



NCAPPS

National Center on Advancing
Person-Centered Practices and Systems

Webinar Transcript: “It’s up to us, what kind of life we want to live:” Promoting Meaningful Person-Centered Practices in Home and Community-Based Service Delivery

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SPEAKERS

Bevin Croft, Bathey Fong, Hector Manuel Ramirez, Lindsay DuBois, Reveca Torres, Tonie Sadler

Bevin Croft 00:00

Hello everyone. Welcome. Bevin Croft here, I co-direct the National Center on Advancing Person-Centered Practices and Systems or NCAPPS. I'll do a brief visual description to start. I am a white woman, I have long blonde hair with bangs, I am in a room with pink walls and some fairly brightly colored art, and it is very rainy outside the windows behind me. I'm pleased to welcome you all to our September webinar. Titled: "it's up to us what kind of life we want to live, promoting meaningful Person-Centered practices in home and community-based service delivery." This webinar topic is at the core of everything that we do at NCAPPS. And it also happens to be at the core of what our colleagues do, who have partnered with us on this webinar at the Shirley Ryan AbilityLab, where they operate the home and community-based services, rehabilitation research and training center. This is one of the NCAPPS webinars where we feature research findings alongside lived experience perspectives to bring to life key issues in person centered practices. You'll be hearing today about, and you'll be receiving lots of wisdom and lots of resources.

Bevin Croft 01:57

And before we get started, I also would like to call your attention to a few NCAPPS resources that you may find useful in your own work as you take these practices home with you. One is the Five Competencies for Person-Centered Planning Facilitation that we've developed. And also, the Person-Centered Practices Self-Assessment. These are two resources that were developed through NCAPPS technical assistance, and Saska will put the links to those resources into chat. You also may be interested in a series of short videos that we are proud to feature on our website that take up issues of culture and Person-Centered practices and the many ways that person-centered practices must reflect and honor the unique cultural identities of people who use services. So, with that, we will move to the next slide.

Bevin Croft 03:16

For those of you who are not familiar with NCAPPS, we are thankful to be funded by the Administration for Community Living and the Centers for Medicare and Medicaid Services. And we are administered by the Human Services Research Institute or HSRI. And we are excited to be joined by Lindsay DuBois



and her team at the Shirley Ryan ability lab. Next slide please. And NCAPP's overarching goal is to promote systems change that makes person centered principles not just an aspiration, that are reality in the lives of everyone who, who may use services or supports at any age. So, it's a broad topic, but we seek to provide specific and actionable tools to support this work. Next slide please.

Bevin Croft 04:31

This is a webinar format. So, you are all muted during the webinar. But please do and many of you are already doing this. Use chat to say hello to communicate, to ask questions to raise ideas. If you would like to chat with the whole group of us and there are several 100 on this afternoon or morning depending on where you are, be sure that you select everyone in the panel just next to the chat box. We may not have much time for Q&A in this webinar because we have so many wonderful panelists, but we will do our best to respond to questions in chat and to provide written responses to questions that we don't get to. This webinar is being live caption in English and there are live interpretation services available in Spanish Sashka will place instructions in to chat and I will also read them separate a accent there Hola, interpreter Seon in espanol en vivo siendo click and tone interpretation in la parte de inferiore de la pantalla de zoom, a Canada Mundo one of us canal Espanol por for celeb Za, I audio or Regina. And we have just a couple of polls in this webinar, one in a moment and one at the end. And we would appreciate your interaction. Next slide please. You are always welcome to reach out to us at NCAPPS at HSRI dot ORG (NCAPPS@hsri.org). We are all busy facilitating this webinar. So won't respond to emails during the webinar. But we will certainly respond after and as always, the recording the PDF version of the slides and a plain language summary will be available on our website and ncapps.acl.gov in a few weeks. Next slide please.

Bevin Croft 06:56

Okay, let's find out who is here. I can tell from chat that people are here from all across the country. But we'd like to know in what roles you self-identify and identify, and you may select all that apply here. So, in the poll that has come up for you, please identify how you please identify for us what perspective you're representing a person with a disability or someone who uses long term services and supports a family member or a loved one, self-advocate or advocate, peer specialist or peer mentor, social worker, counselor or care manager, a researcher, analyst, provider, organization employee, or government employee, or I should say and or. And always there are identities that are not represented in these in this list. So please, please share your identity in chat. It's always wonderful to know who's with us today. I will leave the poll open for another five seconds or so and then we'll close it out.

Bevin Croft 08:25

Okay, responses still coming in.

