

# Finding the Balance: Person-Centered Supports that Honor Safety and Dignity of Risk

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NCAPPS



# Welcome to Today's Webinar



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Thank you for joining us to learn about Person-centered supports that honor safety *and* dignity of risk.

This webinar series is sponsored by the National Center on Advancing Person-Centered Practices and Systems. NCAPPS is funded by the Administration for Community Living and Centers for Medicare & Medicaid Services.

NCAPPS webinars are free and open to the public.

The goal of NCAPPS is to promote systems change that makes person-centered principles not just an aspiration but a reality in the lives of people across the lifespan.





# Webinar Logistics

- Participants will be muted during this webinar. You can use the **chat** feature in Zoom to post questions and communicate with the hosts.
- Toward the end of the webinar, our speakers will have an opportunity to **respond to questions** that have been entered into **chat**.
- The webinar will be live captioned in English and Spanish. To access the Spanish captions, please use this link: <https://www.streamtext.net/player?event=HSRI-SPANISH>
- This live webinar includes polls and evaluation questions. Please be prepared to interact during polling times.



# Feedback and Follow-Up

- After the webinar, you can send follow-up questions and feedback about the webinar to [NCAPPS@hsri.org](mailto:NCAPPS@hsri.org)

**(Please note that this email address is not monitored during the webinar.)**

- The recorded webinar, along with a pdf version of the slides and a Plain Language summary, will be available within two weeks at [NCAPPS.acl.gov](http://NCAPPS.acl.gov). We will also include questions and responses in the materials that are posted following the webinar.

# In this webinar, we will

- 1) *Hear from people with disabilities about their experience in planning, navigating concerns about well-being, and seeking the dignity of risk.*
- 2) *Learn from providers of supports about requirements, challenges, and successes in the delivery of quality person-centered supports that considers health and safety while honoring a person's right to make decisions that may not always be in their best interest.*
- 3) *Learn about training available for direct support providers that will equip them with the skills and strategies to help manage health and safety concerns in a person-centered way.*

# Meet Our Speakers



Nicole LeBlanc



Chester Finn



Marian Frattarola-Saulino



Michelle Murphy



John Raffaele



# Dignity of Risk – why it's important

Nicole LeBlanc



# Starting with a couple questions for people on this webinar.

Poll Question #1:

Please choose a statement that is closest to how you think about issues of health, safety, and risk for people with disabilities?

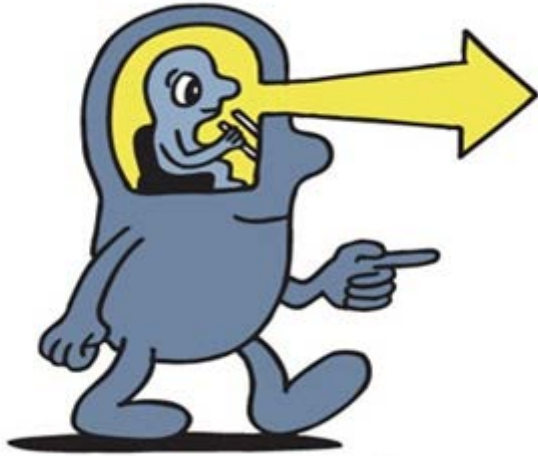
1. It is my job to keep people safe. I start there, and then see what choices people can have.
2. I support people making choices within a range of safe and healthy choices.
3. A person's choice should usually be supported, unless it puts them at risk of serious harm.
4. People should have the opportunity to try things, but they should not be supported to do something that is not good for them.
5. People should be supported to explore and act upon new and potentially risky choices, even if there are bad consequences.

## Poll Question #2

What is your experience with supporting people to experience the dignity of risk?

1. Not much experience.
2. Some experience.
3. A lot of experience.

You can share your experience in supporting someone to experience dignity of risk by typing it into Chat.



Control your own destiny...  
or someone else will.

