



# Dignity of Risk Toolkit

Developmental Disabilities (DD) Section  
April 2024



Health & Human Services

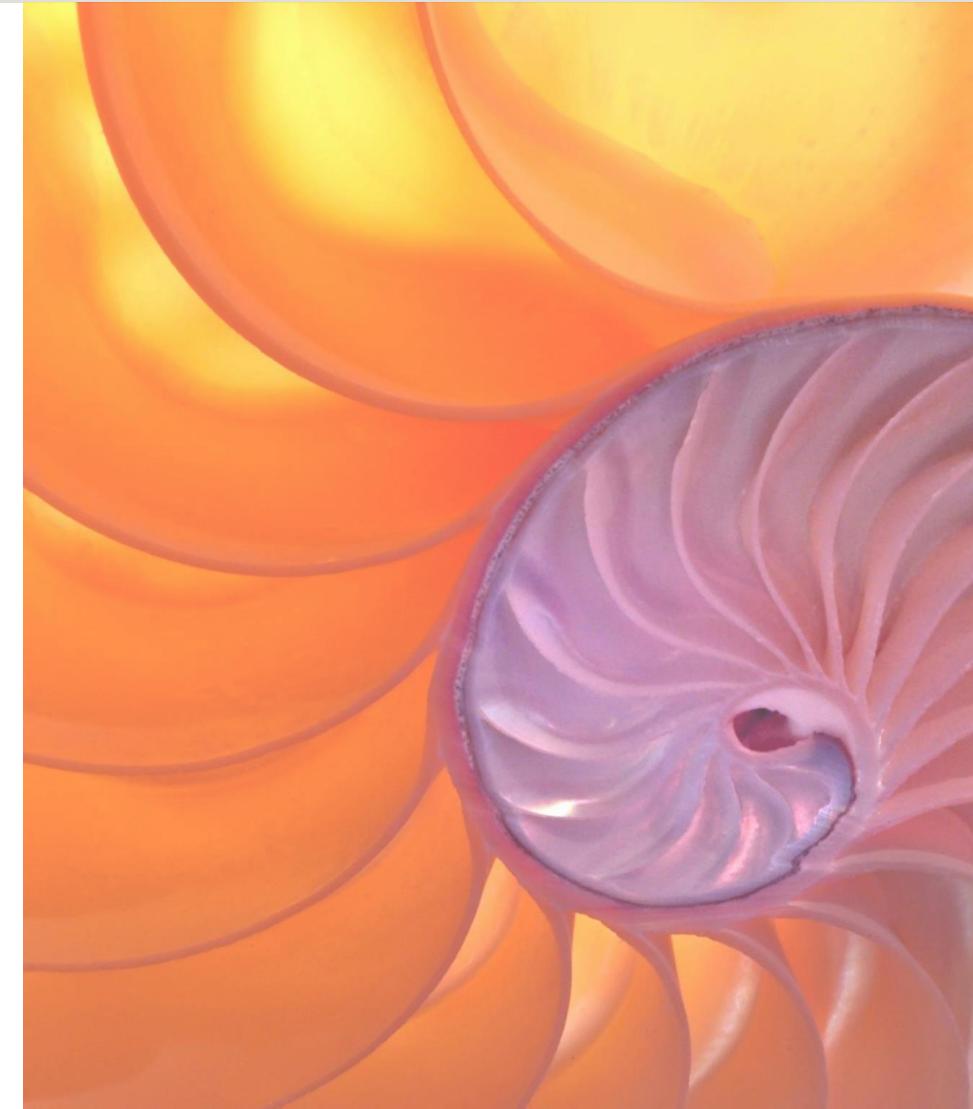
# Agenda + Presenters



- Background & Toolkit Introduction
- Person-Centered Approach to Risk
- Balancing Choice & Risk
- Tools for Teams
- Least Restrictive
- Fading Plans
- Comments

# Housekeeping

- Intent is to familiarize people with toolkit information & resources
- Not feasible to address all individual or specific situations & what ifs
- Understand liability is a concern
- Time for input at the end, in the meantime put thoughts, & reactions in chat



# Complete the Attendance Form

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# Activity



HOW DO YOU FEEL TODAY?



