NORTH Dakota | Health & Human Services
Be Legendary.

Developmental Disabilities: Person-Centered Approach to Risk Toolkit

TABLE OF CONTENTS

Contents

Background

The North Dakota Developmental Disabilities (DD) Section engaged with the Human Services Research Institute (HRSI) and the National Center on Advancing Person-Centered Practices and Systems (NCAPPS) to develop a strong and consistent statewide vision and universal understanding of person-centeredness. Person-centered approach to risk was identified as a focus area with the goal to develop and distribute guidance on how service planning teams can assess and identify the balance between a person's desires and the rights to take reasonable risks.

The information was gathered using National trainings, Centers for Medicare and Medicaid (CMS) material, and examples from other states. DD also gathered information from Protection and Advocacy (P&A), DD providers, and corporate guardians. DD collaborated with internal work groups to develop the material based on information gathered and then solicited public input from people receiving services, guardians/family members, advocacy organizations, providers, and other interested stakeholders.

This document is meant to be a resource and to provide guidance to people receiving DD services, guardians, family members, and service planning team members.

Acknowledgments

The material developed in this toolkit was gathered from a variety of sources and trainings:

- *Centers for Medicare and Medicaid (CMS)*
- *Person Centered Consulting*
- *Tennessee Division of TennCare*
- *Montana* Developmental Disabilities (mt.gov)
- *Alabama* Division of Developmental Disabilities – Alabama Department of Mental Health
- *South Dakota* SD Department of Human Services
- *Minnesota* Disability Services / Minnesota.gov (mn.gov)
- *John Finn*
- *Human Services Research Institute (HRSI)*
- *National Center on Advancing Person-Centered Practices and Systems (NCAPPS)*
- *American Association on Intellectual and Developmental Disabilities (AAIDD)*
- *All Group, ND self-advocacy group*

Hearing from People with Disabilities

Introduction to Dignity of Risk

Dignity of risk was first used by Robert Perske in a 1972 article he wrote and was inspired by the normalization principle in relation to people living with disabilities.

> *"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".*

There is never a guarantee that people will not experience risk or a negative outcome. All people, disabled or not, have potential risks, take risks, and have a right to risk.

Life happens to all of us. However, people with disabilities may be more vulnerable and have more difficulty in making informed decisions about risky behaviors and their possible consequences. However, being vulnerable in one areas of life does not mean that a person requires protections in all areas of life. Additionally, there should be no presumption that people are completely incapable of participating in the risk management process and the person should be supported and involved. Informed choice and decision-making abilities are individualized and can vary with the person depending on the topic, skills, situation, etc.

Dignity of risk reflects a person's right to control their destiny and fully experience life, both the good and bad. Like the person's needs and preferences that are addressed in planning, risks are also highly individualized. Risk is a combination of individual circumstances, events, and perceptions.

Balancing a person's right to make choices, including potentially unhealthy or unsafe ones, with the need to assure the health and welfare of a person is challenging. Health and welfare safety are not an absence of risk, instead, it is matching the level of risk to the person's wellbeing, which leads to the challenge of managing the risk.

People with disabilities have the same rights as every citizen. The goal is not to unnecessarily overprotect, control or change a person, or base decisions on our own personal values. Therefore, it is essential that the team elicits, is aware, and considers what rights are most important to the person and how the person would be affected if a restriction is imposed. Discussions and decisions should not be done in isolation and should involve the person. Additionally, there may be times where the team may not be in full agreement, however, all points of view should be expressed, considered, and respected.

Risk identification is more than a conversation between people, their families, program managers and others. It also involves a comprehensive documentation of that conversation. Such documentation provides the context and rationale for elements in the service plan and provides evidence that a risk

management process is in place. It includes three related and embedded concepts: preference, opportunities, and control.

The team needs to plan with an understanding of what people desire for their happiness and then examine the risks entailed, as risk is both relative and contextual. The degree of risk is determined by weighing the dangers in the environment, individual skills, experiences, and supports. No specific guidelines can ensure unquestionable safety for everybody. CMS has not published thresholds for acceptable levels of risk because risk is highly individualized. Risk identification and mitigation is not to prevent people from living and fully experiencing their community. In addressing between choice and safety, service planning teams will best be served by documenting:

- The concerns of the person, staff, providers, and any other stakeholders.
- The negotiations process and the analysis and rationale for decisions made and actions take.
- Decisions regarding what risk are acceptable or not.
- Explain why certain decisions on risks for the person were agreed upon.