Bevin Croft 08:29

All right, great participation, everybody. Thank you. You can go ahead and close the poll now and show the results. Great, I am seeing that about 40% of you identify as social workers, counselors, or care



managers. And we have a good number of folks spread across the other categories as well. And I'm sure many of you have multiple identities. And thank you for all of the additional descriptions you're providing in chat. Thank you. It's great to know who's here. Next slide, please.

Bevin Croft 09:19

All right, it's time to meet our speakers. A little later. This hour. You will hear from Bathey Fong. Bathey is a self-advocate living in Hawaii who has a learning disability and cerebral palsy. She is a college student who's very active in her community and is the president of the self-advocacy program for her Developmental Disabilities Council, and she works on emergency preparedness for people with disabilities. Later you will also hear from Hector Manuel Ramirez, who is an Titicaca, Apache, and Mexican autistic person who is hard of hearing and has a psychiatric disability. Hector does local, state, and federal level policy work in the areas of equity and disparities and is on the board of directors with Disability Rights California and the National Disability Rights Network. Reveca Torres is an artist filmmaker and disability advocate after being paralyzed in a car accident as a teenager, Reveca started a nonprofit called backbones after realizing that years of interaction and friendship with others living with spinal injuries made a significant impact on her own life. We have two researchers here today who you'll hear from. To start, you will hear from Tonie Sadler, who is a postdoctoral fellow in health services and outcomes research at Northwestern University and the Center for rehabilitation Outcomes Research at Shirley Ryan Ability lab. Her research focuses on disability health services and policies that affect people with disabilities and their families throughout the life course. And to start to begin with I will pass things over to Lindsey DuBois who is the project manager for the Rehabilitation and Research Training Center on home and community-based services outcomes, research, and measurement. Lindsay has more than 10 years of experience in disability research and her emphasis is on monitoring and evaluation of health inequities for people with disabilities. So, with that, I will turn things over to our partner Lindsey Dubois to share out about her work.

Lindsay DuBois 11:45

Thank you so much for the introductions, Bevin. My name is Lindsay DuBois. I am a white woman in my mid-30s. I wear glasses, I have shoulder length, blond hair, I am wearing a pastel pink shirt. My background is blurred. But you'll see sort of blurry pictures and drawings behind me. And my pronouns are she her. So, we are really delighted today to be here and to speak with you about promoting meaningful person-centered practices in home and community-based service delivery, we can move to our next slide.

Lindsay DuBois 12:27

And actually, we'll go one more straight to the agenda. Thank you. So today, my colleague, Tonie Sadler, and I will go over some of the research we have been doing on a person-centered home and community-based services. We'll start with some background, then describe our project goals, our project methods, some preliminary results, and then this will lead us into our panel discussion. You could go to the next slide, please.



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Lindsay DuBois 13:03

So, the center for rehabilitation outcomes research is at the Shirley Ryan Ability Lab in Chicago, Illinois. And we're conducting this work, and we just started the third year of our grant. The funding for this project comes from the National Institute on Disability, Independent Living and Rehabilitation Research. Next slide, please.

Lindsay DuBois 13:31

So, we know that many folks on this webinar are probably quite familiar with home and community-based services. But I always like to start with that 10,000-foot view of what are HCBS what are the scope of HCBS, so HCBS are health related and social services that assist people with disabilities and older adults and living independently in the community. So HCBS can provide supports for employment, transportation, home care or home health supports for activities of daily living, personal care, financial or budgeting support, and assistive technology or home modifications to name a few.

Lindsay DuBois 14:18

HCBS are most often paid for by health insurance and Medicaid is the main payer of HCBS. And in 2018, there were more than 4.7 million people in the United States receiving Medicaid funded HCBS. There are also sometimes very long waiting lists for HCBS depending on what state you live in, or you know what, what group of people you might represent. The other important thing to know about HCBS is that each state has a slightly different or sometimes very different system. So as part of sort of state flexibility around Medicaid and HCBS. States can choose which populations to offer, which types of HCBS to offer, through the use of Medicaid waivers. And then many states, you know, cover HCBS for people with intellectual and developmental disabilities, and those with physical disabilities. Other states might also offer HCBS to people with serious mental illness. And then there are some other groups that might receive services on waivers as well. But every state looks a little different. So, if I can go to the next slide, and talk a little bit more about the workforce, since quite a bit of our work is focused on this aspect of HCBS.