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TO [POLLEV.COM/KARLAKALANEK578](http://POLLEV.COM/KARLAKALANEK578)

## How do you feel today?



0%



0%



0%



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# Statewide + Systemwide Initiative

North Dakota has been 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



## Person-Centered Planning Definition

Every person should have the opportunity to define their happiness and the life they desire. A person's life is realized when family, friends, community members, and service providers actively listen to what matters to a person, by respecting and honoring their values, strengths, culture, hopes, and dreams. Person-Centered Practices occur through the development and implementation of services and supports that are informed by a person's preferences, strengths, and choices.

## Person-Centered Planning Guiding Principles

- 1. Emphasize Person First, with Customized Supports and Services**
- 2. Focus on the Person's Strengths**
- 3. Balance Choice and Risk**
- 4. Meet the Person Where They Are**
- 5. Regularly Review Goals**
- 6. Build Equity of Voice**
- 7. Equip the Person to Make Informed Decisions**
- 8. Be Kind**

# NORTH DAKOTA

## Person-Centered Practices Self-Assessment

### PURPOSE

The Person-Centered Practices Self-Assessment is an internal tool for people who manage programs that offer support services to measure their progress toward building a more person-centered system.

### ACTION STEPS



Assign Division Lead and Determine Participants



Participants Take Online Self-Assessment



Review Scores and Establish Consensus on Baseline Status



Engage Stakeholders, Including Service Users, to Inform Action Plan



Use Information to Create Action Plan



Communicate Action Plan Throughout the Division



Evaluate Progress Every 9 Months



Update System Goals

### AREAS COVERED IN ASSESSMENT

#### PERSON-CENTERED CULTURE

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

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

#### ELIGIBILITY & SERVICE ACCESS

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

#### FINANCING

How are agreements with providers structured and how well are services helping people reach their goals.

#### PERSON-CENTERED SERVICE PLANNING

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

#### WORKFORCE CAPACITY & CAPABILITY

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

#### COLLABORATION & PARTNERSHIP

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

#### QUALITY & INNOVATION

The agency's mission and standards.

# Self-Assessment

- Tool that supports programs to evaluate, create action plans, and measure progress toward building a more person-centered system



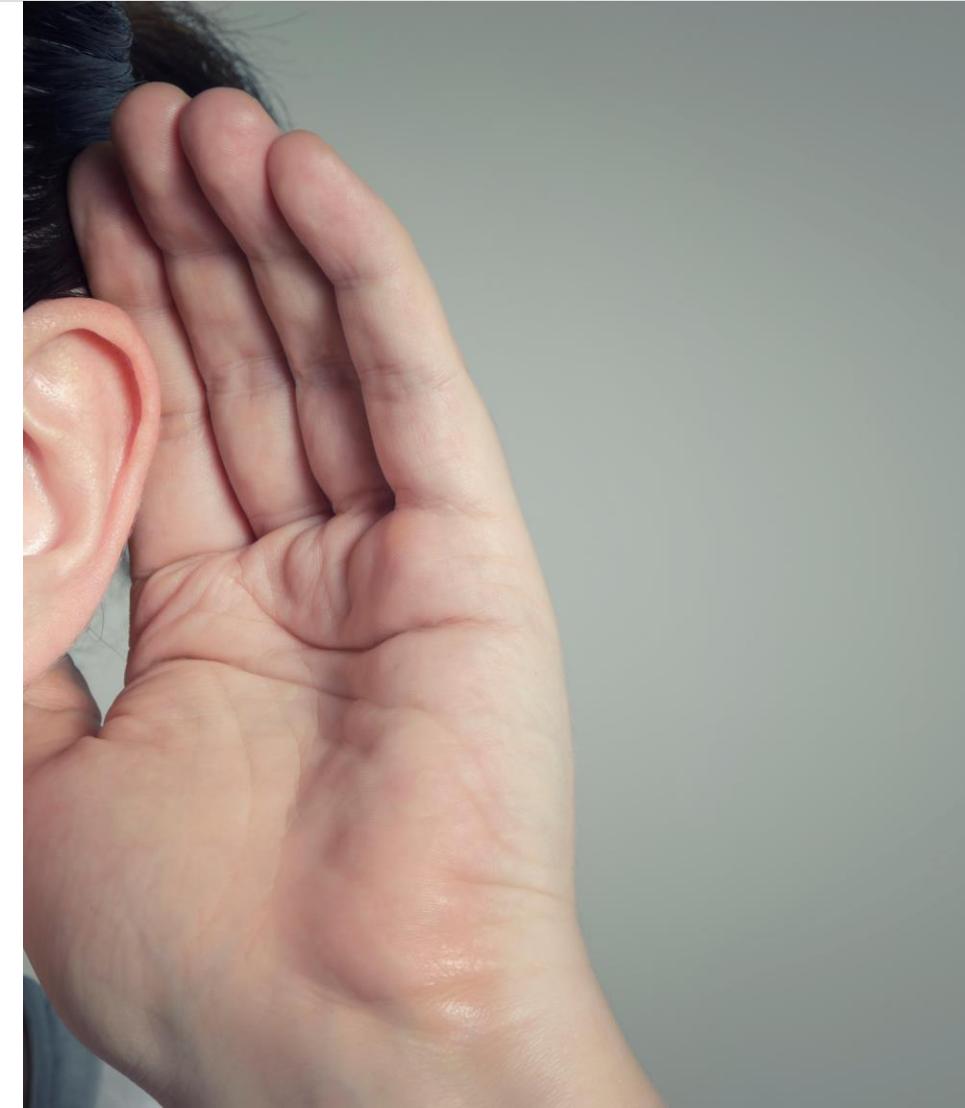
# Developmental Disabilities (DD) Focus Area

