PERSON CENTERED APPROACHES TO HEALTH, WELFARE AND RISK

Objective: To balance "important to" and "important for" and ensure the appropriate information is included in a Person Centered Plan when addressing health, welfare and known or likely risk.

Ohio | Department of Developmental Disabilities

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Introduction

DODD has adopted the following person centered principles:

1. **Beginning with a comprehensive understanding of the person is essential.**

   A thorough knowledge about the person receiving services – their unique history and experiences, their likes and dislikes, their risks and concerns, their interests and culture, and their strengths, talents and goals – is essential to planning supports.

2. **Empowering informed choices increases independence.**

   Increasing opportunities for decision making in small everyday matters and life-defining matters encourages self-expression, self-determination, advocacy, and independence.

3. **Involving trusted supports increases opportunities for success.**

   Involving trusted supports such as close friends in service and support planning brings additional perspectives from those th at know the person best. These supports promote physical and emotional well-being, and can offer encouragement as an individual works toward their goals.

4. **Increased community membership enhances natural supports**.

   Expanding involvement in meaningful community activities and employment opportunities enhances a person's network of personal relationships, or natural supports. Part of everyday life/everyone's experience, these are individuals who see one another regularly, and look out for and help each other – such as coworkers, fellow volunteers, and members of your church.

5. **Ensuring plans and services are driven by the person is vital.**

   Developing a plan starts with the person receiving services – what is important to them and for them – and involves others chosen by that individual to aid in informed decision-making. The plan is coordinated by the individual's Service and Support Administrator (SSA). For adults, the individual receiving services functions as the leader of the team; for children, the parent functions as the lead er of the team and transitions that role to their child during the teen years, if not before.

These principles apply to all areas of planning and service delivery. By following these guiding principles, Service and Support Administrators will assess and address health, welfare and risk from the perspective of the person, their family, friends and community, and ensure that supports are in place to increase community membership and quality of life without compromising health and safety.

Background

Historically, Individual Service Plans (ISPs) have attempted to address health, welfare and risk by including language that references a "level of supervision" (i.e., "line of sight," "arm's length," "one-on-one" etc.). In reviewing plans and outcomes, we have discovered several concerns with this approach:

1. It does not appear to reflect a balance of what is important to the person and what is important for the person.
2. It is often applied broadly, and is not clear, specific and tied to an assessed need or identified risk.
3. It often relies exclusively on staff support and does not incorporate or utilize less "restrictive" measures or resources.
4. It is subjective and interpreted differently by SSAs, families, providers and others.
5. It tends to remain in plans, unchanged for years.

These "levels of supervision" are more simply described as supports. When supports are needed to ensure health and welfare or prevent or minimize risk, language in the person-centered plan should clearly and specifically indicate what supports are needed and why, identify when and for how long they are needed and under what circumstances. Staff support is not the only way to address health, welfare and risk. Plans may include technology, adaptations, and other supports and should balance what is important to a person to promote satisfaction and achievement of desired outcomes and what is important for the person to maintain health and welfare. It is in everyone's best interest to clearly know and understand what the support is, why it is needed, and what is expected of staff.

To that end, we have created this guide and other tools to assist teams as they assess health, welfare and risk and develop person-centered plans.

> "…the purpose of any risk assessment is just as much about the happiness of the person, their family and the community as it is about their safety."
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> – Neill, Allen, Woodhead, Reid, Irwin & Sanderson

Health and Welfare

"When done thoughtfully, person-centered planning creates a space of empowerment —a level playing field—that allows for consideration of personal preferences as well as health and safety needs, ***without unnecessarily restricting freedoms****. The best person-centered planning helps people to live better lives, with support to do the things most important to them."* – U.S. Department of Health & Human Services, Administration for Community Living

In developing person-centered plans, it is essential to balance "important to" and "important for." Important to is what really matters to the person and/or family, from their perspective. Important for is the help or support they need to stay healthy, safe and well. We are usually very good at describing and delivering what is important for someone - for example what medication the person needs, how they must be positioned, how to make sure they are clean. What is usually missing is what matters to the person, how they want their supports provided, and the balance between the two.

For example, a common "important for" consideration may be a restricted diet (i.e., low fat, low calorie, low sodium, no soda, etc.), but eating/drinking what you like is a common "important to." The team, led by the person, should have thoughtful and meaningful discussion around balancing important to and important for. In this example, the team may document the discussion and the individual's decision to go on eating what they like, even if that falls outside the restrictions. The documentation should reflect the person understood and/or was supported to understand the possible consequences of this choice and ways to mitigate any potential consequences as appropriate (i.e., weight gain, high cholesterol, etc.). Perhaps the person decides they will start exercising more to balance what is important to them with what is important for them, or, perhaps, like many adults, they decide simply to go on eating what they like. In situations where someone's health is significantly compromised by eating/drinking what they like, unrestricted eating/drinking would not reflect the balance we are seeking.