# Core values and principles

- People need to be able to make choices
- Overprotection might seem kind, but it might smother a person
- Letting people try things that may seem risky or scary for parents or professionals.
- It allows people to “Get Out Of Their Comfort Zone” to try new things.  
Ex moving to a new state or city.
- Being able to make choices, and live the consequences of choices promotes **Self Determination** and **High Expectations**



- Being overprotective as a parent or professional is not helpful.
- It can squeeze the life out of people's hopes and dreams.
- It takes away our dignity and keeps us from becoming all that we can become!
- This is why its important for parents, case managers and service providers to embrace the Dignity of Risk and learn to let go

# What if...

What if you never got to make a mistake?

What if your money was always kept in an envelope where you couldn't get it?

What if you were never given a chance to do well at something?

What if you were always treated like a child?

What if your only chance to be with people different from you was with your own family?

What if the job you did was not useful?

What if you never got to make a decision?

What if the only risky thing you could do was to act out?

What if you couldn't go outside because the last time you went it rained?

# What if... (continued)

What if you took the wrong bus once and now you can't take another one?

What if you got into trouble and were sent away and you couldn't come back because they always remember your "trouble"?

What if you worked and got paid \$.46 an hour?

What if you had to wear your winter coat when it rained because it was all you had?

What if you had no privacy?

What if you could do part of the grocery shopping but weren't allowed to do any because you weren't able to do all of the shopping?

What if you spent three hours every day just waiting?

What if you grew old and never knew adulthood?

*What if you never got a chance?*



“

**Such over-protection endangers the person’s human dignity & tends to keep [them] from experiencing the risk-taking of everyday life which is necessary for normal human growth & development**

Robert Perske, The Dignity of Risk, February 1972



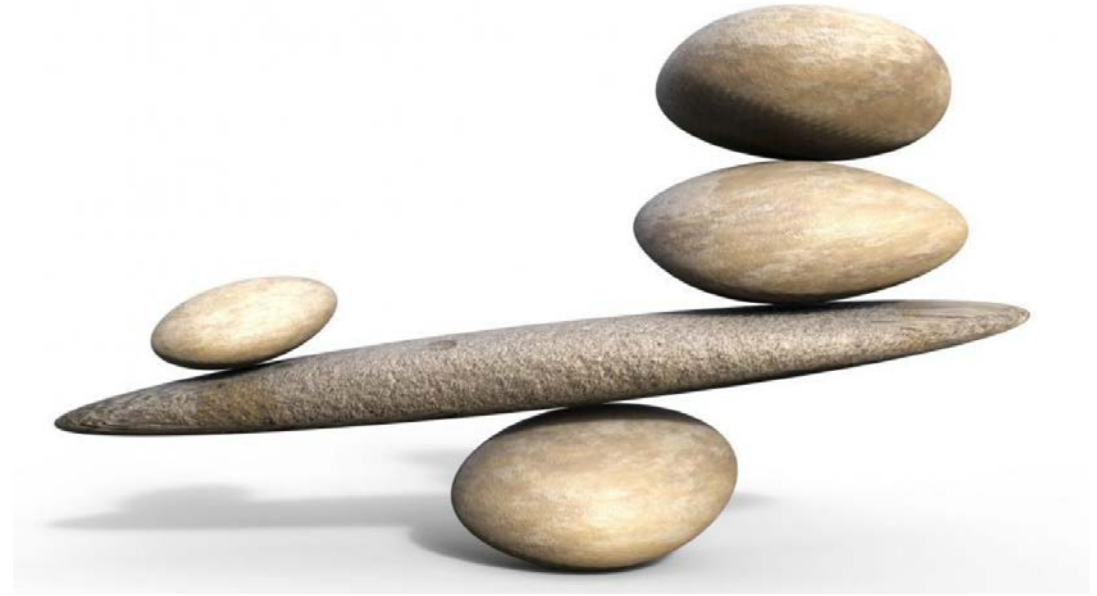


# Impact of Dignity of Risk on Self Advocates

- Its at the Heart of being Truly Person-Centered.
- It Shows Respect!
- Gives us Freedom to Make Choices.
- Provides Opportunities for us personal growth and learning.
- Allows us to say what matters
- We get Responsibility for a meaningful Life in the Community.



