

Dignity of Risk

NORTH
Dakota | Health & Human Services
Be Legendary.

"Overprotection may appear on the surface to be kind, but it can be really evil. An oversupply can smother people emotionally, squeeze the life out of their hopes and expectations, and strip them of their dignity. Overprotection can keep people from becoming all they could become. Many of our best achievements came the hard way: We took risks, fell flat, suffered, picked ourselves up, and tried again"

-Author of Dignity of Risk, Robert Perske, 1972



Introductions-

**Developmental
Disabilities Section**

Agenda

Introductions

Process to Date

Definitions and Guiding Principles

Balancing Choice and Risk

Hearing from Stakeholders

Thank you and Next Steps



Process to Date

Statewide + Systemwide Initiative

North Dakota is working alongside NCAPPS and HSRI to develop a strong and consistent statewide vision and universal understanding of person-centeredness across all North Dakota Department of Health and Human Services entities and community partners.



Human Services
Research Institute



NCAPPS

Areas Covered in Self-Assessment



1 Leadership

How well people in charge know about and support person-centered practices



2 Person Centered Culture

How person-centered is the intake and assessment process for people seeking supports.



3 Eligibility and Service Access

How person-centered is the system's culture and how can person-centered approaches help address risks



4 Person-Centered Service Planning & Monitoring

How is the process for creating person-centered plans and ensuring services are working



5 Finance

How are agreements with providers structured, are services helping people reach their goals



6 Workforce Capacity & Capability

How well staff know about and have the skills to deliver person-centered planning and supports



7 Collaboration & Partnership

How are partnerships with service users, families, service providers, and advocacy organizations



8 Quality & Innovation

The agency's missions and standards

Person-Centered Practices Self-Assessment



Focus Areas

1 Build Trust with Advocacy Organizations

Goal: Developmental Disabilities seeks feedback from advocacy organizations on all policy changes and view opportunities for improvement through their perspective, in addition to other stakeholders.

Strategy: Conducted a survey with P&A and working together to develop and communicate clear roles and responsibilities.

2 Person-Centered Approach to Risk

Goal: Develop and distribute guidance on how service planning teams will assess and identify the balance between a person's desire and rights to take reasonable risks when exploring their community or learning new skills, and the potential harm that may occur.

Internal Work Groups: Person-Centered Approach to Risk

1 Balance what's important to and for the person while maintaining dignity of risk

- Develop the Developmental Disabilities definition of dignity of risk
- Utilize the definition to identify how dignity of risk is important to and for providers, guardians, and Developmental Disability Program Managers (DDPM)

2 Provider/Guardian/DDPM Training on Roles, Rights, and Risks

- Define the roles of providers, guardians, and Developmental Disability Program Managers
- Communicate the defined roles to providers, guardians, and Developmental Disability Program Managers



**Definitions +
Principles +
Guidance**

How the Definitions, Principles, and Guidance on PCP were Developed

- 1** Revisited previous trainings and training materials including CMS materials
- 2** Documented work examples from other states
- 3** Reviewed information from partners in North Dakota including surveys with P&A, DD Providers and corporate guardians
- 4** Collaborated with the internal work groups to draft definitions and guiding principles
- 5** In Process: Sharing draft information with stakeholders for feedback before finalizing

February 2022 Survey Themes

- Balancing and promoting dignity of risk was the biggest challenge when implementing right restrictions followed by teams having higher expectations than what they would expect of themselves or not be attainable for the person
- Most challenging areas include sexual health/relationships, food/diets and access to money, personal, and household items
- Focus on paperwork appeared to be a slight precedence over being person-centered
- Responders were familiar with components to fading plans, however, struggled with developing fading strategies

February 2022 Survey Themes Cont.

- What's working well
 - Human Right Committees
 - Team meetings and discussions
- Challenges
 - Rights and due process education with guardians and family members
 - Determining what is or isn't a right restriction
 - Imposing our own personal values on others
 - Having a clear fading plan, collecting data, and consistency
- Team roles and responsibilities
 - Advocate for the rights of people and ensure least restrictive
 - Listen and understand what the person wants
 - Provide opportunities for people to make choices and learn

Dignity of Risk: Definition

Dignity of Risk: the right of every person, including those with a disability, to make informed choices and take reasonable risks to learn, grow, and have better quality of life.