When states document these aspects of their monitoring activities, they will have solid evidence to support their policies and individual plan.

Refer to Appendix on team member responsibilities.

Definitions and Guiding Principles

Dignity of Risk

Dignity of risk is 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.

The definitions of key terms below are offered for operational purposes in this document.

Informed Choice

Informed choice is a voluntary, well-considered set of options that a person or the person's guardian (where legally required) evaluates based on 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.

Due Process

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

Fading Plan

A fading plan is a way to reduce or eliminate restrictions over a defined period of time to achieve least restrictive supports.

Least Restrictive

Least restrictive is 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.

Plain Language

Plain language is 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.

Dignity of Risk

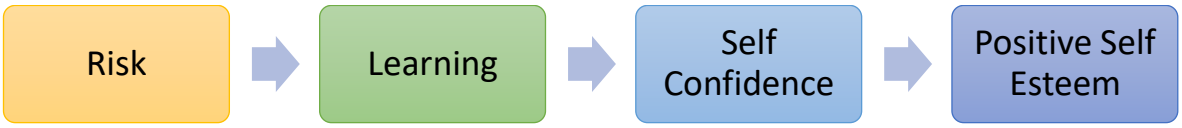
Definition

Dignity of risk is 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.

Importance of Dignity of 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".*

Everyone has a right to self-determination, to live their life to the fullest, make decisions, and live the life that they choose.



Self-Determination refers to a person's right to make choices about their own life and to have the same rights and responsibilities as others. Some ways self-determination can be achieved may include:

- Problem solving
- Self-advocacy
- Independent living (risk taking and safety skills)
- Goal setting and attainment
- Self-regulation
- Positive self-efficacy and outcome expectancy
- Internal locus of control – the ability to take action, be effective, influence your own life, and assume responsibility for your behaviors
- Self-awareness
- Supported decision making

<u>Areas of individual choices for self-determination include but not limited to:</u>

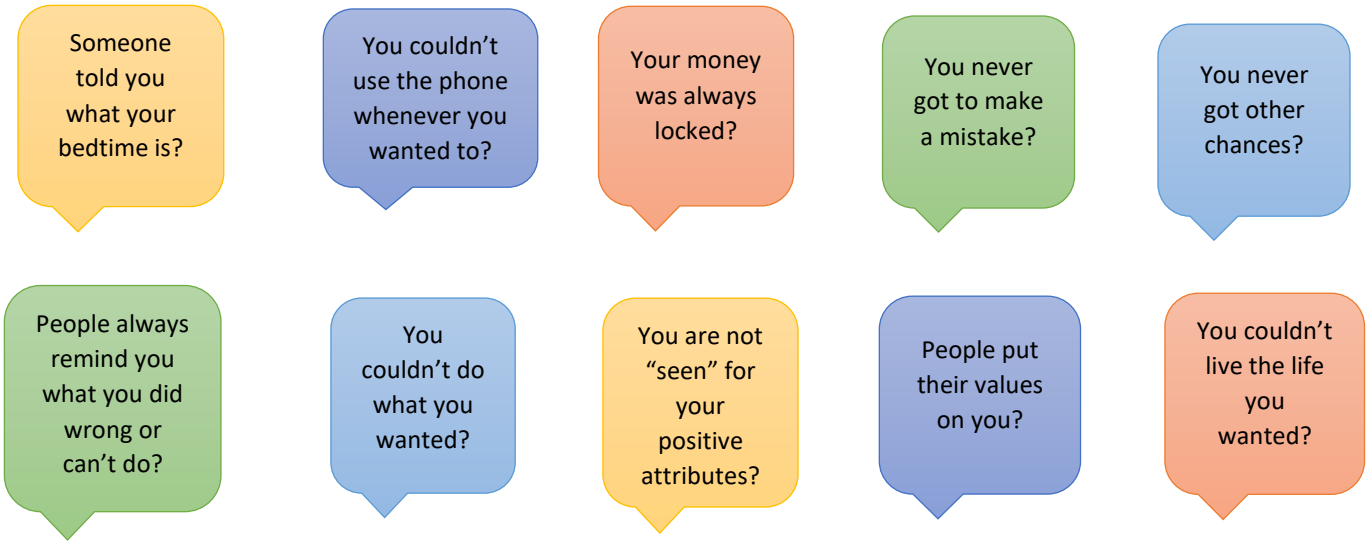
- Everyday decisions: going shopping at the grocery store, sleeping during the day, staying up all night, playing loud music, making a cup of tea, eating at any time.