Lindsay DuBois 15:46

So, I mentioned that almost 5 million people use Medicaid funded HCBS. So, to meet that, you know, pretty significant need, there is a really large workforce of woman community-based service providers. And there's a lot of different types of providers. So, you know, HCBS are provided by individuals or sometimes groups of providers in an organization. And then there's many different types with sort of different specialties, different jobs, sometimes they serve different individuals or different populations. So the figure on this slide is kind of intended to think about the workforce as kind of a system. So you have the HCBS user at the center of the system. And the next level of the system are the different providers who deliver direct supports. So those are folks who interact with people using HCBS on a regular, often daily basis. So, this would include direct care workers, sometimes behavioral specialists, or recovery, recovery aides, sometimes PTs, OTs, it really depends on the person and the services,



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they're receiving another important group in this direct support our family members, they are an essential backbone of the HCBS. System. And one of the reasons that that HCBS tends to be quite successful and sometimes more affordable, is because of those informal supports. Some, some states do have options to pay family members, for supports. However, many family members are not paid. And that's probably another topic for another day. And then the next level that we kind of have categorized and use to think about supports is that outer level or the indirect supports level. In this level, you have the workers who may not interact with people who use services as regularly. But they are still really vital to making sure that we have the service system, we need to meet the needs of users. And so, examples here would be you know, caseworkers or care managers, the supervisors have direct support professionals, state coordinators, and others. So, when taken as a whole, you know, when we think about the workforce as a whole, there's really a tremendous number of people supporting individuals who use HCBS. And kind of thinking about the different roles that they have, we can go to the next slide.

Lindsay DuBois 18:24

The other important thing I wanted to mention about the HCBS workforce is something that comes up a lot. And it's the crisis in kind of recruiting new quality providers, retaining sufficient numbers of providers to meet the needs of the population. And of course, COVID-19 really amplified this crisis further. So this slide has some data from HSRI's Staff Stability Survey, which showed that in 2020, there was an average turnover rate of 43%. There's also some data here from PhD national, showing that in the last 10 or so years, there was a significant increase in direct care jobs added as a result of people aging, and that the boomer generation aging, and then when we look forward to the next 10 or so years, they're estimating that demand will continue to increase. And then as a result of those high rates of turnover, there would be an estimated 7.9 million openings in direct care over the next 10 or so years. So, this is kind of staggering. And the reason that this matters so much is because these high rates of turnover, the high rates of vacancy, it really contributes in a in a major way to people not getting Person Centered supports.

Lindsay DuBois 19:48

On the next slide, I wanted to just highlight the person-centered federal requirements from the HCBS final settings rule, because this is another influence for you know, whether or not people are receiving Person Centered supports the CMS passed this regulation in 2014. And the compliance for this rule goes into effect next year. And the rule requires a few things. But the ones I wanted to highlight are, are two things the requirement that every state ensures that HCBS meets minimum standards for integration, access to community life, choice, and autonomy. And that's going to be really important to our discussion later. And then the second thing is that every person who uses HCBS should have a person-centered plan.

Lindsay DuBois 20:39

So, the final piece of background information I wanted to cover is on our next slide. And this is some data from the National Core Indicators, and the National Core Indicators, aging, and disability. And it's



showing us a little bit about what we know about the outcomes of people who use HCBS right now. And so, from this data, we see that 91% of people will say that their services and supports are helping them to have a good life. And 89% say that their staff have the right training to meet their needs. So that's quite promising. But where we see room for improvement is in how well services meet all the needs and goals, currently for users. So that's only about 72%. And this is where we feel like Person Centered supports can be a really wonderful solution. If we do it, right. So, the project that we're leading, if we can go to the next slide, is focused on figuring out those key ingredients or competencies that are needed to have an HCBS workforce that's really skilled in delivering Person Centered supports.

Lindsay DuBois 21:52

So, to do this, we have interviewed about 20 people who either deliver, oversee, or are involved in payments for HCBS and 20. People who use HCBS. And we're looking to get their opinions on the skills that are needed, you know, examples of times they've gotten those Person Centered supports and times where they haven't, so that we can really kind of package that with other best practices that we know about. And after we complete analysis of the interviews, we'll have a framework of those key ingredients or competencies. And we'll be able to do some case studies with HCBS provider organizations that are doing a really great job of delivering Person Centered supports. So that's kind of the objective and the next steps for our work. And I will hand it off to Tonie now to talk more about the methods and the results.

Tonie Sadler 22:52

Thank you so much, Lindsay. And thank you everyone for being on today. Before I start, I'll just give a little visual description of myself. I'm a white female in my 30s I have medium length, brown hair, I have a black cardigan on, and I have a necklace that's supposed to somehow balance my mind and body. But we'll see how that works. So, I'm gonna kind of take off from where Lindsey started and talk more about what we're finding and what we're hearing from folks who are, you know, at the ground level, implementing and receiving home and community-based services. So, I'll start broadly with just our sample. And I just want to emphasize to before I kind of go through some of the early findings, these are early findings, we're actually still in the process of interviewing, and the fight. The findings that I'll be presenting today are from about 40. Recipients of HCBS, as well as providers of HCBS. So, we've sought to have a diversity in our sample in terms of disability, race, ethnicity, HCBS services provided and geographical representation. We started interviews with convenience and purposive sampling methods. Based on nominations from multiple partners that we've worked with, as well as advisory boards, participant Council, we also have a participant Council of folks with disabilities. And then from there we've also incorporated snowball sampling techniques to recruit folks that provide an experience or receive or use home and community-based services. And we've also put an emphasis on talking to folks that, you know, have been recognized in their excellence in, in providing services. So that is another focus that we've, or something that we focused on. So next slide, please.