## 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.

# How the Toolkit was Developed

1. Used National trainings, Centers for Medicare and Medicaid (CMS) material, and examples from other states.
2. Gathered information Protection and Advocacy (P&A), DD Providers and corporate guardians
3. Collaborated with internal work groups to develop the material
4. Gathered and solicited public input from people receiving services, guardians, family members, advocacy organizations, etc.



# Toolkit Intended Outcome

- *Available for people receiving services, guardians, DD providers, and DDPM's*
- *Information for professionals to be able to support & guide people/guardians/families*
- *Whole systems change & collaboration*
- *Acknowledges responsibility & fears that may lead to overprotection*
- *Recognizes the person-centered way in which dignity of risk must be upheld & offer this as guidance not policy*
- *Assist teams in navigating the complexity of dignity of risk while promoting people's rights*

# Toolkit Contents



- Definitions and Guiding Principles
- Importance of dignity of risk
- Hearing from people with disabilities



- Components to balancing choice and risk
- Choices
- Strategies
- Monitoring



- Tools for teams
- Considerations
- Planning questions
- Minimizing risk
- Building opportunities



- Least restrictive
- Fading plans
- Roles and Responsibilities

# The Voice of People Supported

- *"Too many safety nets make goals hard to accomplish."*
- *"I want to go skydiving but why do I need a safety net and you don't?"*
- *"Meet me where I am at."*
- *"Mistakes happen, let me learn and grow from it."*
- *"Do not base on team member preferences or values, this can do more harm than good."*



# Common Team Challenges



- Balancing & promoting dignity of risk with right restrictions
  - Sexual health/relationships, food/diets, access to money & personal/household items
- Teams having higher expectations than expect for themselves
- Creating non-attainable objectives & imposing own values
- Developing fading strategies
- Need for team roles, expectations, & guardian education

# Activity



HOW DO YOU RATE YOURSELF ON A  
SCALE OF OVERPROTECTIVE TO  
BALANCED APPROACH?



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## How do you rate yourself?

Overprotective — 1

2

Neutral— 3

4

Balanced approach— 5

0%

0%

0%

0%

0%



# Importance of Dignity of Risk

# Dignity of Risk

*"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

# Dignity of Risk

## Definition

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.



## 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.

# A Few Key Points

Everyone takes & experiences risk

Right to control our destiny & fully experience life

Right to make decisions is not based on “the right decisions”

“Readiness factor” – how much are we completely prepared for?

Think about your life & what if.....

