

Person Centered Planning in a Time of Crisis

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Program Website: www.cjapnj.org

Main Website: www.arcnj.org

Jessica: **What is person centered planning?**

Carol: *Person-centered planning is a couple of things:*

- *Set of values & intentions (a way of 'being') – for example: a deep value of person-centered planning is that all people are born with gifts, capacity and purpose in life. The intention that supports the value is to look for and help create opportunities for these to emerge and evolve for the person and for the benefit of our communities.*
- *Set of methodologies, tools, practices (a way of 'doing')- there are structured processes designed as a container to hold important information about the person across an array of areas in life. There is no standardized 'one size fits all' way to practice person-centered planning. That's why it is "person" centered... we customize the way we work with each person, taking our lead from them.*

There are processes, which are usually called maps, that help a person share their dream for the future so we can help them move in that direction. The process, regardless of the map template you might or might not use, is a process of exploration and discovery. For example, I developed a process called A Framework for Planning that when completed, offers a positive profile of the person based on their attributes, interests, values and ideals, and points to how these gifts and interests can support the person to make contributions to the community in ways that are meaningful to the person and to the community.

At its heart, person-centered planning is about getting to know a person and their family/close allies by listening deeply to them and learning from them. Then acting on what we have heard and learned – by taking direction from them. Above all else, it is about engaging in authentic relationships with people – it is not about working on or working for a person, but working with – in balanced partnerships.

Jessica: **How does that look?**

Carol: Because every person is unique, the planning process looks different for everyone. Deciding if or when or how to select and use a process will depend on why we are doing planning in the first place. Sometimes, it's as simple as having a deep conversation using active and reflective listening. Other times it might be a scheduled session with invited participants and maps on the wall to gather information. It depends.

The 'end game' is about ensuring the person has been given the power and authority to direct their own life – how that happens very much depends on individual circumstances. A side note: person-centered planning has become an embedded part of the disability service delivery system- and as systems do, it has become less of what we are talking about here (individualized, customized, self-directed..) and more standardized. Standardized approaches by their very nature, are not person-centered. This has been a point of confusion, and even contention, in the field.

- *There are common elements for being and doing work that is person-centered – with or without the use of a tool. These include (but are not limited to):*
 - The assumption that the person (their family and selected allies) know themselves the best and as such, are the primary authority of what they want and need in order to enjoy a life most of us would agree is pretty good;
 - Looking for what a person wants more of in terms of the quality of their life. It is strengths-based – focusing on what is right with the person (rather than trying to fix a perceived deficit);
 - There is a presumption of competence and capacity and potential;
 - Ensuring dignity and respect of the person
 - Identifies what good support needs to look like- the ways that maximize their potential for full involvement and contribution and minimizes/eliminates the barriers that prohibit this
 - Active engagement and support in all aspects of decision-making that affect the person's life – big decisions, small decisions and everything in between

Jessica: **How do we continue to do person centered planning in a time of crisis such as this pandemic? How do we keep from abandoning this process in the face of difficulty?**

Carol: When you think about the amount of concentrated effort it takes to enter into and sustain the kind of relationship we have just been talking about, you can imagine how easy it is to slip away from an empowering approach to one we are more accustomed to: taking full control of the situation.

Of course there are lots of reasons we revert to systematic, institutionalized behavior – a crisis calls for immediate action. We may feel we need to protect people who are vulnerable from harm. We feel compelled or are commanded to ensure health and safety in the most efficient way possible.

We have a knee-jerk reaction rather than taking a moment to consider including the person in figuring out a shared response. We mean well, but of course, there is a collateral damage to our good intentions. We inadvertently strip people of their rights and power and we break our promise to be person-centered.

This creates an integrity gap: a split between what we say we are committed to do (be person-centered) and how we actually behave (command and control)

- *One way to keep from abandoning our commitment to be person-centered is to remember we are working in partnership with people. Being intentional about “minding the gap.” Under the circumstances, this is where the proof lies in the pudding.*

Keeping in mind person-centered practice is both a “being” and a “doing.” Crisis disrupts the normal pattern of everyday life – in situations like COVID-19, life as we knew it will likely never return to the way it was. We don’t know what the next ‘normal’ will look like. This is a prime time to work with people to co-create the future we will both be living in during and beyond this pandemic. My greatest fear is that we are back sliding – losing the momentum of “people first” and community integration. It is critical that we use this time to think about how to move FORWARD. How to remove the structures that keep people with disabilities segregated and marginalized from mainstream community life. Isn’t this the BEST time to recognize that going back to day programs that shelter people are dangerous to people’s health and safety and look for new ways to support people?

