org>
**Subject:** RE: restraints

A complicated issue indeed. Thanks so much for digging into the topic with your team. My idea of a social story was likely me jumping to a solution before fully unpacking the problem…my bad…

Interestingly, we just finished another meeting where a couple other directors were asking about resources that would help support community conversations allowing the opportunity for people with developmental disabilities to express concerns and learn fact-based information that support informed consent decisions regarding the vaccine, rather than be pushed to get the vaccine and not have their concerns addressed and questions answered. One of the directors implemented a statewide survey asking for feedback about vaccine concerns and hesitations (I’m probably not explaining that accurately) and will use the results to create supportive materials to inform the consent process. They’ll be sharing the survey questions and results, which I’ll gladly share further!

I so appreciate you.

*~ Dawn*

**From:** Ayers, Kara <Kara.Ayers@cchmc.org>
**Sent:** Wednesday, January 20, 2021 5:29 PM
**To:** Dawn Rudolph <drudolph@AUCD.ORG>
**Cc:** Smith, Leah <Leah.Smith@cchmc.org>
**Subject:** RE: restraints

Thanks Dawn-

This is such a complicated issue. Our COVID-19 workgroup was intrigued when it was brought up on the AUCD Network call. We met the next afternoon and it was discussed. No conclusions reached but we can be more intentional about creating something on this issue.

I’m looping in Leah, our Project Coordinator, and we’ll circle back to give you an update soon.

Thanks,

Kara

Kara Ayers, PhD

Assistant Professor
Associate Director

[University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEDD)](http://www.ucucedd.org/)
**Cincinnati Children's Hospital Medical Center**
Division of Developmental and Behavioral Pediatrics
3333 Burnet Avenue, MLC 4002, Cincinnati, OH 45229
**Phone:** 513-445-2286

**Email:**kara.ayers@cchmc.org

**To schedule a meeting:** <https://calendly.com/kara-ayers/45min>

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**From:** Dawn Rudolph <drudolph@AUCD.ORG>
**Sent:** Tuesday, January 19, 2021 10:25 AM
**To:** Ayers, Kara <Kara.Ayers@cchmc.org>
**Subject:** FW: restraints

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Hi Kara, I hope you are doing well, had a good weekend, and are looking forward to a reason to celebrate this week! 😊

I’m touching base on a topic that was raised during our network COVID call last week, as the network members on the call had no response, so I thought it might be helpful to see what resources you might have (or be able to create).

This is the issue that was raised on the network call:

* Several questions have been raised from physicians and from community provider organizations about the use of restraint in order to administer vaccination, for individuals with or without guardianship. [FAQs for Guardians](https://www.guardianship.org/wp-content/uploads/FAQ-vaccine-01012021.pdf) indicates the need for a person-centered decision. We have responded with information on person-centered practices, communication support tools, trauma-informed care, informed consent, desensitization and/or anti-anxiety medications as appropriate to address needs anxiety, and positive behavioral interventions and supports, but we have not been able to find a resource that captures this information succinctly and in the context of a COVID vaccine in a global pandemic. Does anyone know of any such resource?

It turns out that no one on the network call had information or resources to share during the call, though Evon Lee (LEND Director at Vanderbilt) followed up afterwards – see thread below.

I would hope that existing person-centered trauma-informed policies outlined by DD state agencies would address this topic, but it doesn’t appear that folks are putting the dots together in the covid context. At least the folks who are asking the question haven’t put the dots together, and it’s quite worrisome to me that the folks who are asking are the community provider organizations (who ought to know each individual’s needs in this context) and physicians themselves.

I wondered if the Center for Dignity in Healthcare might be able to create something to address this? At the very least, wanted to bring this to your attention.

Thanks so much, and have a great week,

*~ Dawn*

**From:** Dawn Rudolph
**Sent:** Tuesday, January 19, 2021 10:09 AM
**To:** Lee, Evon <evon.lee@vumc.org>
**Subject:** RE: restraints

Thanks so much Evon, it’s vey thoughtful of you to follow up on this with the UCEDD and behavior analysts. 😊 I appreciate the viewpoint, and note that it aligns with most of what we have shared with the individuals who have raised this question. (Without being part of someone’s team, and without being a healthcare professional with knowledge about someone’s health conditions or history with trauma, I admit that I haven’t added that last sentence.)

What I can’t seem to get my hands on is a set of resources that can be shared broadly to help inform clinicians on the topic of use of restraints specifically for COVID. I wonder if trauma-informed care might be a helpful framework for such resources. While there isn’t much research available on the topic of restraint and trauma in adults with developmental disabilities, [there is a bit available](https://omh.ny.gov/omhweb/dqm/restraint-seclusion/trauma.html).

I think I’ll reach out to Kara Ayers at the Center for Dignity in Healthcare to see if she and her team would be able to develop resources to help inform adults with intellectual and developmental disabilities about the risks, benefits, and other information related to informed consent, as well as resources to help inform clinicians and other providers. She probably has a list of needs a mile long, and maybe this topic can make its way to the list.

I’m grateful for you!

Have a good week,

*~ Dawn*

**From:** Lee, Evon <evon.lee@vumc.org>
**Sent:** Sunday, January 17, 2021 5:30 PM
**To:** Dawn Rudolph <drudolph@AUCD.ORG>
**Subject:** restraints

Hi Dawn,

I hope you are holding up well during these tense times.

I asked some of my UCEDD friends the question about use of restraints.

They in turn asked an experienced  behavior analyst who deals with these issues.

I know that’s circuitous, but this was his response:

We try to avoid restraints at all costs and most times, one strategy or another allows us to do so.  It really comes down to a benefit – risk analysis.  We don’t generally think taking an everyday medication is worth the risk of doing a restraint.  However, receiving a life-saving treatment may be worth it.  Especially when you consider the additional risk of resistive or aggressive behavior with a needle present.  Still when it’s possible, I always want to work with the person to help them desensitize.  As it relates to receiving the COVID vaccine, my opinion is that it is worth the risk of restraining if there is no other way to safely get it done and the person does not have the capacity to consent.

Hope this viewpoint is helpful.

Take care,

Evon

Evon Batey Lee, Ph.D.

Associate Professor of Pediatrics, Psychology and Psychiatry

Vanderbilt Consortium LEND Director

UCEDD Training Director

Vanderbilt Kennedy Center for Research on Human Development

One Magnolia Circle, Room 407B

evon.lee@vumc.org