Being vulnerable doesn't mean all areas of life “protected”

Balancing choice & health/safety is challenging

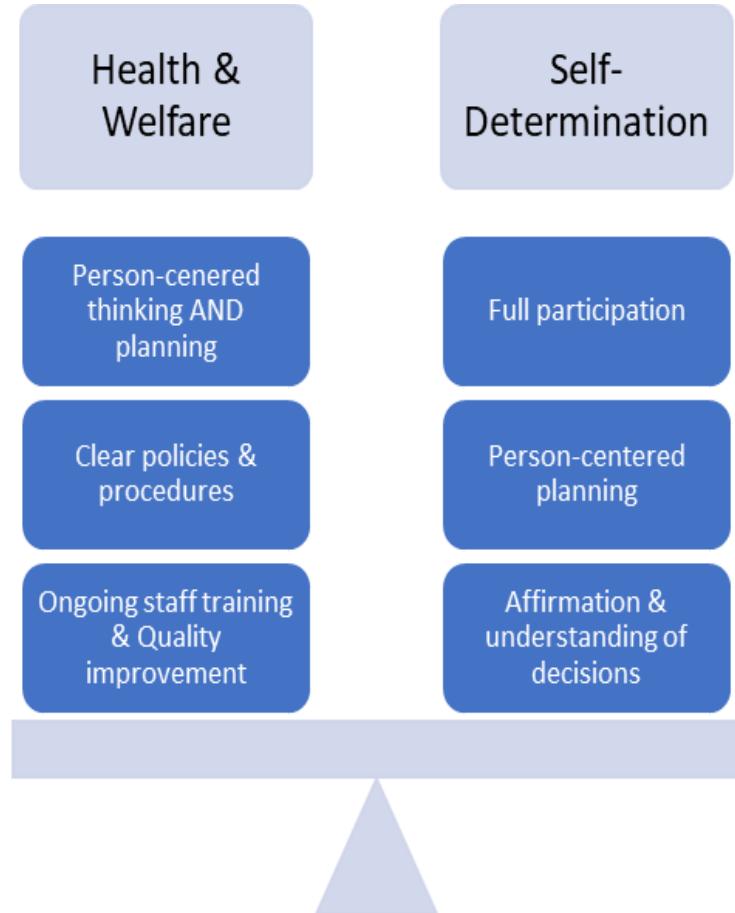
Know what's important to the person

Individualized risk & supports



Dignity of Risk = Dignity of Choice

# Balancing Choice and Risk



CMS states:

*"Dignity of risk is the idea that self-determination and the right to take reasonable risks are essential for dignity and self-esteem, therefore should not be impeded by caregivers, concerned about their responsibility to ensure health and welfare".*

# Home & Community Based Requirements



- No threshold for levels of risk
- Individualized
- Honor choices & mitigate risks
- Promote dignity & autonomy



- Direct own plan
- Make informed decisions
- Choose services & supports
- Least restrictive



- Reflect choices, goals, desired outcomes
- Reflect risk factors
- Minimize risks