Jessica: **How does PCP have a place during the crisis? Do you have suggestions or thoughts about how practically to ensure this practice is used?**

Carol: *We need to recognize our urge to take control over people's lives while we wait and wish for things to return to go back to the way they used to be. We need to operationalize a discipline for person-centered ways:*

- *Establish sustainable relational partnerships with people*
- *Ensure people understand what is going on so they can work with us to decide how to navigate the crisis in ways that are best for them from their perspective*
 - *A fabulous resource can be found on the Green Mountain Self-Advocacy website (www.gmsavt.org). First of all, this Vermont self-advocacy group has it going on – their website is full of ideas because they are actively involved in really important advocacy issues. One of the things they have available to people is “A Self-Advocates Guide to COVID-19. It is a downloadable toolkit that covers critical issues impacting people's lives. This alone would be a great way to engage people in planning their response to handling the virus – and how they can be direct their own support. Do yourself a favor and check it out.*
- *Negotiate hard rules together to find a balance that works for both of us*
- *Take advantage of this experience to deepen relationships by getting to know the person better. For example, I have a workbook I wrote called “The Soul of Person-Centered Planning.” It asks people to use it as a tool to explore and discover what matters to a person and what their gifts are in relation to the head, hands and heart. Exploring interests, talents, positive traits, values and identities gives us insight into what can be...*

Jessica: For example, how can people participate in the community? Is there a way to do this?

Carol: I really think so. When we seek to discover and understand a person from the inside-out, it gets easier to imagine how they and their gifts can contribute to community life in ways that are good for most everyone. Let's imagine that we have gotten to know a person – I'll call her Jessica – by watching, listening and sharing in different activities and experiences. We are discovering that for Jessica these things are emerging as important interests

Head	Hand	Heart
<i>Reading</i>	<i>Puzzles</i>	<i>Connecting</i>
<i>Puzzles</i>	<i>Drawing</i>	<i>Caring</i>
<i>Movies</i>	<i>Cooking</i>	<i>Giving</i>
<i>Planning</i>	<i>Gardening</i>	<i>Compassion</i>
<i>Collecting</i>	<i>Painting</i>	<i>Serving</i>
<i>Writing</i>	<i>Knitting</i>	<i>Spiritual Praise</i>

What happens when we begin to see these interests as gifts Jessica has to offer? At the same time, we can begin to see what we can do – even in isolation – that can support her interests AND her ability to make contributions to/in community.

For example: organize a neighborhood food pantry drive – make or draw written invitations to participate and put these in mailboxes on the street.

Gather clay pots, paint them and plant seeds. When they sprout set up a table out front and invite people to take them. Include some inspirational quote

Make blankets and caps for newborns and donate them to local hospitals. Or nursing homes.

Start a 'community' garden in the front yard.

Host a virtual talent show with friends

Raise money for charity – collect works of art and host a virtual art auction

Start a class together to teach self-advocacy skills to others via Zoom

Any one of these ideas could literally take up full days and quite possibly be billable services!

Jessica: **Finally, here in NJ, we have a policy in place now that a person with a disability can have someone accompany them into a hospital-is there a way that PCP can be ensured in a hospital setting? Is there anything the accompanying person should know or be cognizant of?**

Carol: *I recently attended an excellent 1 hour webinar hosted by TASH. It was called “Tools for Supporting People when Familiar Supports Aren’t Available. I believe it is available as an archive on the TASH website: www.TASH.org I highly recommend watching it.*

There were some really great and practical suggestions for making sure that the person’s voice was heard – even when they are not able to use traditional ways of communicating.

- Develop a **one page profile** (adapted for specific contexts, such as going to the hospital or orienting new staff to supporting them) For instance, a one page profile prepared in the event the person must be hospitalized can include bulleted information about the person’s positive qualities, preferences in food, television programs, personal care rituals, how people communicate with them, etc.) as well as medical basics (medications, allergies, positioning requirements, etc.) and what helps the person to feel safe and supported.
- Develop a **communication dictionary** using pictures, words, or both of frequently used terms, directions, items that will facilitate clear expression of wants and needs to someone by pointing to the word/picture.
- Create **transition books** that put the person in the story that is unfolding to prepare them for upcoming transitions – to prepare them for what to expect and how they can navigate the change
- Use **video conferencing** to include others who know, care and support the person have input into their treatment

- Use technologies like, iMovies, Noteability to deepen use of tools like iPads. Research “Talk to Me Technologies” that are out there as assistive communications applications

Of course, all of these ideas are great for any time, but especially important now. Don't wait until they are needed. Work with the person now to design their personalized support-folio! There has never been a time to put person-centered promises into practice!

Thank you for the opportunity to talk about a subject near and dear to my heart!

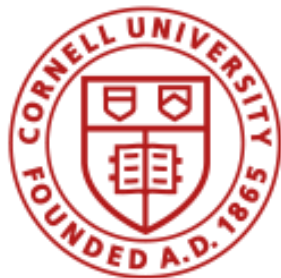
Contact Carol for more information on person-centered planning or her landmark work in Citizen-Centered Leadership (www.cclds.org)

Carol Blessing, MSW
Senior Extension Associate

cjb39@cornell.edu
518.265.3759 (cell)
www.yti.cornell.edu

K. Lisa Yang and Hock E. Tan
Institute on Employment and Disability

ILR School, Cornell University



“Isn't it always the first rumble that starts the avalanche? Let us be disrupters and agents of change and bring true meaning to diversity in the work force.” K. Lisa Yang
ILR '74

