

Community NOW!

Generating a Truly Person-Centered System

Recommendations:

1. Establish a quality **Person-Centered Planning** (PCP) process based on PCP best practice. PCP is the foundation upon which a meaningful support system is generated, and outcomes can be measurably achieved. PCP is a process that looks at an adult's whole life before any service planning takes place. In order to do PCP correctly, the entire planning processes, schedule, and mindset must be restructured. While an ICDD/Medicaid Work Group is planned to generate specifics about Idaho's PCP structure during fall/winter 2017, Community NOW! participants identified the following characteristics they expect that structure to accommodate:
 - a. The adult leads the process. No exceptions. "Leading" will look different for different people.
 - b. Each adult has the accommodations he or she needs to lead.
 - c. A PCP-trained specialist, of the adult's choosing, supports the adult to prepare to lead their meeting. Supports include the following: having discussion with the adult about the process and the adult's preferences before the meeting; identifying and preparing the people in the person's circle of support to meaningfully engage in the PCP process, helping to coordinate and facilitate the meeting, and documenting the discussion and results of the meeting.
 - d. The process focuses on identifying the adult's strengths, gifts, interests, dreams and life goals (including their desired employment) instead of listing their deficits or limitations. PCP focuses on leveraging an adult's strengths and abilities to achieve these goals.
 - e. The process features a dedicated and meaningful discussion of rights.
 - f. There are built-in opportunities for checking in on milestones to ensure that progress toward goals is happening with an understanding that some goals are ongoing.
 - g. Materials created as a result of the meeting are provided in accessible formats to help the adult share information and knowledge with people providing their support. There is an expectation that support staff will engage in this information sharing process.
 - h. The PCP process will include an opportunity to discuss the development of relationships within typical community settings, should the adult so choose.
 - i. PCP-specialists will ask the adult prior to the PCP if they would like to discuss ways and opportunities to have safe discussions about issues related to relationships during their PCP.

2. Use the **Individual Service Plan (ISP)** and **Support and Spending Plan (SSP)** to identify and document how supports (paid and unpaid) are used to achieve the life goals identified in the PCP. The ISP and SSP will feature the following characteristics:
 - a. The plan connects the life goals identified by the adult in the PCP process, including employment (and how employment may affect disability benefits).
 - b. The plan will identify both paid and unpaid supports that are relevant to the adult's goals. Care must be taken to ensure the paid supports don't drive the plan. Life goals, as outlined in the PCP, should drive the plan. This includes giving TSCs the flexibility to pursue opportunities, including activities outside of paid supports that may support a person's life goal.
 - c. Objectives within a plan tie to a goal in a way that is meaningful to the person. If the objective proves ineffective in achieving the goal, a new objective will take its place.
 - d. The plan provides evidence that the adult will have the opportunity to practice and share their identified strengths.
 - e. Limit skill building requirements to skills the adult wishes to obtain.
 - f. The plan and related information is provided to the adult in a way that is understandable to them. This includes providing access to the full list of available Medicaid waiver services to allow for fully-informed choice.
 - g. Make supports available to aid adults in pursuing academic and life-enhancing opportunities.
 - h. Risk is understood and addressed as a normal part of a person's life and learning experience. Limitations based on risk are narrowly defined and regularly reevaluated, with an understanding that people can learn and grow, impacting the scope of those limitations.
 - i. The PCP meeting includes a dedicated and meaningful discussion of rights.
 - j. Quality assurance is tied to the adult's personal goals. Focus is on determining that the services and supports are helping the person achieve what is important to them.

3. Establish an early and ongoing expectation and process to understand, develop, and support **the adult's most effective and preferred communication method(s)**. Attention to communication must start at the earliest possible age and be integrated and maintained within any planning, support, or service provided. Techniques include the following:
 - a. Provide adults the ability to try different methods of communication. Possible need for a different communication, including assistive technology, must be assessed. If a need exists, the ISP/SSP should reflect and address that need.
 - b. Recognize that all behavior is communication. Assist providers and those who work with adults to understand this fact and find ways to foster effective communication with the adults they support.

- c. Service provision should include paid staff time to review and understand the person's history and communication. Increase capacity for effective communication through training programs, quality assurance processes, and the development and sharing of family and adult expertise of the adult's story.
 - d. Assist providers in understanding the use of positive behavioral intervention strategies.
 - e. Make interpreter services a paid support available in any setting.
 - f. Coordinate a way for communication devices to follow the person from school into adulthood, even when the communication devices were paid for in the school setting.
4. Take a proactive role in creating and fostering a **culture where rights are known, understood, exercised, and respected**. This culture should include an emphasis on understanding and using supported decision-making processes to help adults make informed choices. Strategies include the following:
- a. Provide training on the rights of adults with I/DD to adults, advocates, guardians, educators, and providers. Highlight times of transition (moving from the children's DD program into the adult DD program, moving from another state, first signing up for DD services, etc.) and life changes (such as when someone initiates guardianship proceedings, when a guardian changes or dies, when an adult experiences significant changes in services, etc.). Rights training should specifically cover what exercising rights looks like in practice in a variety of possible settings.
 - b. Find ways for self-advocates to act as peer trainers regarding how to advocate for rights.
 - c. Make rights information more accessible (video, infographics, screen readers, etc.). Start the rights discussion within the PCP process, continue in the plan development process, and assess through quality assurance.
 - d. Ensure that adults know who to contact, and how, when rights are being violated (e.g. flow chart).
 - e. Establish a myth-busting process (like a hotline to DHW) where adults can ask questions about rules, rights, and restrictions, and report when they feel their rights are not being respected.
 - f. Provide comprehensive training for support staff on the rights of adults, and conduct quality assurance to measure understanding of those rights.
 - g. Develop a standardized process for adults to read, or be read, what staff write about them, making sure information is in accessible formats so that this right can be meaningfully exercised. Whenever possible, staff notes should be written collaboratively with the adult receiving services.
 - h. Develop ways to measure whether rights are being respected. Potential ways could include: asking adults with I/DD, measuring compliance with the HCBS rules, etc.

- 5. Emphasize and enforce HCBS rules** related to adults determining where they live, who they live with, and who provides their support. Specific strategies to meet the intent of these rules include the following:
- a. Develop standardized processes that involve adults and family members reviewing and selecting potential roommates, selecting living settings, and interviewing and selecting staff.
 - b. Require that adults and families are informed as soon as possible about upcoming staffing changes (when staff leave, when new staff are hired, and when temporary staff will be used).
 - c. Provide or require that adults and family members have access to the same orientation training as direct staff to aid in keeping staff accountable.
 - d. Make adults, and their guardians as appropriate, primary participants in the staff evaluation process.
 - e. Create a regional infrastructure to aid adults using self-direction in identifying and connecting with qualified providers who may be able to support additional people.