- Reason for restrictions
- What previously tried
- Use data for discussions

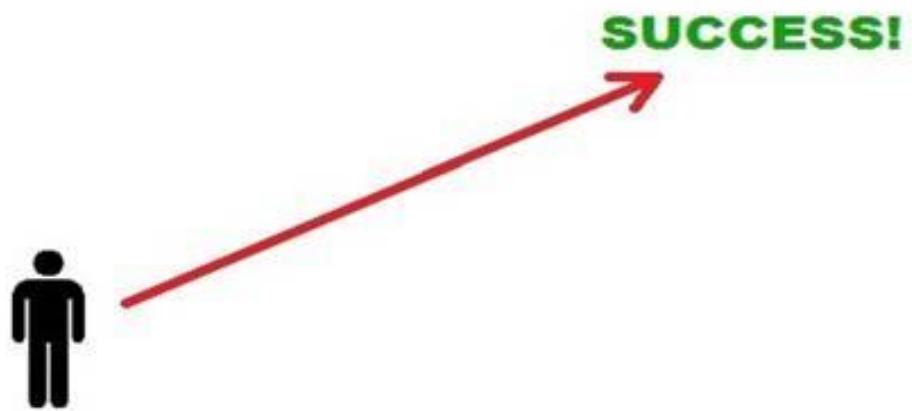


# Person-Centered Planning Process

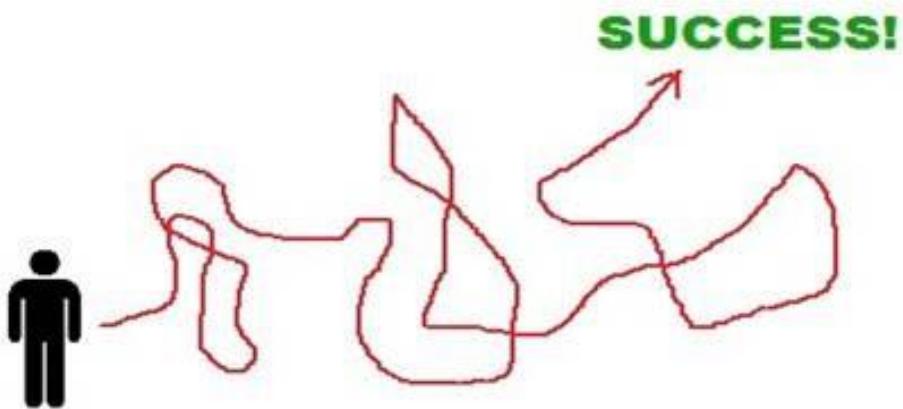
**Important to note, there is no change to current processes which includes:**

- Assessments- rights most important to the person, risks, functions of behavior, etc.
- Team discussions
- Positive behavior support plans
- Identifying least restrictive restrictions
- Informed consent by the person and/or guardian
- Due process through Human Rights Committee & Behavior Support Committee
- Service plan documentation-
  - Reason for restriction
  - Previous least restrictive strategies tried
  - On-going review of data collection to determine need for restrictions
  - Consent
  - Review dates

**OUR EXPECTATION...**



**OUR REALITY...**



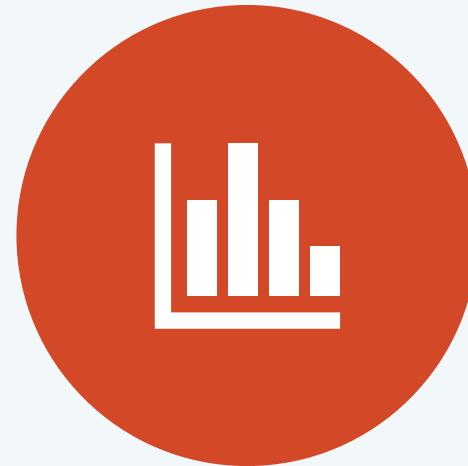
Can you relate  
to this?

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# Activity



WHAT ARE THE BARRIERS, WORRIES,  
OR FEARS?



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## What are the barriers, fears, or worries?

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Nobody has responded yet.

Hang tight! Responses are coming in.



## Components to Balancing Choice + Risk

# Component 1-Identify Choice & Risks

**Assessment(s) should gather:**

1. Person's choices
2. Person's capacity to make decisions for those choices
3. Risks based on needs, preferences, choices
4. Previous mitigation approaches
5. Adverse outcomes previously experienced

**Example-**

**Person wants to independently navigate community:**

- Determine extent of navigation (where, how often) & what resources needed
- Determine if risk to independent navigation (being stranded, harm, complexity of bus route)
- Identify prior mitigation (person became lost & responded by calling staff)
- Identity past adverse outcomes (became upset when lost)

# Component 2-Individualized Strategies

**Person-centered service discussion & plan includes:**

1. What/why choice important
2. Potential risks & mitigation strategies
3. Benefits to person
4. Alternatives to chosen activity
5. Effectiveness of approaches measured & monitored
6. Trailing, testing, temporary responses, revisiting

**Example-**

**Person wants to independently navigate community:**

- Identify risks (injury, exploitation)
- Review alternatives (staff supervise navigation)
- Risk mitigation (travel safety training)
- Use of on-going reminders or education
- When/how revisiting, monitored, etc.

# Component 3-On-Going Monitoring

**Ensure balance is sustained regularly:**

1. Revisit choice & risk discussion
2. Analyze data
3. Obtain person's satisfaction, experience, outcomes
4. Monitor risks
5. Modify plans as needed

## **Example-**

**Person wants to independently navigate community:**

- Review real or perceived adverse incidents
- Revisit alternatives
- Re-affirm choice or revise choice
- Modify mitigation strategies
- Revise staff rolls
- Determine future revisiting, analyzing, modifying, etc.