- Healthcare treatment options: taking medications, refusing care or services.
- Decisions that are not recommended for anyone (smoking, eating cake for breakfast, etc.)
- Decisions that are not recommended for the specific person based on their circumstances (drinking sugary beverages all day when diabetic)
- Decisions that are objectively dangerous to self and others (smoking in bed, having a barbeque grill inside the house)

Dignity of Risk = Dignity of Choice

Risk exists for all of us - no one is risk free-this is a "typical" life experience. The right to make decisions is not only contingent on making "the right decisions". The things that keep us safe are the same for all people and 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.

Think about your life and what if…



Without risk we fail to know the potential of people with disabilities. Are there such things as the "readiness factor"? How much things in life are we truly always completely prepared for? Life is always throwing curve balls and is messy.

> *"You are never going to be able to improve in your situation and enjoy life unless you recognize that there is a little bit of risk everywhere"-Quincy Abbott, Disability Advocate*

Dignity of risk involves being able to make a choice and consider potential risks:

- Experiencing negative consequences helps all of us to learn. Negative consequences could include getting injured, getting lost, and being heartbroken.
- Trying new things and making mistakes is part of how we learn and grow as people.
- Risks may provide opportunities to recognize and resist abuse and endangerment.
- Experiences may provide people with learning opportunities to navigate the world.
- There is always the potential for positive outcomes, not all risk taking is bad.

It is natural to want to protect someone that we care about, but it's important to not take away someone's dignity of risk. When someone has both self-determination and dignity of risk, they are more likely to become independent, have meaningful life experiences, and have a higher quality of life.

People with disabilities have the right to be in charge of the choices made about their lives. Even if they have legal guardians, people should be included in decisions made about them and still have dignity of risk. This can be accomplished through person-centered service planning and can assist people in feeling more confident in themselves and their choices.

A common barrier that limits self-determination and dignity of risk is when others make decisions for people with disabilities because of their desire to protect them by making decisions for them. This desire to protect is well-intentioned but may stem from the misconception that people with disabilities do not have the ability/skills to make their own decisions or are a result of our own personal values/beliefs.

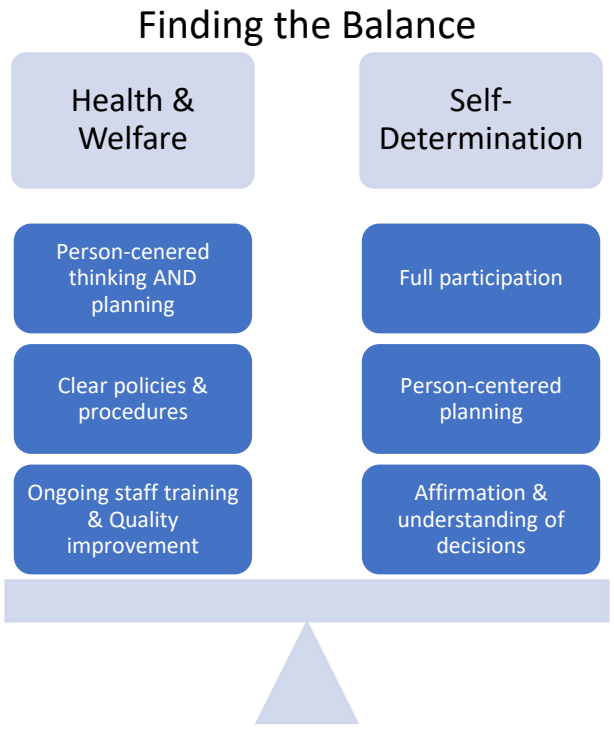
> *"Freedom to make choices, even choices that may result in harm, is a freedom that most people cherish. Freedom of choice is one of the highest American ideals."-Burton Blatt, Advocate of deinstitutionalization and inclusive education*

People's needs and wants change over time as we learn and grow. Choices made today might be different than choices made 5 years from now or after. This comes with experiences, learning from successes as well as mistakes. Therefore, dignity of risk should be evaluated on-going and results from past situations should not automatically prevent or hinder future opportunities as risk levels or the likelihood may have changed with time or new circumstances.