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Tonie Sadler 25:23

Okay, so, like I said, so we have demographic information for about 27 participants, but I'll be presenting qualitative data from about 36 participants, but I'll reiterate that. So currently, for our statistical demographics, we have 12 providers and 15 users, most of the participants are female, we do have five male participants and three non-binary participants. And then the average age of providers is 49, an average age of users is 44. Okay, next slide, please.

Tonie Sadler 26:08

So, most of our participants are white. But we are continuing to seek out diverse participants for this, these interviews, we do have representation of Asian African American, American Indian and Latina X participants as well, both on the HCBS user and each CBS provider side how, and then just to know also, we are actually targeting some of our future recruitment efforts to make sure where, where we don't have good representation that we are finding folks that that we can talk to, that can help fill those gaps. So next slide.

Tonie Sadler 26:57

Okay, so in terms of disability, for folks that receive home and community-based services, currently, we have folks that have a mental health related disability, intellectual, developmental disability, or physical disability, or are both or multiple disabilities sorry. Currently, we are also targeting interviews for folks with age related disabilities as well. Okay, next slide, please. And then in terms of our providers, I just want to note that the providers represent multiple levels of providers. So, folks at the state level, who are, you know, coordinating services for their state. Also, managed care organizations are also represented in this group, but the vast majority are folks that are either directly providing services or like or organize organizational leaders, like the director of day service programs, something like that. And over 90% of our providers are I have over five years of experience. And then we have quite a few with much more than that. So, it's been really interesting to talk to folks about the evolution of person-centered planning and practices and how things have changed over time as well. All right, next slide, please.

Tonie Sadler 28:42

Okay, so, again, today, I'm just going to talk about some of the early findings. And I'm not going to talk too much, because we would like to most of the time to be devoted to our panel. And we can also answer you know, specific questions about the research we're conducting either, you know, via email, or if we do have time for questions at the end. But today, I'll be focusing most of the early findings on competencies of Person-Centered practices and HCBS. So NCAPPS has been very helpful and generous in, you know, helping us start our research with a framework. And so today in terms of what we'll be talking about our participants and interview respondents' experiences with choice and control and dignity of risk. And if we have time, I'll also touch on some organization and training considerations. And then I will talk a little bit about COVID-19 as well and how that has impacted person centered planning. and practices.



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Tonie Sadler 30:02

Okay, next slide, please. Okay, so this slide, I think, kind of helps, at least me think about what, you know, these interviews were trying to get on. And, you know, we have a lot of understanding about person centered policies, we know about the final setting rule. There are a lot of resources for Person centered planning and person-centered training out there. We've actually done some systematic reviews on those types of things. But one kind of gap that we've seen is, is how are these person-centered practices being implemented? And then is that does that implementation then led to outcomes, in terms of Person-Centered Outcomes, quality outcomes, so I just want to emphasize the interviews, we're really trying to get at how individuals experience services at the ground level. And talk a little bit about some of you know, possibly the barriers and facilitators associated with providing good person-centered planning and practices. Okay, next slide, please.

Tonie Sadler 31:21

Okay, so, on this slide, there are a lot of words, but I am going to talk you through this, in touch on the key elements that we think are important to highlight. So here is a chart that displays facilitators of choice and control and barriers to achieving choice and control based on our early findings from interviews, and we have this split up between provider perceptions, and percent recipient or users of HCBS perceptions. So, first facilitators of choice and control from a provider, or state leader perspective often focused a lot on administrative and structural elements, including, you know, are we doing enough in staff training, are we auditing and documenting Person-Centered practices so we can improve on them, and also, interest in interventions such as, you know, harm reduction when, when discussing things like dignity of risk, or motivational interviewing. So, at the provider level, a lot of the facilitators that were identified for choice and control, were kind of at the organizational level, and included, you know, structurally how to implement and achieve those goals. On the contrary from, you know, users of HCBS folks that utilize these services, we had a very different perspective of what you know, facilitators of choice and control are, and from perspectives of those who receive these services. facilitators of choice and control office often focused on distinguishing between meaningful and significant choice and control for more performative forms of choice and control. And one element includes choice and control of, you know, choosing and hiring staff. That was that was something that was identified as very important to move multiple folks when it came to goal setting and planning meetings. Some people who have received HCBS desired more of a leadership role, rather than just kind of being a part of that process or helping facilitate but really leading that process. And then another topic that was brought up by people who received services were transparency of goals, and transparency of the planning around so really having a collaborative effort with organizations to plan out their goals in their lives, but also having transparency of how organizations are keeping that information, being able to contribute and change those documents. That was also another important thing. Some people stated that they did not have access to their plans and notes and, and that definitely was a barrier. Another important facilitator to choice and control, was not just choice and control over, you know, activities and goals and things you do in the day, but the time that you do them and how you do them, so being able to have flexibility to cancel things, and to change your schedule