# Provider Agency Systems

- Ensure policies & practices reflect processes to achieve balance, respond to situations, assessments, plan development
- Ongoing staff training & education
- Ongoing quality improvement supports





Key Take  
Aways-It's  
About:

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Conversations

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Rationale

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Documentation

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Careful planning & thought

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Person-centered Service Planning

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# Tools for Teams

# Travel the Journey with People, Not for Them



The **goal** of person-centered planning is to **minimize** and **manage** risk vs. risk elimination and avoiding all risk.

It doesn't mean that teams ignore health, safety, and responsibility, but it's a balance.

# Team Considerations:

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Success or lack of success is not sole responsibility of person

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Change focus to helping people recover from consequences

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Denial of opportunities may not facilitate growth

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Create safe/secure environment so people do not rely on ineffective behaviors/responses

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Understand individual situations, their history, past traumas

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Provide effective staff support, training & quality relationship building

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Increase motivation & success by including what's important TO the person

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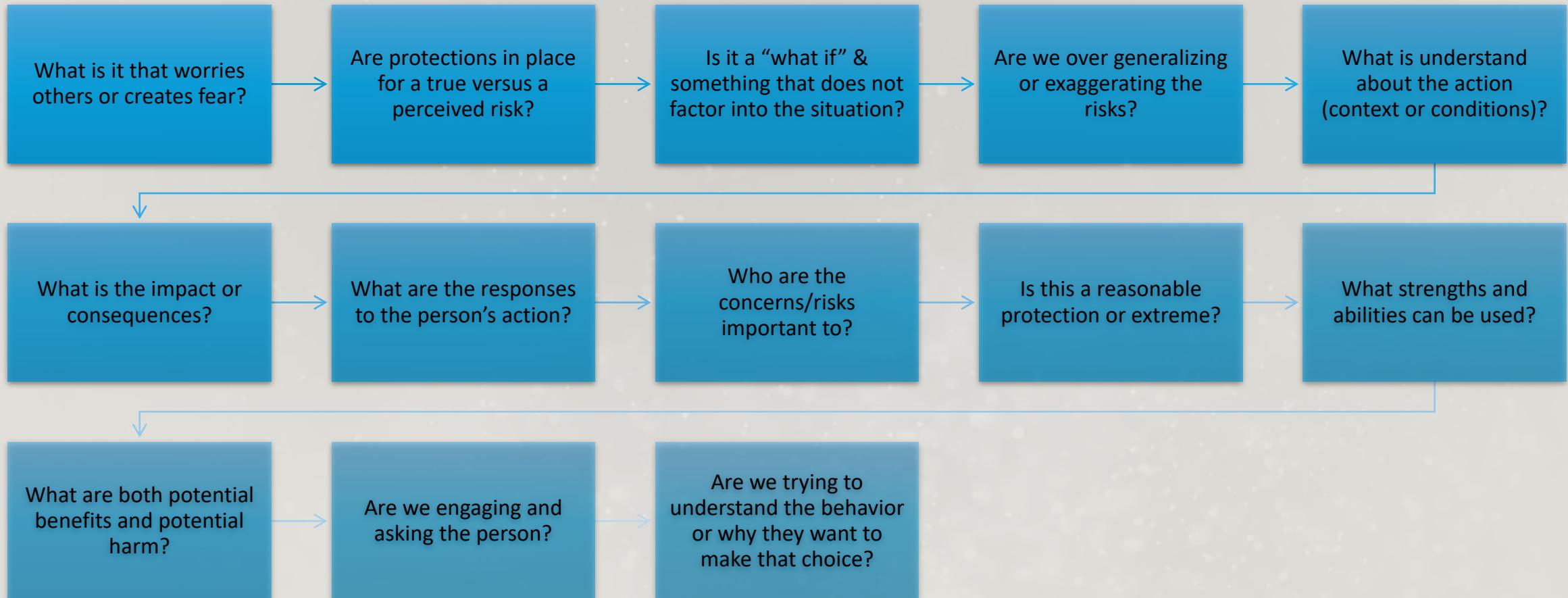
Support person to make connections with choices & outcomes