Components to Balancing Choice and Risk

Balancing honors both choice and self-determination while assuring health and welfare of people. With careful planning and thought, it is possible to honor choices and mitigate risks.

There is no mandated threshold for acceptable levels of risk because risk is so individualized. This section is guidance that CMS has provided on how to balance choice and risk. It's about conversations, rationale, and documentation. This may be achieved through the person-centered service planning process/steps. *Refer to Appendix for CMS person-centered planning requirements.*



Component 1-Identify Choice and Risks

Identify and document choices and risks during the initial assessment and reassessment. The assessment should gather information about:

1. The person's choices that are based on interests and self-determination, both with and without risk.
2. The person's capacity to make decisions around those choices to determine whether the person can understand implications, potential consequences, etc.
3. Risks presented by the person's needs, goals, preferences, choices in physical health, behavior health, personal safety, safety of others, financial, and environmental.
4. Prior mitigation approaches used and the effectiveness - what pieces were/are in place to mitigate the risks identified as well as past strategies and the effectiveness of these different efforts.

5. Adverse outcomes previously experienced related to the risks identified - what has previously occurred will help in understanding the likelihood of harm from the risk(s) and will help in measuring the weight and scope of the potential harm from the risk(s).

   Example: Person wants to independently navigate the community. The assessment should:

   - *Determine the extent of the navigation, where, how often, what resources are needed.*
   - *Determine if there is a risk to independent navigation such as being stranded, harm, complexity of bus route.*
   - *Identify prior mitigation such as person has been able to navigate around their neighborhood successfully or in the past if the person became lost, they responded by calling the provider for assistance.*
   - *Identity any past adverse outcomes, such as the person became upset and panicked when they realized they were lost.*

Component 2-Individualized Strategies

The person-centered service discussion and plan should include individualized strategies to honor choices and address each risk including how the needs, goals, preferences, choices, and risk that were identified during assessments will be addressed.

1. What and why the choice is important to the person.
2. What are potential risks and include risk mitigation strategies such as
   a. Care management elements
   b. Personal care/staff task adjustments
   c. Specific training, policies, and protocols, necessary to implement the plan.
   d. Family/natural supports
   e. Behavioral approaches
   f. Covered Items and Services
   g. Technology supports.
3. What are the benefits to the person.
4. What are the alternatives to the chosen activity.
5. How the effectiveness of the approaches will be measured or monitored and when it may need to be reviewed again.
6. Teams should be open to trialing, testing, and temporary responses that may need to be revisited.

   Example: Person wants to independently navigate the community. The planning process would reflect:

   - *Identify the risks such as risk of injury, physical safety/exploitation concerns, disruption to other scheduled services, etc.*
   - *Review alternatives such as joint outings with friends, staff supervised community navigation, etc.*
   - *Agreement on risk mitigation such as travel safety training, neighborhood familiarity training, assessment of the person's ability to apply information from*

the training, training on use of phone if running late or get lost, limits on time of day for independent travel at first to ensure staff are available if needed, etc.

- *The use of on-going reminders and education.*
- *Outline when and how it will be revisited, monitored, modified, etc.*

Component 3-On-Going Monitoring

Ensure balance is sustained regularly.

1. Revisit choice and risk discussion.
2. Analyze any data (e.g., tracking forms, critical incident management system).
3. Obtain the person's satisfaction, experience, and their outcomes.
4. Monitor individual risks.
5. Modify plans as needed.

   Example: Person wants to independently navigate the community. The planning process would:

   - *Review any real or perceived adverse incidents.*
   - *Revisit alternatives.*
   - *Re-affirm the person's choice or revise the choice.*
   - *Modify risk mitigation strategies.*
   - *Revise staff roles.*
   - *Determine future revisiting, analyzing, monitoring, or modifying.*

In addition to the person-centered service planning process, it is also important that providers review and address their agency system. This may include:

1. Ensuring tools, policies, and practices reflect concepts of and processes to achieve balance, respond to situations, assessment tools, and plan development.
2. Conduct ongoing staff training and education pertaining to their role, how to provide individualized supports, philosophy, and practices around balancing choice and risk.
3. Conduct ongoing quality improvement as supports can always be improved upon, ensure policies and practices are being implemented as designed, and review what is effective or not.

