Bonus Q&A
NCAPPS Webinar from July 9, 2020

*"Person-Centered Planning and the Pandemic:
Tools and Approaches for COVID-19 and Beyond"*

Q1: I am interested in learning how this process has been helpful and applied with people of color (in particular Latinos - non-English Speakers)?

Jenny: The LifeCourse Nexus has found, through working with our partners, that peer support in facilitation of a person centered planning conversation has been most successful. We have worked with organization who use the promatora model – as well as other family leaders – to build the capacity of their peer mentors in guiding individuals and families in the use of the Charting the LifeCourse (CtLC) tools for reflection and discussion, planning and problem solving. In general, these have been "informal" conversations that are guided by the *principles* of the CtLC framework in the types of questions that have been asked. The tools are sometimes used to capture notes or information. The intention of these sessions (and, it usually is over several sessions that this type of reflection and planning is done) is to prepare individuals and families for the more "formal" planning conversations with schools, LTSS system, etc.

Q2: Where can I find the blank form of the triangle example?

Amye: There is no form – but I have printed off a triangle before when doing this activity with a group at an agency.   If I am doing it on my own at home, I just draw my own triangle. Here is a link to a sample triangle:
https://printableparadise.com/shapes/triangle-shape.pdf

"Q3: I am a WRAP facilitator and have been one for 6 years. I've never seen/heard of the feelings pyramid. Where did you learn that?"

Amye: Here is the link to the Feelings Pyramid - https://mentalhealthrecovery.com/info-center/feelings-pyramid/

"Q4: "What do we do when people we support can't have access to the relationships and environment that make them feel safe, given the social distancing measures and in case of being admitted to hospital?"

Janis: As it relates to critical relationships when an individual with a disability is hospitalized, I am not sure how this looks across the country in individual states, but I do know that the Office of Civil Rights has ruled in favor of people with disabilities and protected their right to have "essential support persons" accompany them in the hospital

should they be admitted with COVID-19. This is required as a reasonable accommodation to ensure that people with disabilities have equal access to care and are able to adequately comprehend information and communicate effectively with their hospital care team. In the states I am familiar with the person with a disability is able to designate two support persons, but only one is allowed to physically be present at a time. This article (https://www.hhs.gov/about/news/2020/06/09/ocr-resolves-complaints-after-state-connecticut-private-hospital-safeguard-rights-persons.html) provides specific information re: OCR's ruling here in Connecticut and I would encourage the individual to carefully explore the status of this issue in their own state.

Jenny: Creative problem solving is really critical as we identify person centered and individual solutions to these types of challenges. All of us are grappling with the loss of some control (or perceived control) as a result of this pandemic and the health and safety measures that are required/recommended. It is important to – as much as possible – identify what about those relationships or environments foster a sense of safety. Are there elements or aspects that can be "recreated" in another way – whether through technology, alternative activities, etc. The CtLC Integrated Support Star could be a good tool for identifying what is available to help someone feel safe and happy. Engaging the person in this problem solving may also "give back" the sense of control that many of us feel we have lost. "Pre-planning" and identifying a "what will I do if…" solutions, which could include developing a vision of/defining what will make me feel "safe" and/or "happy" (using the CtLC Trajectory), as well as identifying the supports that **are/will be** available (using the CtLC Integrated Support Star) may help someone to feel more in control when their choices and options are limited.

> Q5: "How do you support someone in person-centered planning when you really feel their decision/choice is not wise?"

Jenny: It is important to understand a person's vision and their "why" for making that choice – what is important to them and what is their vision of a good life, and how does this decision/choice take them towards that vision? Having all team members do a CtLC trajectory can be helpful for letting each person voice their perspective – including their fears/concerns. This can then be used to facilitate conversation that finds common ground, including identifying/communicating the potential risks, and allowing the person to make a truly informed choice by understanding the potential impact of their decision for themselves and others. As we all exist within the context of family and community, communicating with the person how their choices may affect others – including fear/worry – may support a conversation of how to develop strategies that will support the person to make their choice, but to consider their reciprocal roles/relationships with their family, friends, and community.

Janis: I'm not sure if this was a question specific to the experience of COVID and others may have weighed in on this. But if it is helpful, we have written about this tension in our paper, The top ten concerns about person-centered care planning in mental health systems   (Tondora et al., 2012) – see Concern #1 on page 417. This offers a different way of thinking about balancing risk with autonomy. For me, the most

critical thing to keep in mind on this topic is that choice is mediated by each individual's unique cost/benefit analysis. And a person's cost-benefit analysis may look very different from a professional's analysis based on what matters most to them in their lives. For example, a person may make a choice to re-enter the workforce even though prior attempts to do so may have triggered stress and an increase in symptoms associated with a psychiatric disability. From the doctor's perspective, decisions are often made with a primary goal of reducing or eliminating symptoms. Thus, people living with the experience of mental illness are sometimes discouraged by professionals from pursuing employment out of a concern it is not a "wise" or the "best" choice for them. But from the person's perspective, the increased stress or symptoms may be worth it to get back to that valued role of "worker" or "provider" for one's family, i.e., they may be willing to tolerate/manage the "cost" of increased symptoms because those are outweighed by the "benefits" of a renewed sense of self-agency, productivity and pride in a valued role. At the end of the day, unless there are imminent safety issues involved or emergency circumstances, the "best" and only choice is really the one that respects the individual's own personal cost-benefit analysis.

Q6: "How would you use the tools at a day program for adults with disabilities?"

Jenny: There are many ways that the Charting the LifeCourse (CtLC) tools can be used at a day program – both for organizational/programmatic planning, as well as for individual planning, problem-solving, and decision making. Please check out the LifeCourse Nexus webpage and/or our Facebook page: Charting the LifeCourse in Action for examples and ideas from our network of providers who have implemented the framework and tools in their programs and organizations.

Q7: "My experience is no person-centered planning is occurring. Policy is designed to meet the worst case scenario at the expense of less at risk residents like my family member. How is this accomplished? Who can reach the decision makers?"

Jenny: The National Community of Practice for Supporting Families is working with 21 states across the country to identify policy, practice, and authority changes at the state system level that will enhance person- and family-centered policies and practices. Through collaborative efforts with the Developmental Disability Councils and the I/DD Agencies in each of those states, teams are working to identify, influence, and impact state level system change to better support individuals and their families.

Resources shared

NCAPPS COVID-19 Resources page: https://ncapps.acl.gov/covid-19-resources.html

NCAPPS Shorts #PandemicWisdom: https://ncapps.acl.gov/ncapps-shorts.html

LifeCourse Nexus: https://www.lifecoursetools.com/

Support Development Associates: https://www.sdaus.com/

Racial Equity Tools: https://www.racialequitytools.org/home

4 plus 1 questions: http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/4-plus-1-questions/

Coming Out of Quarantine Safety Plan by Pat Deegan: https://www.commongroundprogram.com/offers/Z2nkahzE/checkout

AID in PA: https://aidinpa.org/

Box Breathing: https://quietkit.com/box-breathing/#:~:text=Here%20are%20the%20directions%20%3A%201%20Inhale%20for,4%20seconds%20%28as%20the%20circle%20is%20contracted%29%20

Your Roadmap and Guide Back into the Community for Self-Advocates: https://www.myodp.org/pluginfile.php/339338/mod_book/chapter/215/Individual%20Transition%20Guide%20%281%29.pdf