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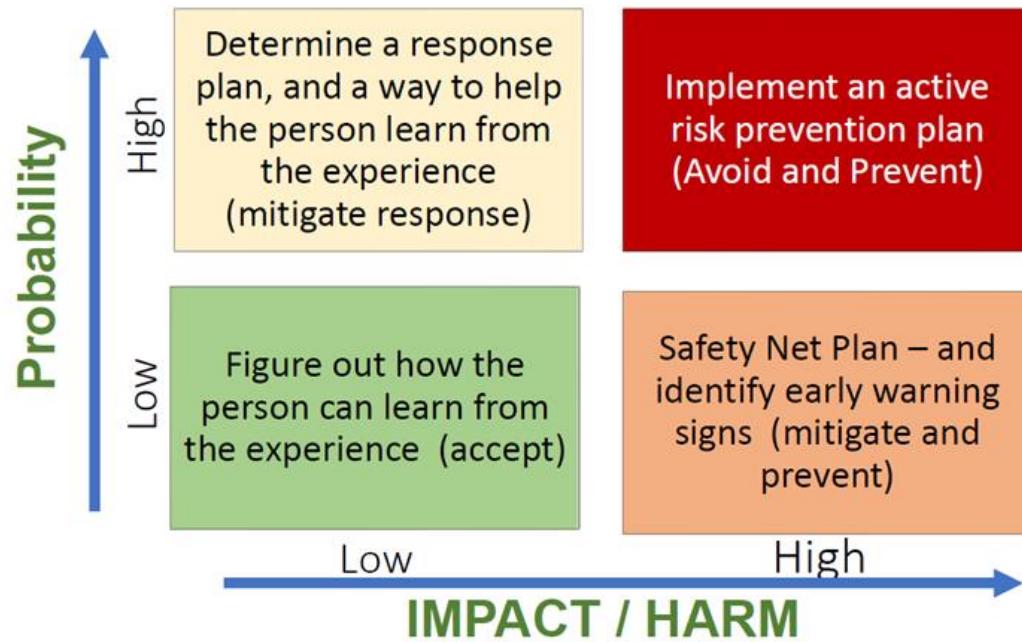
Decisions & imposing restrictions are DATA driven

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# Team Planning Questions

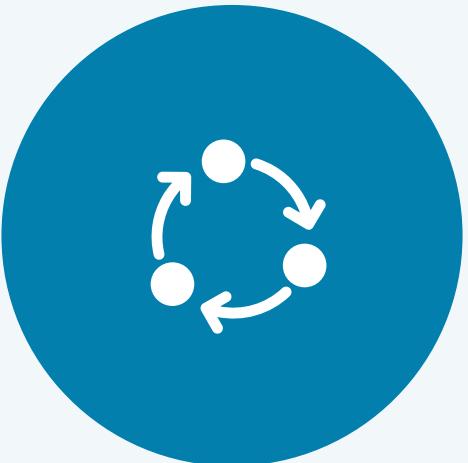


# Determining Occurrence + Impact/Harm

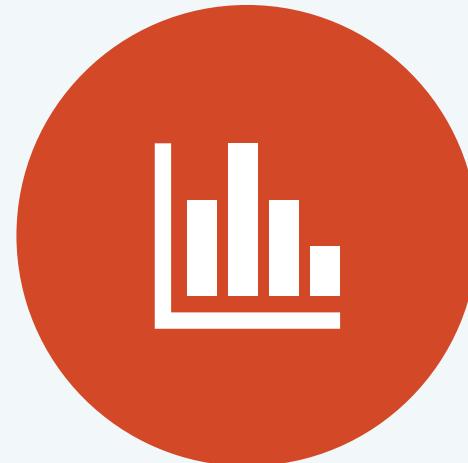


- There may be times where interventions are necessary.
- Some risks may be too great to be considered tolerable, such as risks with a high probability of death, serious injury, violation of the law.
- Other risks are considered part of everyday life, such as risk of negative reaction from peers, failure on first try, etc.

# Activity



WHAT ARE SOME WAYS TO  
MINIMIZE OR MANAGE RISK?



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## Ways to minimize or manage risks?

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Nobody has responded yet.

Hang tight! Responses are coming in.