A word about informed choice…

The term informed choice refers to a person's knowledge of the consequence and responsibility of the decisions he/she is about to make. Historically, people with disabilities have not had experience in or opportunity to make a wealth of choices or decisions about their lives. When they have made decisions, and especially "mistakes", their choices are often immediately limited or restricted all together and/or other people begin making decisions for them. This may be particularly true for people who do not communicate in traditional ways. Therefore, people making choices may need support to more fully understand their responsibilities and the possible consequences when making choices. This is a key responsibility of the team, and should not be used to limit or eliminate choice, but rather to empower decision making through information and education.

Risk

There is no such thing as a risk-free life, and the goal of addressing risk is to find options that will keep the person and/or community safe as they navigate risks, not to eliminate risk all together. It is important to know and understand that everyone has a different tolerance for risk and interprets risk differently. Known and likely risks must be considered and addressed based on their potential for harm AND their potential for growth, freedom and improved quality of life.

It is also necessary to consider when the known or likely risk is real, and not to over-generalize from one area of the person's life to another. For example, Jane may be likely to give personal information to strangers when in public and has been exploited in the past – historically, we might see "level of supervision" in her plan that would be applied broadly and at all times. In reality, Jane does not answer the door or the phone when she is home alone, and does not need these supports unless she is in a place where there are strangers. Acting on risks that are not real can prevent a person from participating in activities that are the most meaningful to him/her and can best contribute to growth, freedom and quality of life.

Additionally, it is important to demonstrate what discussions have occurred and that there is agreement on what, if any, safeguards are needed to mitigate risks. Whether or not the team determines a safeguard or support is currently needed, the provider should be made aware of the known and likely risk(s). The team, led by the individual, should decide what risks are known or likely, under what circumstances/in what environment the risk exists, and how and when those risks will be mitigated and/or addressed. As the potential for harm increases, it is likely the support needs will also increase. The discussion should also include what to do if the potential risk is realized. For example, if someone has a known risk of running away, supports are put in place to mitigate this risk, and the person still runs away, what should the team do?

Finally, circumstances may arise in a person-centered planning discussion in which a team or family member may not support a person's expressed goals and priorities. They may feel that these decisions put the person at risk. The person and the team must seek to balance supporting the person and mitigating the risk – taking risks is a normal, life growth experience, with the obligation to keep the person and the community safe. The PCP process offers an opportunity for the person and the team to share their concerns and together develop solutions.

Example A: *Donna*

Donna does not wish to go out to eat and to a movie every Friday night with the other four housemates. Donna wants to stay home and eat a sandwich and watch her favorite Friday night TV shows.

Current Plan	Person-Centered Alternative
Option #1: Donna must go with everyone else because there was no funding for Donna to have 1:1 staffing if she stayed home alone. Since Donna does not want to do this, there are significant issues leading up to Friday and Donna now has behavior support strategies in her plan. **OR** Option #2: Donna has 1:1 staff on Friday nights *In reviewing the person-centered plan information, could someone unfamiliar with Donna or her situation know exactly why and how supports should be provided? Is the staff's role clearly defined? Are there any terms that should be better defined?*	**The team discovered that Donna** Can use the microwave safely—it is not certain that she can use the stove safely without staff supervision Can use the phone if number is available—cannot remember phone numbers Is able to answer the phone appropriately and safely should someone ask for staff or other housemates Does not give any information to people she does not know There are no behaviors that have occurred that would appear to put Donna in an unsafe situation to be home without staff during this period of time Has always evacuated appropriately during fire drills, each year at least one fire drill is conducted when she was home by herself *How the team balanced important to and important for:* *Donna will stay home alone on Friday nights.* **Support Considerations:** 1. Donna cannot use stove—she can use the microwave. 2. Donna will have the staff phone number or pager number to reach in case Donna feels she needs help. 3. A back up on-call number will also be available. 4. Donna is to leave all the doors closed and locked. 5. Donna may answer the phone should the phone ring. **Documentation:** Time left without staff 6:00 pm, Time staff returned: 8:57 pm *Observations:* Donna was in her room watching TV when staff returned. She indicated that she was ok. There was no visible evidence that Donna used the stove or had any problems while staff was out of the home.

Example B: *Amar*

Amar has a history of inappropriate interactions with children. He has been known to talk to children inappropriately or touch children inappropriately.