Chester Finn



# A balancing act for providers

Marian Fratterola-Saulino

# Values Into Action: A Partnering Organization

- ***Offers*** individualized services and supports exclusively in people's own homes and communities
- ***Believes*** that a person's aspirations and strengths define who they are, and that everyone has a right to self determination
- ***Demonstrates*** that the more complex and significant a person's support needs, the more compelling the reason they must control their services, and direct their lives



# The Alliance for Citizen Directed Supports

- Membership based on cause, not constituency, for the sole purpose of advancing citizen-direction through global collaboration.
- Aligned with the United Nations Convention on the Rights of Persons with Disabilities | **All citizens are respected for their inherent dignity and have the full and equal enjoyment of all human rights and fundamental freedoms.**



Co-production is a practice that involves all stakeholders, working together in an equal way...sharing expertise, experience, information and skills to design, deliver and evaluate the service and supports

-A multitude of sources including Sherry R. Arnstein



YES NO



*A question for webinar participants:*

**As providers of services, what is holding us back?**

What are we afraid of?

What stops us short of honoring and supporting people's choices?

You can type your responses into Webinar Chat box.

# The role of Direct Support Providers

Michelle Murphy and John Raffaele

# What is Informed Decision Making?

(A comprehensive definition for Direct Support Professionals)

1. Informed decision making is a process where a person supported has obtained information and knowledge about a situation or problem
2. With the assistance of a direct support professional or other person, the person supported understands the choices available to them and the outcomes possible
3. When they make a final choice it reflects their personal values, not those of the people assisting or supporting them
4. Finally, it is the acceptance of the associated responsibility and risk of the decision. This decision is their decision alone and non-coerced by the professional.

Slide content from: National Alliance for Direct Support Professionals

# The process of informed decision making – the NADSP 5 STEP process

1. Understand the decision/issue/situation
2. Gather information
3. Explore options and consider outcomes
4. Decide, act, and empower
5. Evaluate the decision