and to do the things that you want to do when you want to do them. So that was also something that was very much emphasized by people who receive services. And then when it came to barriers of choice and control, there were several overlapping themes from both providers and people who receive services. As Lindsay mentioned, the workforce crisis. And, you know, high turnover rates of direct support workers was mentioned in virtually every interview that we talked about, often unprompted. So, this is, you know, I think a lot of folks here today will resonate with this, that it's a very serious issue. And I know that there, there's a lot of work being done right now to try to amend some of these challenges. But when you have such an unstable workforce, folks that receive services have noted that your choices really become constraint, one with who provide services to you, but also the types of supports that are available to them. So that really constrains choice and control. Another comments or barrier to achieving choice and control were choices that were constrained by the environment or the organization itself. And by the environment, that could mean something as macro as you know, folks who were in a lived in a rural environment might have a much smaller choice architecture than those who you know, hadn't had more access or choices within an urban environments. And then that could also mean, you know, choices within an organization. You know, in the types of services that they provide, there might not be a lot of choice within the constraints of the services being provided. And then recipients of HCBS also just discussed quality of services, and how, you know, services that may have lacked quality or from their perspective, really was a barrier for their choice and control in their lives. Okay, next slide, please.

Tonie Sadler 37:55

Okay, so I went over just a lot of content overviewing, how providers and recipients of HCBS perceive some of the barriers and facilitators to choice and control. But I just wanted to provide a few quick examples. I don't want to go too deep into this, because we have folks here that, that will be able to speak to some of these things as well. But in terms of organizational or bureaucratic barriers, we had one individual state that sometimes services make me feel trapped. Another person stated services are a barrier to facilitating rights and choice and control. And obviously this, you know, dependent on the person being interviewed and the types of services you know, they were receiving at the time, but sometimes the constraints within the service provision, often limited their choice and control in their actual daily lived lives. In terms of choice and control over time, when asked what does choice and control mean to you, one respondent stated being able to decide what time I get to what time I want to get out of bed in the morning, if I want to take a shower, not what food I want to eat time I want to go out. So, really an emphasis on time. And that was brought up several times. And then in terms of distinguishing between meaningful choice and not just choices, kind of performance. One end of Joel said, you know, I don't get to make choices, but I have input into choices that are available. So that was definitely, you know, a theme that was brought up among folks that receive services that you know, even if they're there are choices, are they meaningful to me Is it what I really want? Or is it just what's available. And then finally, in terms of leadership, one individual exclaimed my choice my way. And then to paraphrase, these are my goals, but I need your help to accomplish them. So those are just some examples to kind of touch on some of the things that I discussed in the, in the previous slide.



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Tonie Sadler 40:27

Okay, can I go on to the next slide, please. And actually, I'm going to skip forward to the next slide. Great.

Tonie Sadler 40:38

So, I just didn't want to miss out on a little bit of a discussion on COVID-19. So, you know, in our interviews, we definitely leave space to talk about COVID-19. This is not an afterthought, this is very much integrated into, you know, the conversations that we have with folks and, and also just how we're going to move forward and research and policy in addressing some of these challenges. So, some of the themes that stood out when discussing COVID-19, and person-centered planning and practices were hiring and retention. Also, you know, in person, versus virtual. So, in terms of hiring and retention, most of the organizations, my probably all the organizations that we talked to talk to noticed a pretty significant drop in in either losing employees or difficult difficulty finding them. And this was already, you know, a problem that that they were facing. And then in terms of in person versus virtual folks that were, you know, just transitioning from in person services to virtual we've we heard a lot of success stories of, you know, organizations really just, you know, not skipping a beat and really doing everything they can to meet, you know, their clients. But we also heard the flip side where were folks that were receiving services really felt left behind, or, or services completely stopped. And then I just want to also mention, we heard a lot of wonderful stories about, you know, resiliency and charity, and just creative ways of trying to get through this crisis together. And so, I'm actually going to end this portion of the presentation, we just wanted to share some of our initial findings. Nevada, who works with us is going to put some links in the chat so you can learn more about some of the work. But now I want to focus on our panelists today. And hopefully facilitate a wonderful conversation with them about their experiences, receiving home and community-based services, but also just, you know, their life experiences focused on things like choice and control. So, I will hand it back off to Lindsay to kind of start that conversation off.

