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CENTERING THE PERSON WITH PERSON-CENTERED PLANNING (PCP) IN ARIZONA'S DEVELOPMENTAL DISABILITY SERVICES

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Many state systems that provide services for people with disabilities are based on an old care/medical model that hinge on the belief that people with disabilities are going to remain dependent for the rest of their lives and will have limited options. This stigma does not give individuals the freedom they deserve. There have been many laws put in place to rectify this, but the stigma of disability dependence in our state disability systems remain. The proper use of Person-Centered Planning (PCP) can challenge these assumptions and give control back to the person who has a disability.

PCP involves a substantial shift in thinking from that which has long governed approaches to care. It puts the individual at the center of planning so that they have the freedom to make their own choices, instead of others making their choices for them.

The PCP process offers a way for others to learn about a person's choices and interests that define their idea of a good life. It also identifies the supports, both paid and unpaid, that are needed to achieve that life. It is not something you do to a person, nor is it something you do for a person; instead, it is directed by the person, with support from a facilitator as needed and desired. While this is the desired outcome, many agencies still struggle with how to do it. The formal definition below offers a way to approach this process using concrete principles.

PCP "refers to a group of approaches to organizing and guiding community change in alliance with people with disabilities and their families and friends." To qualify as a "Person-Centered" approach, it should include the following practices:

- **Get to know the interests and desires of the person with the disability, not just those of the family.**

The person should be at the center of the planning process. The person's desires should be heard, honored, valued, and reflected in the services received. People who are important in the person's life should be part of the planning process, but it is important to note that *family members' voices shouldn't drown out the voice of the person*. To the extent possible, the person's interests and choices should be honored and supported.

Some people with disabilities may use non-traditional methods of communication. These may include technology, manual signing, body language, and behavior patterns. Every disability is unique. With person-centered planning it doesn't matter what disability you have. Each plan is developed for that individual. To that end, if the individual is nonverbal, use any devices, equipment, or methods to amplify their voice as much as possible.

In person-centered planning, an individual who is non-verbal includes on their team members who know how to communicate with them using their preferred method of communication. This way the person can understand and truly be heard. PCP allows the plan to change over time to reflect the individual's changing interests and captures advances in technology that may better support the individual.

In the minority of cases, a trusted member of the team may need to make those choices for the person. To support PCP, it is critically important that the trusted member honor the desires and wishes of the person with a disability.

The [Arizona Technology Assistance Program \(Az-TAP\)](#) assists individuals with disabilities of all types and ages as well as family members, service providers, employers, and the general public to become better educated about the value and use of assistive technology and may have additional suggestions to support communication.

- **Assemble a team.**

The team is constructed of people who want to contribute their time and talents, because they care about the individual person and want to help the individual person achieve the results they desire. The team will help develop a comprehensive personal profile of the individual. The profile consists of the individual's gifts, talents, desires, and dreams, rather than their perceived barriers, such as their IQ. It should be noted as well that the individual is part of the team and helps determine who is on the team. Team members may change based on who would be best to support the person's life goals. For example, team members could include a neighbor, a shop owner, a swim coach, their best friend, etc....This team ultimately serve as the person's circle of support at that time of their life. Everybody (partnerships, collaborations, and support staff) must be fully invested in the process to achieve the goals developed through PCP.

- **The person should have access to an array of individualized services that meet their needs.**

The team should have full working knowledge of the support systems around the individual as plans are developed. These include both paid and unpaid supports they have, such as caregivers, medical professionals, financial support systems, assisted technology and social networks. The team should also know how each service works together to maximize the individual's outcome so they can help inform a well-suited PCP.

- **Ensure that the plan includes how a person can actively contribute to their community.**

People must be fully included in their communities and be treated with dignity and respect. Their opinions and their voices for how they would like to be included and how they would like to contribute should be heard. Accommodations and out-of-the-box thinking to support this value is encouraged.

BACKGROUND

PCP is the result of nearly 30 years of dialogue and investigation, starting in the US and Canada. Its origins can be traced to changes that took place in the early 1970s as part of a move to 'normalization,' or ordinary living, when institutions for disabled people began to close. PCP provides an atmosphere of unconditional positive regard while assisting individuals with disabilities to reach their dreams. It is the individual (and those who know him or her best) who exert control over the planning process.

The PCP approach emerged from the work of John O'Brien to rethink service effectiveness in terms of accomplishments (Galloway, 1978, O'Brien, Poole, and

Galloway, 1981). The five elements which make a significant difference to the lives of people with disabilities include community presence, choice, respect, competence, and community participation. Individual Service Design (ISD) is a method used in PCP that focuses a set of questions on an individual person rather than a group. ISD guides service workers to a deeper understanding of a person's experience. The most powerful idea underlying PCP is a person who needs services better understood, valued, and respected by those who deliver that service.

A young man who had cerebral palsy and used a wheelchair wanted to be part of his high school marching band. The school rented a special rack enabling the young man to play the drums, despite his disability and allowing him to be a valuable part of the band. The band competed for the 4-A state championship, and the young man was able to travel the whole state, enjoying the same experiences his peers did.