Travel the Journey with People, Not for Them

Tools for Teams

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

- Success or lack of success is not the sole responsibility of the person receiving services.
- Change the focus to helping people also recover from the consequences and impact of negative outcomes from choices.
    - Ensure supports are available for recovering from the impact of the naturally occurring consequences which can occur when things don't go as expected.
    - These supports should unconditionally be available regardless of if the risk was chosen because setbacks are inevitable and one of the functions of supports is to ensure recovery from setbacks.
        - *Example:* An adult in services that has a diabetic condition may not follow a diabetic diet daily and may not always follow their doctor recommendations. This could result in high glucose readings, and the service provider may support recovery from the choice of not following the diabetic diet by how to decrease the current glucose levels, review healthy options for meal planning, and discuss the consequences of that choice.
- Denial of opportunities may not facilitate growth.
- Create a safe and secure environment so people will not rely on ineffective behaviors/responses.
- Create environments that are also most supportive to what their ideal life is.

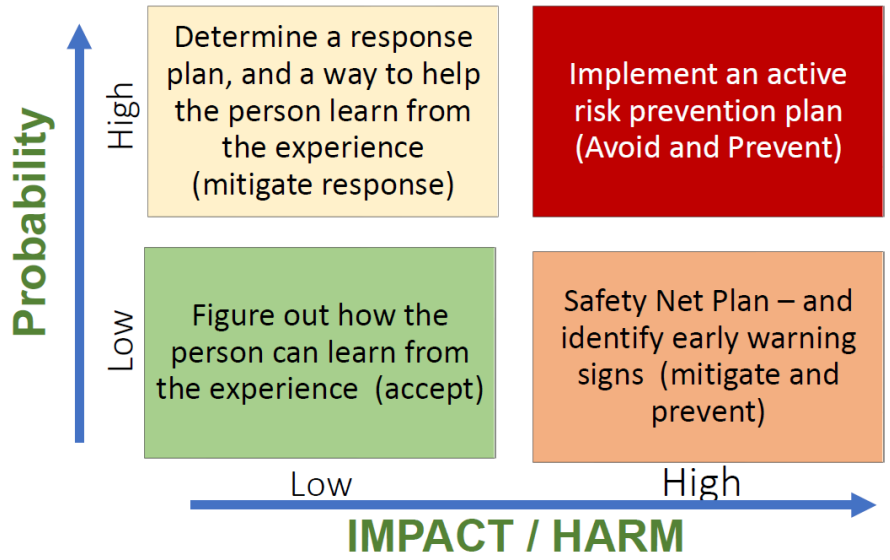
- Understand individualized situations, their history, and any past trauma.
- Provide effective staff support and training.
- Don't underestimate the importance of quality relationship building.
- Include what's important TO the person to increase motivation and success.
    - Identify risks but also include the person's hopes, dreams, and aspirations.
- Support the person to make connections with their choices and outcomes.
    - Take into consideration the person's learning style, cognitive abilities, adapt strategies to fit the person, etc.
- Decisions and imposing restrictions should be data driven.

Thoughtful Team Planning Questions

- What is it that the person does (actions taken, behavior observed)?
- What is it about this action that worries others or creates fear (the risk)?
- Are we putting protections in place for a true risk versus a perceived risk?
- What do we understand about the action (context or conditions)?
- What are the results of the action (impact or consequences)?
- What keeps the person from doing it (prevention)?
- What do people do when the person engages in the action (response)?
- Who are the concerns/risks important to?
- Are these protections important to the health and safety of the person?
- Are these protections important only to the system?
- Is this a reasonable protection or extreme?
- Is the risk a "what if" that does not factor into the person's recent history or situation?
- Are we overcompensating, over generalizing, or exaggerating the risks?
- What are the persons strengths, desires, skills, and abilities that can be used? What are both the potential benefits with potential harm?
- Be mindful and inquire with the person instead of only talking among team members. Are we engaging the person and asking them "What do you think about this?"
- Are we inquiring and understanding the behavior or why the person wants to make that choice?

How likely is the risk in this situation?	How significant is the potential impact for the person/others?
•What circumstances contribute to the risk? •In similiar settings/circumstances, how frequently has the risk occurred? •What other factors contribute to the likelihood the risk will occur?	•What might happen to the person/others as a result? •Would the results be long or short term? •Are the results likely to cause trauma, be life changing, life threatening, or devastating to person/others?