Lindsay DuBois 43:21

Thank you, Tonie. So, if we could have Bathey, and Hector and Reveca turn their cameras on. Thank you. And if we could have you all introduce yourselves. Can we start with Hector, please?

Hector Manuel Ramirez 43:47

Yes, thank you very much for having me here today. My name is Hector Manuel Ramirez. I am Titicaca, Apache and Mexican. My pronouns are they them. I am coming to you today from the unceded lands, the San Gabriel Lineo band of Mission Indians, Los Angeles. A visual description for my background, I'm using a background that shows a wheat field of flowers with the sun setting and a corner logo for the California Memorial Project, which is a project that we have in California, that commemorates the number of people that have died in State Hospital and developmental centers, because they couldn't live in the communities. And so, this is an event we have once a year. I have a red t shirt with the United Farmworkers logo. I'm always an advocate on my clothes has a cause and I am 47 years old, and my hair is pulled back in a ponytail. Thank you.



Lindsay DuBois 44:57

Thank you, Hector. Reveca, can you please introduce yourself?

Reveca Torres 45:03

Thank you for having me. My name is Reveca Torres. I am a Mexican American woman with brown skin, brown shoulder length hair. Today I'm wearing a teal sweater and I'm in my office with black cabinets behind me. I am also a person with a disability from a spinal cord injury at the cervical level and I have used a power wheelchair and HCBS services for a very, very long time. So, thank you for having me.

Lindsay DuBois 45:40

Thank you. And last but not least Bathey.

Bathey Fong 45:45

Hello, everyone. Can everybody hear me? Yes, I am Bathey Fong, I am a person with a disability. I have a learning disability and also physical disability; I use a walker and also a wheelchair and I live in a foster home. So, I live in a group home here in Hawaii. And also, I am a college student. And I also participate in a lot of thing in a community here in Hawaii. And I'm our emergency partners with people with disability, and also a DD council member. And I'm a staff president for the self-advocacy program with people with disability, and also a TEC impact trainer for people with disability. And today I'm wearing an Aloha shirt. In my background, I'm in the living room. Thank you for inviting me.

Lindsay DuBois 47:01

Thank you. So, for our first question. We wanted to hear from each of you directly about sort of the fundamental question of our work, which is what do Person Centered supports mean to people who use HCBS? So, if we could hear from Buffy and then actor and then Reveca, I will hand it off to you guys.

Bathey Fong 47:29

Can you actually put it in another way? So, I can understand what is the question please? Thank you.

Lindsay DuBois 47:36

Absolutely. So, researchers might think that they know what person-centered supports are, or, you know, people who deliver services might know what person-centered supports are through training. But sometimes people who use services might have a different idea of what that means. So, we think it's important to hear from as many people who use services as we can about what they think Person Centered supports are.



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Bathey Fong 48:07

So, person-centered services to me. Actually, in the beginning, it didn't work for me really well. Because I actually didn't really have a voice for myself, I let other people have a voice for me. So, I didn't make a lot of choices for myself before. So, it's a really challenging for me to have a voice in a lot of things before because people will make a lot of choices. And it was a very difficult thing to have a life that I want. But now I like you know a lot of things that has been changing since before. Now I can make choices now. Things that I want in life but it's also very easy now for me to have choices that I want, and people will support me, but I will make the choices on my own. And, and it's very hard for me to figure out what I want in my life and what is a good life for me, but it's it says it's a very challenge thing to do all the time.

Lindsay DuBois 50:05

Thank you, Bathey, I appreciated hearing you talk about kind of the journey. And Person-Centered supports is, is constantly there. And there are times where it comes more naturally in times where it doesn't. Thank you for sharing your experience. Can we hear from Hector?

Hector Manuel Ramirez 50:25

Thank you, Person Center, you know, nothing about us without us. Let's just start off with that, you know, I come from a State Hospital Developmental Center. And I remember being there. And all of our choices and decisions were made by other people, when we had to get up, when we ate, where we went, everything literally was made for us. And when I came out of this State Developmental Center, it was pretty interesting to know, first of all, that there were a lot of choices that could be made. I was still underage. But then as I became of age, I had the opportunity to make every single choice that I wanted, without having to ask for somebody's permission, or having it to get approved or having to do a form. And then when it came to getting services, it wasn't that. So, I think that's what I wanted. I just, I see me, and then the services that I need or want around me. That's what I think of person centered. Everything about me with me. You know, it seems like such a radical thing for some people. But that's what most people do every day. And that's kind of what I think of it and for this particular conversation.