Dignity of Risk: Guiding Principles

- 1 Treat people fairly.** People with disabilities have the same rights as everyone.
- 2 Be an advocate for promoting people to exercise their rights to the full extent possible.** Assure due process is adequately completed for any right restrictions.
- 3 Support the person's preferences and values, rather than your own.** Avoid placing your personal values and expectations on the person.
- 4 Provide supports for health and safety by using least restrictive methods.** Support people to exercise their rights responsibly while promoting dignity of risk.
- 5 Be realistic with expectations.** Allow flexibility and do not hold people with disabilities to a higher standard than what we would expect for ourselves.

Definitions of Other Key Terms

Informed Choice: a voluntary, well-considered set of options that a person or the person's guardian (where legally required) evaluates on the basis of appropriate options, information, and understanding.

Informed Consent: giving voluntary permission for a well-considered decision that a person, or where legally required, the person's legal guardian, makes based on appropriate options, information, and understanding.

Definitions of Other Key Terms

Least Restrictive: the least amount of influence or interventions from others that still provide people the most freedom to exercise their rights, have independence, choices, and fully participate while ensuring health and safety.

Due Process: ensure restrictions are agreed upon by the person/legal decision maker and their team, reviewed by a third-party committee, and implemented fairly and timely.

Definitions of Other Key Terms

Fading Plan: a way to reduce or eliminate restrictions over a defined time period to achieve least restrictive supports.

Plain Language: written or verbal communication that considers the person's age, profession, education, and skills, and uses language that is easy to read, understand, and use.



Balancing Choice and Risk

Why is Dignity of Risk Important?

Risk exists for all of us, no one is risk free. The right to make decisions is not always contingent on making “the right decisions”.

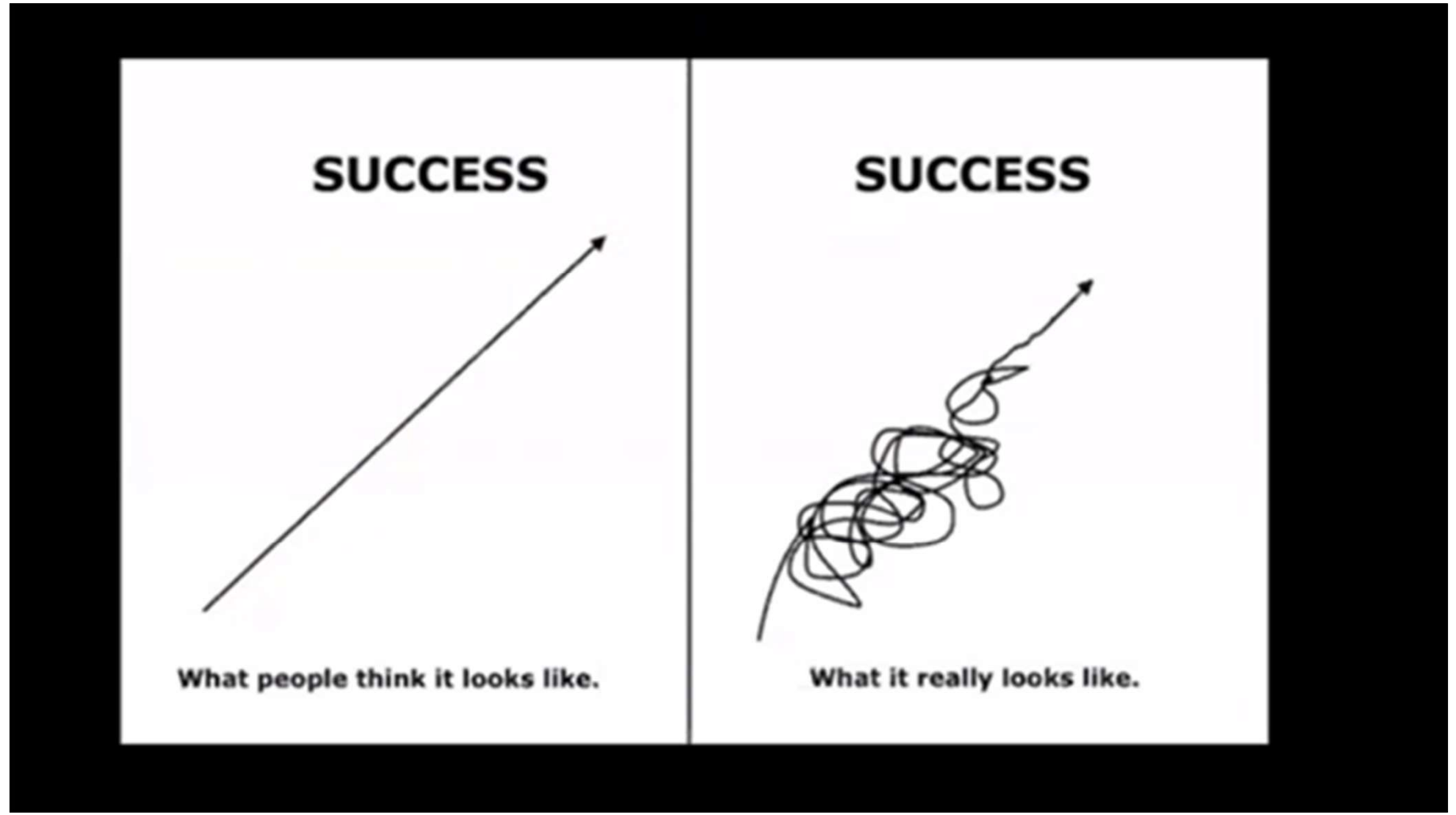
The things that keep us safe are the same for all people. They are also the same things that are needed to have a good life – freedom, relationships, opportunities for learning and growth, participation in community, and control over what happens in our day-to-day lives.