HOW CAN PERSON-CENTERED PLANNING BE USED IN ARIZONA?

Many agencies in Arizona would say that they are person-centered; however, to be fully person-centered the individual must maintain control in every aspect of their life. The person is not simply placed in pre-existing services and expected to adjust their goals based on what is available; rather, the team helps the person identify and coordinate both formal and informal services and supports to help them meet their personal goals.

In 2015 the [Graduation Cliff report](#) released survey data of Arizona high school special education students and families. The results showed that the involvement of Arizona governmental agencies had a negative predictive effect on parental expectations for their child. Regardless of the significance of the disability, with agency involvement, parents and guardians were less likely to think that their student could live away from home, graduate from college, or even get a job and support themselves. Additionally, interview data from state agency staff revealed that agencies tend to underestimate the person's abilities, and they have limited services that don't always meet the person's needs. These lowered

expectations in a formal disability services system with limited resources negatively impact the outlook of youth with disabilities.

True PCP is not limited by what the system provides. It requires out-of-the-box thinking. Person-centered approaches braid supports, resources, and services outside of the disability system with formal disability services. Goals are not limited by what the formal system provides.

ARIZONA'S DIVISION OF DEVELOPMENTAL DISABILITIES

The Arizona Division of Developmental Disabilities (DDD) has begun the process of requiring all employees to complete a course on PCP. While a step in the right direction, it is unclear how effective the training will be, especially if it is centered around completing the current DDD form. The current [DDD Person-Centered Plan](#) is 29 pages long. There is no plain language or condensed version available for members. It is recommended that DDD:

- Split the current form into two parts - a functional needs assessment needed by DDD staff and a person-centered plan needed by individuals and families.
- Make the person-centered plan in plain language, or in a format that is easily understood by the member. Examples are included on the next page.
- Include information around the member's hopes and dreams and design it to use positive statements and avoid deficit language.
- DDD should consider investing in Life Course: <https://www.lifecoursetools.com/> It's simple, comprehensive, member-focused, and easy to understand.
- DDD should also consider conducting an organizational assessment. The National Association of State Directors of Developmental Disabilities Services (NASDDS) [Self-Assessment Tool](#) is a good tool to use for assessing the person-centered practices in an organization. The Self-Assessment is divided into eight sections, each of which must be addressed to achieve full person-centered thinking within the organization.

Recently, in Arizona there has been a push to create legislation entitled [Supported Decision-Making](#). Supported Decision-Making is an alternative to guardianship that is totally focused on the person making their own decisions, surrounded by a support system of his or her choosing. Many states have similar legislation. The legislation contains the key principles of building a team to support PCP to help individuals make their own life decisions.

CONCLUSION

Too many times, individuals, families, and state agencies believe that a person's life choices are dictated by what the system can provide – but that can be considered agency-centered planning. PCP seeks to flip that perception on its head, allowing people with disabilities to make their own choices and decisions. The planning process looks at what's possible using

resources from both inside and outside the disability services system, allowing individuals to flourish. It's time we think out of the box on how we approach care planning. A true Person-Centered Plan can help us get there.

The Story of Wilf

(Excerpt from <https://www.preparingforadulthood.org.uk/downloads/independent-living/wilfs-story.htm>)

Wilf is 18 years old. He attends college three days a week and volunteers at Spitalfields City Farm once a week.

Wilf and his family are talking about him continuing his education, getting a job, and leaving home to share a home with friends in the future. Much the same discussion is being had with his 17-year-old brother; except Wilf is autistic, has significant learning disabilities and severe communication problems. Wilf and his family decided to try person centered planning to accomplish these plans.

The first step was having a Person-Centered Planning Meeting with most of the involved parties and turning vague plans into specific goals. Wilf enjoyed the meeting and was engaged for longer than usual because he enjoyed hearing positive things about himself and he understood the basic plan about mapping out his life. Next a comprehensive Support Plan was written. This details Wilf's support needs, his likes, and dislikes, and how he is assisted to make decisions and his aspirations for the future. It has doubled up as a useful reference tool for careers when considering how to best guide Wilf's.

Wilf now has a personal budget for his social care needs and is building up a trusted team of helpers to support him to go out without his mother, and to stay at home without his parents for increasing amounts of time. The aim is that this team will support Wilf to go away for weekends soon and to live in the community when he leaves home.

Wilf's volunteer work is being well-received by the colleges that are being approached about animal care courses for next September. A job coach will start working with Wilf soon and a work profile is being created. Housing options are being considered and a housing need profile is being made. Wilf's friend's families are being approached about possible house sharing and arranging joint social activities.

Wilf is positive about being a young man, working on a farm and leaving home in the future.

His previous plan was to be retired!

Individuals and families can build their own PCP. Following are additional resources on how they can do so:

Young Individuals from the state of Oregon

<https://www.factorogon.org/person-centered-profiles>

Provides a plan as well as how to facilitate the plan (starting on page 5).

https://ccids.umaine.edu/wp-content/uploads/sites/26/2020/11/STEM_Module-section_5-20201123.pdf

ADDITIONAL PERSON-CENTERED PLANNING INFORMATION

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