Current Plan	Person-Centered Alternative
Option #1: Amar must have 1:1 staffing at all times and cannot got to parks or other public places where children may be present. There can be no children in the home. **OR** Option #2: Amar requires line of sight supervision	**The team discovered that Amar** Was sexually abused as a child and did not learn how to relate to others appropriately Is currently going to counseling to learn about appropriate boundaries and having healthy relationships Loves playing basketball at the park and going for walks *How the team balanced important to and important for:* *Amar can go for walks and play basketball.* **Support Considerations:** 1. Anytime Amar leaves the apartment staff must follow him outside. 2. When children are present or could be present, staff are to remain at most 8 feet away from Amar to monitor the environment and ensure children and Amar are safe. 3. If Amar does become unsafe (describe in plan), staff should ask Amar to leave (follow behavior support strategies in plan). 4. Male staff should accompany Amar to community activities that are not within walking distance from home, so if Amar needs to use restroom they can be in the Men's bathroom with him; staff can wait in restroom outside of stall.
In reviewing the person-centered plan information, could someone unfamiliar with Amar or his situation know exactly why and how supports should be provided? Is the staff's role clearly defined? Are there any terms that should be better defined?	**Documentation:** Staff is to document Amar's reaction when children are present and any action staff was required to take while Amar is in the presence of children. If no issue occurs, this should be documented, as well.

Example C: *Regina*

During community activities, Regina tends to wander away from others in her group. She needs to be watched very closely, or she can disappear within seconds, especially when she is in stores or other areas where there are a lot of people. Regina loves to greet everyone she sees with hugs (especially strangers).

Current Plan	Person-Centered Alternative
Option #1: Regina needs 1:1 staffing **OR** Option #2: Eyes on at all times *In reviewing the person-centered plan information, could someone familiar with Regina or her situation know exactly why and how supports should be provided? Is the staff's role clearly defined? Are there any terms that should be better defined?*	**The team discovered that Regina** Likes to go for rides in the car, sight-seeing, getting a snack at a drive through, going to a friend's house Is very friendly and social and loves being around people Has little to no feelings of "stranger danger" *How the team balanced important to and important for:* *Regina can do all the things she enjoys with support when necessary.* **Support Considerations:** 1. When Regina is in the community, staff need to be able to see her and get to her quickly if she starts to wander. 2. When Regina is in the car or at a house with a fenced in yard, staff do not need to be able to see her. 3. Regina carries a cell-phone and the GPS is enabled. 4. Regina will learn "stranger danger" skills and street safety.

Example D: *Joe*

Joe has cerebral palsy and has a history of tripping and falling on uneven surfaces and/or unfamiliar terrain.

Current Plan	Person-Centered Alternative
Option #1: Joe needs arm's length supervision *In reviewing the person-centered plan information, could someone unfamiliar with Joe or his situation know exactly why and how supports should be provided? Is the staff's role clearly defined? Are there any terms that should be better defined?*	**The team discovered that Joe** Loves going new places Enjoys trying new things Quickly becomes familiar with places Has a cane and walker but does not like to use either *How the team balanced important to and important for:* *Joe can go anywhere he wants with supports when necessary.* **Support Considerations:** 1. When Joe is going somewhere for the first time or is on uneven or slippery surfaces, staff should be near enough to steady him if becomes unstable. 2. If the surface is dry and even and/or Joe is familiar with a place, staff should be available to help him if needed, but do not need to be right by his side. 3. Joe's cane or walker may be offered to him, but Joe may (and likely will) refuse to use them. **Documentation:** Staff should document where Joe went and who was with him, what the conditions were like, if support was needed, if cane/walker were offered and if there were any slips, trips or falls. If there were none, that should also be documented.

Example E: *Malia*

Malia is non-verbal and ambulatory in her w/c. She can transfer to and from her wheelchair/ chairs/bed with staff assistance. She has a history of falling.

Current Plan	Person-Centered Alternative
Option #1: Staff will remain with Malia in the bathroom and assist her as needed. *In reviewing the person-centered plan information, could someone unfamiliar with Malia or her situation know exactly why and how supports should be provided? Is the staff's role clearly defined? Are there any terms that should be better defined?*	**The team discovered that Malia** Likes her privacy Is able to hold onto the grab bar for support Can indicate when she is "done" by vocalizing Needs staff assistance for thorough hygiene Ambulates in her wheelchair by pedaling her feet *How the team balanced important to and important for:* At home and at work, Malia can be by herself when on the toilet. **Support Considerations:** 1. When Malia indicates she needs to use the restroom, staff will assist her to the restroom and from her w/c to the toilet. 2. Staff will talk with Malia about giving her privacy in the bathroom assuring her that they will be outside the bathroom so that she can call out/make a noise if she needs or wants help. 3. If Malia doesn't request help after 15 minutes, staff will knock on the door to make sure she is safe. If there is no reply, staff will knock a second time. If there is no response staff will knock and enter the bathroom to make sure Malia is safe. 4. Staff will immediately assist Malia if she falls. 5. In the community Malia would like to use a family bathroom when possible. 6. There must be a grab bar that she can functionally use near the toilet; otherwise she is agreeable to using the adapted stall in a ladies restroom. Staff will remain discreetly in the restroom until Malia indicates she needs assistance. **Documentation:** Staff should document if there were any slips, trips or falls. If there were none, that should also be documented.