Why CMS says Dignity of Risk is Important?

- Dignity of risk is not only a right, but is also essential for dignity and self esteem and should not be impeded by caregivers
- People have a right to self-determination which is the right to make choices about their life and to have the same rights and responsibilities of others
- Dignity and autonomy demand balance
- It's possible to honor choices and mitigate risks
- Federal law and regulations require a balance (42 CFR 441.725 – Person-Centered Service Planning requirements and 1915(C) waiver assurances)

**Taken from CMS 2019 Training*





Finding Balance



- Person-centered thinking
- Person-centered planning
- Clear policies and protocols
- Ongoing staff training
- Quality improvement

- Full participation
- Person-centered planning
- Affirmation/understanding of decisions

Components to Balancing Choice + Risk

Identify and document choices and risks

- Initial assessment and reassessment
- Choices with and without risk
- Person's capacity to make decisions, understand implications
- Risks based on person's choices
- Prior mitigation approaches
- Adverse outcomes previously experienced
- Potential harm from risks



Develop person-centered service plan

- Individualized strategies to honor choices and address risk
- Why the choice is important
- Include risks and mitigation strategies
- Benefits to the person
- Alternatives to the choice
- How strategies will be monitored
- Ways to build safe opportunities for risk



Regularly revisit choice and risk discussion

- Analyze data (e.g. critical incident management system)
- Obtain person's satisfaction
- Monitor individual risks
- Modify plans, as needed

Ways to Build Opportunities for Risk

- Activities that replicate actual experiences vs simulated
- Relationships-who people have in their lives that will provide experiences that are both successful and not a complete positive experience
- People leading their own meetings to navigate and shine
- Community-based experiences
- Work-based learning
- Extracurricular activities, trying out for new things
- Daily choices- Practice making small choices thoughtfully and for good reason
- Annual goals

Considerations for being Least Restrictive

- Identify all methods and options available, including those available to people who may not have disabilities.
- Discuss what aspect(s) of the person's life would be affected by the intervention or restriction.
- Consider the frequency (how often occurring) and the intensity (to what extent or severity).
- Avoid highly or overly restrictive interventions (natural methods, education, adaptations, etc.)
- Restrictions should be viewed as temporary and revisited minimally every 6 months to a year.
- People will have bad days and can learn from their choices/actions.
- Is it realistic for any person to do or achieve something perfectly 100% of the time?
- Restrictions should not be put in place or continue because that is how it was always done, in case of the what if's, occurred in the past, etc.
- Consider level of impact
- Right restrictions should be supported by:
 - a specific reason using assessment information and/or data collection (what is actually happening);
 - attempting least restrictive alternatives; and
 - using yearly assessment information and/or data collection to determine if the restriction should continue, be discontinued, or faded.

Considerations for being Least Restrictive, cont.