# Minimizing Risk & Opportunities

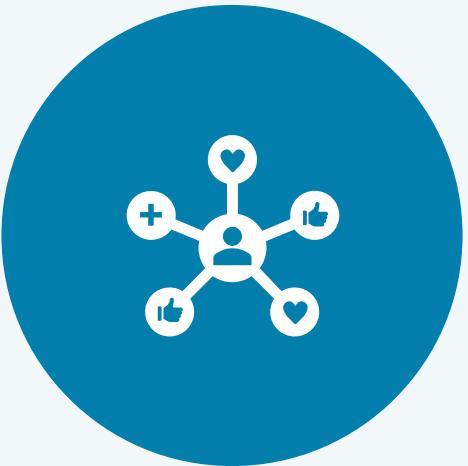
Mitigation is  
not the only  
strategy

Opportunities to experience  
risk while  
building in  
learning  
opportunities

Reasonable or  
tolerable risk =  
willing to  
accept or take

Opportunities &  
life experiences  
= supporting  
people to learn  
independence

# Activity



WHAT ARE SOME WAYS TO BUILD  
LEARNING OPPORTUNITIES FOR RISK?



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## Ways to build opportunities for risk?

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Nobody has responded yet.

Hang tight! Responses are coming in.



# Least Restrictive

# Least Restrictive

## Definition

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



## Best Practices

- Based on known risks vs “what if’s”, past occurrence, etc.
- Consider common & natural methods
- Explore alternative ways people can enjoy life
- Consider frequency & intensity
- People will have bad days & can learn from actions
- It may not be realistic to achieve something 100% of time

# Least Restrictive into Practice

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

- How impacts person to both implement or not implement the diet.
- People without disabilities have the opportunity not to follow doctors' orders just like everyone else.
- What non-restrictive methods to try first.
- What data or information to be collected to determine effectiveness & if restrictions should continue.

**Susie shops for dresses & spends all her money on a Friday evening. Before limiting access to debit card, team should consider:**

- We all overspend sometimes.
- Can help support recovery by returning things, re-prioritizing spending in the coming weeks, making a new weekly or monthly budget, eating out less because of our prior spending.
- Rely on least restrictive approaches to support & collect data over time before reacting to single events of difficulty.
- Adjust supports ongoingly to exhaust options for interventions that don't constrain person's access to risk.



# Fading Plans

# Fading Plan



**Definition:** A way to reduce or eliminate restrictions over a defined period of time to achieve least restrictive supports.

- Clear what progress would look like for the person or what is to be achieved.
- When a person is displaying progress, then there are opportunities for the restriction or rights limitation to be decreased.
- It does not mean health/safety commitment is reduced-it's part of the journey.
- Restore rights to avoid person feeling trapped. Provide tangibles.

# Fading Plan Best Practices:

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Use timelines, realistic, measurable, specific, & achievable criteria

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Fading can be gradual in steps, small increments, phases, tiered, etc.

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Fading is individualized, dependent on person, restriction, & specific situations

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Consider frequency & intensity

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Collect & use data toward determining fading plan & measuring success

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Evaluate if fading plan developed for success or failure

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Provide opportunities for achievements & gains to be made

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Continuously assess & consider other methods

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People can change, improve, mature, & make corrections over time

# Fading Plan Examples

*Person has all medications locked due to suicidal tendencies and stating they will take all their pills. The fading plan could include having their vitamin unlocked and slowly unlock more medications until all are unlocked.*

*When person does not elope from their home for two consecutive months, the 1:1 supervision level will be reduced by 5 minutes per day. When person continues to not elope from their home for one month, the 1:1 supervision level will be reduced by 10 minutes per day, and so on.*

*Person has staff within arm's reach while out in the community. Fading could consist of several steps where the staff walks further and further apart while observing and allowing the person opportunities to use replacement behaviors, but staff intervene as needed.*

# Additional Toolkit Contents



Corresponding  
Regulations



Roles &  
Responsibilities



Resources &  
Trainings



Quick Reference  
Guide

# Resources + Links

- ND Person-Centered Practices Initiative

[North Dakota Person-Centered Practices | Human Services Research Institute \(HSRI\)](#)  
[General Information | Health and Human Services North Dakota](#)

- Dignity of Risk Toolkit

[Information for DD Licensed Providers | Health and Human Services North Dakota](#)

- National Center on Advancing Person-Centered Practices and Systems (NCAPPS)

[NCAPPS Home \(acl.gov\)](#)

# Contact Information

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Thank you!