Making a world of difference  
**in people's lives**

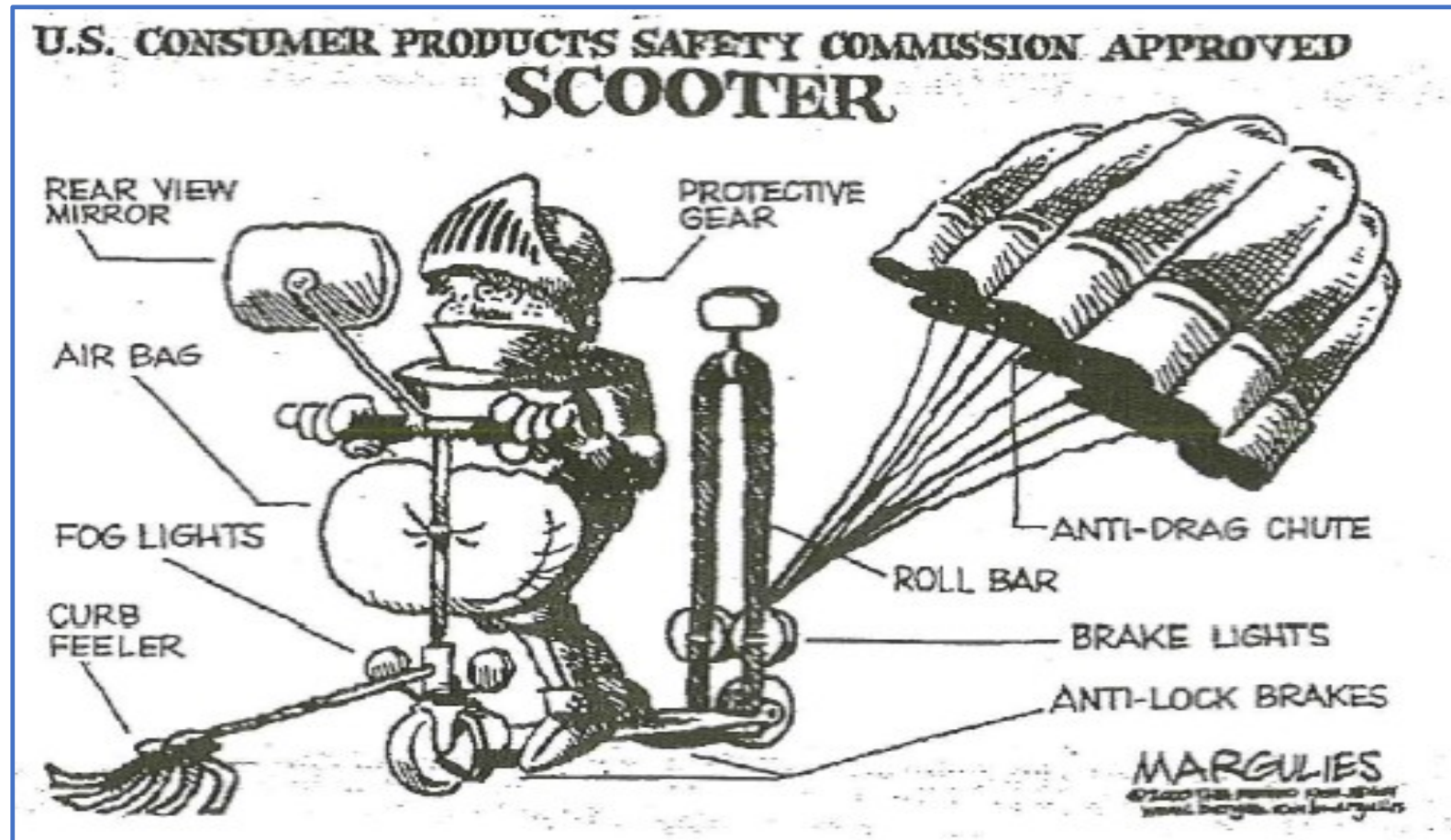
# Vital Questions to ask.....

- What kind of decision is being made?
- Has the person made a decision like this before?
- Has the person been assisted to understand the risks and benefits?  
How big is the impact of this decision in the person's life?
- How long would the person live with the decision? How hard would it be to undo?
- Most important: What is the least restrictive level of support that might work.

~ *National Alliance for Direct Support Professionals*

# PROVIDE CHOICE & ENSURE SAFETY?

**States & Providers must find the balance between choice and risk**



# PROVIDE CHOICE & ENSURE SAFETY?

**States & Providers must find the balance between choice and risk**



# Placeholder for poll questions

- (NOTE) – POLL Questions can be added at any point in the discussion.
- If you want to use slides, it's best to place the questions as slides in the place where you want them.





*Questions*  
*???*

# Real-Time Evaluation Questions

- Please take a moment to respond to these seven evaluation questions to help us deliver high-quality NCAPPS webinars.
- If you have suggestions on how we might improve NCAPPS webinars, or if you have ideas or requests for future webinar topics, please send us a note at [NCAPPS@hsri.org](mailto:NCAPPS@hsri.org)

# Resources

Balancing Choice and Risk

<https://www.medicaid.gov/medicaid/hcbs/downloads/training/balancing-risk-choice.pdf>

Steps to Creating a Person-Centered Service Planning System

<https://www.medicaid.gov/medicaid/hcbs/downloads/training/steps-creating-a-person-centered-planning-system.pdf>

“Believe in your child”. Nicole LeBlanc video(produced by Vermont DD Council) <https://vimeo.com/43125256>

# Thank You.

Register for upcoming webinars at

[ncapps.acl.gov](https://ncapps.acl.gov)

NCAPPS is funded and led by the Administration for Community Living and the Centers for Medicare & Medicaid Services and is administered by HSRI.

The content and views expressed in this webinar are those of the presenters and do not necessarily reflect that of Centers for Medicare and Medicaid Services (CMS) or the Administration for Community Living (ACL) .