Determining the Likelihood of Occurring and the 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.

Ways to Minimize, Manage, Safeguard from Risk

- Interventions
- Services and supports
- Goals and learning objectives
- Training
- Coaching
- Personal care strategies
- Staff task adjustments – optimizing and prioritizing staff resources and responsibilities to ensure they can meet people's needs regarding safety and dignity of risk
- Protocols – ensuring everyday work and support processes allow for the effective minimization of risk
- Natural supports (family, neighbors, church members, friends, employer)
- Technology (smart displays, voice communication devices, visual smoke alarms, automatic stove top timers, medical alert systems)
- Positive behavioral supports
- Innovative options, etc.

Risk mitigation is not the only strategy that should be used. There should also be ways people can experience risk while building in learning opportunities. It's about **reasonable or tolerable risk**, which are those that one is willing to accept or take while using the risk mitigation strategies. If people do not have opportunities and life experiences, we are not supporting people to learn independence.

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 new things
- Daily choices
- Annual goals

Least Restrictive

As part of dignity of risk, it is important that when people's rights may be limited that team members brainstorm and come up with solutions that have the least impact, are not overly restrictive, and provide for as much independence as possible. Least restrictive measures should always be tried first before moving into highly restrictive procedures.

Definition

Least restrictive is 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 for Least Restrictive Strategies/Supports

- Refer to the ND DD Bill of Rights and UN Declaration of Rights for information on people's rights.
- Distinguish between a known risk vs. an unknown risk. Restrictions should be based on known risks.
- 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.
- Avoid highly or overly restrictive interventions. Identify all methods and options available and try the least restrictive/intrusive first before moving on to others or implementing a rights restriction.
- Least restrictive methods may include prompting, natural consequences, education, skill building, adaptations, least amount of staff/supports, etc.
- Consider the most common and natural methods that are also available to people who may not have disabilities.
- Explore alternative ways a person can enjoy life vs. limiting, restricting, or eliminating experiences.
- Consider 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).
- Restrictions should be viewed as temporary and revisited minimally every 6 months to a year.
- Remember that people will have bad days and can learn from their choices/actions.
- Consider if it is realistic for any person to do or achieve something perfectly 100% of the time.
- Right restrictions should be supported by:
    - A specific reason using assessment information and/or data collection (what is actually happening).
    - Attempting least restrictive alternatives.
    - Using yearly assessment information and/or data collection to determine if the restriction should continue, be discontinued, or faded.
- Ensure fair treatment through due process:
    - Reviewed by the person, guardian, and team.
    - Approved through HRC/BSC Committees
    - Documented in the person's service plan.

- Includes a fading plan and teaching objectives.
- Provide ongoing learning opportunities, replacement behaviors, positive behavior supports, etc.
- Brainstorm solutions, least restrictive methods, try new things, and be creative.

Example 1:

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 doctors' 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.*

Example 2:

It is spring and there is an online sale at Old Navy. Susie goes looking for new spring dresses and spends all her money on a Friday evening.

- *Before limiting Susie's access to the internet or to her debit card, the team should consider that we all overspend sometimes and help support recovery by using options like returning things, re-prioritizing and spending differently in the coming weeks, making a new weekly or monthly budget, eating out less because of our prior spending.*

- *Teams should rely on the least restrictive approaches to support and collect data over time before reacting to single events of difficulty.*
- *Adjust supports ongoingly to exhaust the options for interventions that don't constrain the person's access to risk.*

Fading Plans

People's right limitation should be time limited, therefore it should be 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. This can be accomplished through a fading plan.

Definition

A fading plan is a way to reduce or eliminate restrictions over a defined period of time to achieve least restrictive supports.