Lindsay DuBois 51:53

Thank you. And that Hector, if I could throw just a little bit about some conversations, I know you and I have had about making Person Centered supports more culturally appropriate and inclusive, and even the term person centered and, and things like that. So, I don't know, if you want to take a little time to speak to that now as well.

Hector Manuel Ramirez 52:13

No, I think... thank you, for allowing me to go into this further. You know, as a native person, you know, when it was interesting coming into this, with this kind of new ability to make choices. And as a native person, I was always really encouraged, like to be independent, live independently, move away from my family, like a lot of my peers was ever getting older. And it really seemed like that's what person-



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centered was because that's what we had told me that it was. And you know, so I wanted to really follow along in this journey. But I think for me, I realized that person-centered really meant community and family, my family, first of all, being able to go back to my family was a big thing. And in our family and our community, we make our decisions based on each other, and we share with each other. So, I think, for me, it's been a journey of kind of realizing what that is for us not having a choice than having all the choices that people told me. And then actually like, realizing what my choices were. So, for me, like a lot of my personal center services are really based around my family and my community, because I lived on my own for, I think two years. That's, as long as I've ever lived on my own. It was an I moved away from my family to be independent, like I was supposed to. But that was really hard. It was really, really hard, actually very depressing to be away from my family. And I think, for me, the thing that helped me, for me, was really kind of looking to see how person-centered really was like in a collective community, where my family, I am fortunate that my family and my culture are supportive, and to the degree that they can, and that I'm able to really be in that space independently. I have my own place. But I'm with my family. And I think that's another way, you know how Person Centered was a little bit different. There's kind of like the Western idea what person-centered is. And then all of us based on our family culture or ethnic culture, you know, sometimes, you know, that definition, you know, is different from mine is historical. You know, we are collective communities, even people with disabilities, we have roles in my tribe. So that that came into play later on as I really, really had to really think about the different types of person centered. And do you have that choice to?

Lindsay DuBois 54:49

Thank you. I thought that that was a lot of really important points that you touched on and how it can be very different to different people, which is why we're really grateful to hear from you all and to people to talk to so many different folks in the community and hear those different perspectives. So, Reveca, can I ask you to share kind of your perspective then on what person-centered supports are?

Reveca Torres 55:12

Yeah, I really appreciate what both Bathey and don't have mentioned already. And this idea of community and like, we're talking about, you know, person centered care in our communities, and there's so much interdependence that happens in the life of someone with a disability, because we do depend on a lot of people to help us be, you know, productive or functional or independent in our lives. To me, be having person centered care, is me being in control of what happens with my life, whether that is directing my care in the morning, when someone is helping me get in and out of bed or bathing or getting dressed, it means that I get a say on what my care plan looks like, with my case managers. It means I have discussions with my family of like, what, how I need them to support me or how I need them to back off when I need them to. So, it, like Hector said nothing about us without us. And I think it can easily be lost, where, you know, there are these systems with so many layers of things that need to happen for our lives to be, can look at the quality of life that we want, and it can easily be lost, where like, where we are the center of that, and we are being able to direct that.



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Lindsay DuBois 56:52

Absolutely. Thank you for sharing, Reveca. And you touched on this a little bit in your response. So, we'll move to the next question we have, which is kind of thinking more about this emphasis on equity that we're seeing across a lot of different systems, and in particular, the HCBS long- and long-term services and support system. And so that the emphasis on what do we know about outcomes for people from different communities. And we know that the disability community is just incredibly diverse. There are a lot of intersecting identities that people hold. And so, you know, person centered supports does mean a lot of different things. But person-centered supports is also an opportunity to drive the conversations and the actions around equity. So, I wanted to ask first Hector, if you would touch on kind of how you think person-centered supports can be driving conversations and actions around equity for people who use HCBS?