- Fair treatment through due process is:
 - ✓ Reviewed by the person, guardian, and team;
 - ✓ Approved through HRC/BSC Committees;
 - ✓ Documented in the service plan and includes fading plan.
 - ✓ Provides ongoing learning opportunities, replacement behaviors, positive behavior supports, etc. Brainstorm solutions, least restrictive methods, try new things, and be creative.

Example: A doctor orders an 1800 calorie diet with limited sodium intake. Before locking up the person's food the team should consider:

- how it would impact the person to both implement or not implement the diet (consequences)
- people without disabilities have the opportunity not to follow doctor's orders just like everyone else
- what non-restrictive methods to try first (e.g., education, prompting, etc.)
- what data or information to be collected to determine effectiveness and if restrictions should continue

Best Practices for Fading Plans

- People can change, improve, mature, and make corrections over time. Acknowledge that everyone has the right to bad days.
- Provide opportunities for the person to have achievements, gain more experiences or responsibilities, develop skills, experience natural consequences, take small risks, and have access to items.
- Fading can be completed gradually in steps to ensure the person has time to adjust to changes. Steps can be in small increments, phases, multiple steps, or tiered to lessen over time vs. immediately ending the restriction.
- Fading will be individualized and dependent on the person, abilities, challenges, what is the restriction, and specific situations. Discuss if benefits of fading outweigh the risks.
- Collect, use, and share data to determine when, how the restriction should be faded, and to objectively measure how the person is doing.
 - This should include data on progress, skills obtained, replacement behaviors used, etc.

Fading Plans-Best Practices

- If a fading plan is not successful, brainstorm solutions, consider other methods, try new things, and be creative.
- For restrictions that are likely to be long-term or not eliminated, the team should identify the reason and revisit at least annually to ensure that there are no changes.
- Have realistic and achievable criteria.
- Fading plans should
 - Include least restrictive methods
 - Be continuously assessed
 - Include timelines, steps, and specific measurable criteria
 - Revisited with the team yearly

Most importantly:

- Fading is gradual but also dynamic
- Is part of the journey to the life a person desires
- Fading does not mean the commitment to health/safety is reduced
- Restore restrictions as people PROGRESS to avoid the person feeling trapped or they not getting anywhere (tangible benefits)

Travel the journey *with* people

Success or lack of success is not solely by the person receiving services

- Change the focus-help people transition and recover from bad choices
- Create a safe and secure environment so people will not rely on ineffective behaviors/responses
- Understand individualized situations, their history, and any past trauma
- Provide effective staff support and training
- Don't underestimate the important of quality relationship building
- Include what's important TO the person to increase motivation and success
 - Identify risks but also include person's hopes, dreams, and aspirations
 - Risk management should also promote growth
- Support person to make connections with choices and outcomes
- Decisions should be data driven

Intended Outcome

DD recognized a need to develop a toolkit with guidance and examples for people receiving services, guardians, DD providers, and DDPM's.

The information shared with you today is a sample of this material upon which we'd like your feedback.

**We recognize the truly person-centered way in which dignity of risk must be upheld and offer this as guidance not policy.*



Hearing from Stakeholders

Questions for People Receiving Services or Family Members

- What have your experiences been with having your right to risk honored or not honored?
- How have you been best supported to understand available choices and understand likely outcomes?
- Have you experienced limitations based on things that have happened in your past?
- Do you have ideas about how you'd like to be able to take chances?
- Based on experience, what specific materials or information would be most helpful?
- Suggestions for formats and distribution of material?

You may also submit feedback/comments by Friday, January 20th, 2023 via email: dhsddreq@nd.gov

Questions for people providing services

- What experiences have you had successfully supporting people to take risks?
- What have been the primary challenges you've encountered with balancing choice and risk?
- Are there other elements of balancing choice and risk to be considered?
- Based on experience, what specific materials or information would be most helpful?
- Suggestions for formats and distribution of material?

You may also submit feedback/comments by Friday, January 20th, 2023 via email: dhsddreq@nd.gov



Thank you
+
Next Steps

Next Steps

- 1** Review of Comments and integration of changes
- 2** Disseminate final guidance material

Visit DD Website

<https://www.hhs.nd.gov/dd>

**Visit the ND Person-Centered Practices
Website**

<https://www.hsri.org/ND-PCP>

**Submit feedback/comments by
January 20th, 2023**

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