Fading Plan Best Practices

- Fading does not mean the commitment to health and safety is reduced. It is part of the journey to the life a person desires.
- Fading is dynamic and can change frequently.
- Restore rights as people PROGRESS to avoid the person feeling trapped or that they are not getting anywhere. The benefits need to be tangible.
- Have timelines, realistic, measurable, and achievable criteria. If the criteria are too general, the person and team may not understand the expectation or what is the goal.
- Is the goal to reduce the behavior vs. extinction? Is the fading plan developed for success or failure?
- 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.
- Consider the frequency (how often occurring) and the intensity (to what extent or severity).
- Fading plans should include least restrictive methods, be continuously assessed, and revisited with the team at least yearly.
- If a fading plan is not successful, brainstorm solutions, consider other methods, try new things, and be creative.
- Potential risks are assessed during the service plan development process and strategies to mitigate risk are incorporated into the service plan according to the person's needs and preferences.
- 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. These situations may be

due to the person's cognitive, physical limitations, or declining conditions. The fading plan should include this information to support the determination.
    - *Person has cerebral palsy and utilizes a chest strap when sitting in their wheelchair. Assessment identified that the person continues to have daily spastic movements and is unable to gain/maintain strength despite years of physical therapy exercises.*
- If the person has a declining condition, there is the possibility that a behavior or concern no longer exists, and restrictions can end.
    - *Person is in the later stages of Alzheimer's and doesn't seek out and break items that were previously locked, therefore the restriction can end, and these items no longer need to be locked.*

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.

After 3 months with no attempts of self-harm, the person will be encouraged to use knives with supervision from staff for up to 5 minutes a time for 3 times per week. If no attempts to self-harm continue after 1 month, then person's time to use knives will increase in 5 minutes increments. Once the person reaches 30 minutes, the knife restriction will be removed.

To fade elopement, the person will be paired with another individual using 2 staff with one standing back and only there to step in when person elopes, or staff needs help. Person will be paired with someone once a week for 1 hour for 4 weeks. When this is achieved, the same will be done but for 2 times a week for 2 hours for 6 weeks, and so on. When the set achievement criteria are met, the 1:1 staffing will discontinue.

To fade awake Night Staffing, in looking at persons sleep patterns, provider will adjust awake overnight staff hours to include sleep time in increments using an audio monitor.

Appendix 1

Roles and Responsibilities Related to Rights and Risks

Team members may have some varying responsibilities; ensuring people's rights and least restrictive strategies are in place is the responsibility of everyone. The roles of each team member are summarized below to assist the teams in better understanding on how to best support the person rights promotion and dignity of risk.

People Receiving Services

- Be open and honest with what you want and feel.
- Have a voice, speak up, and be heard.
- Share what your hopes, wishes, and dreams are.
- Know your rights and share what rights are most important to you.
- Ask questions of the team to understand where they are coming from.
- Ask for all the necessary information to make an informed decision.
- Remind the team to "meet you where you are at".
- You can invite anyone you want to your team meetings.
- Even though you have a guardian, you should still be involved in decisions.
- Recognize that there are some things we may need assistance with.
- If you need more support to be heard and understood, obtain advocacy services through a trusted friend family member, or Protection and Advocacy (P&A) or seek help from leadership in the place providing your supports.

People Who Assist in Decision Making Supports

This may include legally appointed guardians, parents, family members, etc.

- Provide decision making supports according to the person's best interests.
    - For legally appointed guardian, decision making authority is for the areas authorized by the guardianship court order.
- Listen to the person to understand what the person wants and needs according to their preferences to live the best life they desire.
- Explain information in a way that the person understands the consequences, while weighing all pros and cons.
- Involve the person in decision making to promote the most independence and choice.
- Understand and use all available information to provide informed consent on behalf of the person, including the right to not agree to/decline services and supports.
- Participate in assessments, as desired, and offer input toward rights that are most important to the person and to identify risks, support needs, strengths, abilities, and preferences.

Developmental Disabilities Licensed Provider

- Provide direct services to people and coordinates support among team members, which include, but is not limited to, the person receiving services, guardian, other provider staff, and the Developmental Disabilities Program Manager. Coordinated support is provided in the areas of communication, health services, financial, vocation, and daily living skills.
- Facilitate team discussion and document in the person's service plan the right restrictions, reasons for the restrictions, least restrictive methods tried that were not successful, data/occurrences to support if restrictions should continue, and fading plans.
- Complete assessments which identify the rights that are most important to the person and to identify risks, support needs, strengths, abilities, and preferences.
- Explain in plain language and provide all the necessary information toward informed consent with the person and/or guardian for any right restrictions.
- Take right restrictions through Human Right and Behavior Support Committees.
- Implement the team-approved service plan, including training the team and staff:
    - Support opportunities through coaching, teaching, and guidance across all environments.
    - Ensure programs are in place to provide learning opportunities on how to manage and remain healthy and safe.
    - Implement supports and educate on supports and restrictions.
    - Remain educated and up to date on all policies.

Developmental Disability Program Manager (DDPM)

- State employee who authorizes federal Medicaid and state funds to licensed providers.
- Participate as an active team member in plan development, assure due process/informed consent is obtained, and assure plans are implemented as written.
- Act as the liaison among the person, guardian, and provider.
- Provide mediation when conflict arises among the team.
- Complete the initial risk assessment used to identify the person's risks.
- Listen, understand, and advocate for the person's needs, wants, and choices. Assure individual rights are exercised and least restrictive options are explored while balance health and safety supports.
- Assure the reason(s) for right restrictions, reasonable expectations, data collection, and fading plan are addressed by the team.
- Remain familiar with restrictive interventions and ensure the person's service plan contains the necessary documentation.
- Educate teams on a person's dignity of risk and alternatives when guardianship is considered and discussed.
- Monitor satisfaction with services and ensures the person and/or guardian agrees with services and supports.

Appendix 2
Federal and State Regulations and Requirements

CMS Federal Regulations

In 2014, CMS established the rule 42 CFR 441.725 Home and Community Based Services (HCBS) Regulations. The regulations include Person-Centered Service Planning (PCSP) which requires:

- The service planning process:
  - Allows the person to **direct the process** and make informed choices and decisions.
  - Offers **choices** to the person regarding the services and supports they receive and from whom.
  - Provides necessary information to ensure **informed choices and decisions**.
  - **Prevents** the provision of **unnecessary** or inappropriate services and supports.
- The PCSP reflects:
  - **Strengths and preferences**
  - **Desired goals and outcomes of the person**
  - **Supports** to meet needs identified.
  - Risk factors and measures in place to **minimize** them, including individualized backup plans and strategies when needed.
- When there are right restrictions the PCSP includes the following documentation:
  - Identify a specific and **individualized** assessed need for the restriction.
  - Document the positive interventions and supports used prior to any restrictions and **less intrusive methods** that have been tried and did not work.
  - Include regular collection and review of **data** to measure the ongoing need of the restriction.
  - Include established **time limits** for periodic reviews to determine if the restriction is still necessary or can be terminated.
  - Include **informed consent** of the person; and
  - Include an assurance that the interventions and supports **will cause no harm** to the person.

ICF/IID State Operations Manual

Appendix J-Guidance to Surveyors: Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)

- W125 §483.420(a)(3) Allow and encourage individual clients to exercise their rights as clients of the facility, and as citizens of the United States, including the right to file complaints, and the right to due process.
- W268 §483.450(a)(1)(i)(7) Promote the growth, development, and independence of the client; Staff encourage clients to take risks while providing reasonable safeguards to prevent injury.
- W269 §483.450(a)(1)(ii) Address the extent to which client choice will be accommodated in daily decision-making, emphasizing self-determination and self-management, to the extent possible.
- W278 §483.450(b)(1)(iii) Insure prior to the use of more restrictive techniques, that the client's record documents that programs incorporating the use of less intrusive or more positive techniques have been tried systematically and demonstrated to be ineffective.

Appendix 3

Resources

Council and Quality and Leadership (CQL)

The Three R's-Rights, Risk, and Respect: https://www.c-q-l.org/resources/newsletters/the-three-rs-rights-risk-and-respect/
Dignity of Risk Video: https://youtu.be/UZR6fm7pA2c

UVM Center on Disability & Community Inclusion-Dignity of Risk Video:

https://www.youtube.com/watch?v=LUka52lKtdw&t=22s

Living well Project - Dignity of Risk Video:

https://www.youtube.com/watch?v=FwlpzSunvgw

Finding the Balance: Person Centered Supports that Honor Safety and Dignity of Risk (December 2019 Webinar):

https://www.youtube.com/watch?v=SBZ-XX_I9Uc&t=395s

Support Living Guidebook-Dignity of Experience document:

https://nccdd.org/images/article/initiatives/Supported_Living_Guidebook_2020/Doc_2_Dignity_of_Experience_.pdf

Transition Tennessee-Embracing Dignity of Risk in the Transition Process Webinar:

https://transitiontn.org/embracing-dignity-of-risk-in-the-transition-process/

Person-Centered Approaches to Supporting Dignity of Risk for People with Disabilities Webinar:

https://www.youtube.com/watch?v=Q7WQj3haejA