Hector Manuel Ramirez 58:01

Well, definitely, you know, you look at the people that receive the services. And I mean, just look at the times, we're still in COVID times, it's not we don't get a pandemic hasn't ended. And we know, for example, that since the pandemic started, we have seen that individuals living in congregate settings had the worst health outcomes during this epidemic, you know, and if there was ever further truth, that people with disabilities are safer when they live independently, or supported in their homes, rather than in congregate settings, that we live longer. It's so sad, in our family, you know, when COVID had, you know, we had a lot of first responders and we also had a lot of people with disabilities and their families and the overall casualty that we saw in our family, we lost seven of our people, or disabled people, and, you know, they all did not really survive, because they were, they were in congregate settings, where, you know, they couldn't get the services that they wanted, that they needed, when they needed them. And then, you know, it just kind of really kind of shows, you know, some of the inequities that are very much in the system already. And then you add, for example, some of the really, kind of build biases that are built into the systems, you know, to really make it more difficult for people of color to get community services that are appropriate, what we want and save. You know, it's who we're letting into our home, who we're letting into our families, not just having to worry about whether or not we're going to be saved from COVID but whether or not we might be safe, you know, from of who they are, or with the type of services that they have. I'll share, you know, besides from getting services for myself, my brother also has services. And I spoke to him in the past tense because he was one of the people that pass, and he was a long-term aids survivor, living in his home place, and, you know, we couldn't find anybody to help him. And we got services at home because we had to bring him home. And some of the stuff that we would get was just not appropriate. It wasn't safe. As a Two Spirit person gave persons himself, it was hard. You know, one occasion when we got one, one particular, you know, worker who came from a faith background, which was very homophobic, towards my brother, and you know, in his time of need, in anybody's times of need for just services, which should not be another thing to have to battle at home. And when we talk about equity, we talked about availability of services in the community. And that really sometimes having the option of choosing who's going to come into your door. And that's a very vulnerable situation, specifically, when you have people that really depend on services, and that's what equity really has kind of highlighted this whole ecosystem, the significant failures as someone's like, it's a punishment for people that want to live independently, you know, and they're supposed to



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have services, but if they get those services, oftentimes, they're not the appropriate ones. And this is where we live, you know, it's, it's, it's almost like, I don't want to put us out, but it's almost like you're bringing sometimes an enemy inside. And so, it feels so scary, sometimes. And it's not something that should happen at home, or anywhere when people are getting services. Did that make sense?

Lindsay DuBois 1:01:57

Yeah, I think, you know, the points you made around, we've suspected the inequities for a long time. And COVID-19 in particular, really put a spotlight on data, showing that those inequities were just incredibly pervasive and really baked into the system. And so, you know, going from here, using that data to really think through how systems can better serve all people and how different approaches are needed to serve different people. And I think you touched on quite a bit of that Ecuador. So, if I could ask Reveca to kind of respond to the same question about, you know, how you think Person Centered supports, can drive these conversations that are happening at that national level? Around, you know, how should we address equity and these issues?

Reveca Torres 1:02:54

Well, like I mentioned earlier, I have been receiving services for a long time for over like 25 years, I was injured as a teenager. And it isn't until, you know, this year or last year that I have heard us giving input on how this should be. And someone in the chat earlier said, you know, we there's data collected about who makes these decisions and their race but is there data about how many people with disabilities had a voice in creating and shaping these services on these programs that are for us. And I think that is a big indicator of like, how much our voice is missing from this. And it's important to have these conversations, it's important to start collecting data to come call out when it's not working when the system isn't working, and we need to call it out. And we need to try and find solutions because there is a lot of fear. As I mentioned, there's just fear not even like in the day to day, moments where you know, you may be in a situation that's dangerous and you're fearing that you know that you're not getting the right care or that you're in danger. But there's also I've experienced fear and speaking up about some of these things because maybe I might lose my services or if I say something like it shouldn't be that way. We should feel safe in being able to talk about these things and being able to help our community and help those who are our allies and who are in those like in the in the positions of being like a case manager or manager or something like that. Or are the ones that make these decisions to just be aware of like, what exactly are the needs of the community so that the right choices can be made, and the right decisions can be made?

Lindsay DuBois 1:05:12

Absolutely. And I think the points that you and Hector and Reveca both touched on in terms of fear of losing services is something that we did hear across the board. And I think that's really important for the system to address. There's both, you know, what is the reality? But what is the perception, and those two things are both important when thinking about equitable solutions to ensure people have equitable access to services. So Bathey, is there anything that you would add to the comments that Hector and Reveca shared in terms of how person-centered supports can drive these conversations.



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Bathey Fong 1:05:53

I really agree because every state is very different. So, where I live, first and center, work here in Hawaii, it. For me, it's, I look with other people with disability, it works for other people, for other people with disability, but it won't work for other people with disability, because when I'm here in Hawaii, when we have like, well, we want services from the case manager, and they look at some of our disability, they said, oh, you don't have a disability. So, you don't, you know, you cannot receive services. But for, for me, I still kind of learning that everybody needs to have services. But it's when we cannot have services, that we always have to find a way to make our life very, happier. And to find things that we can do. If we don't qualify for services with what the case manager one is to have in our life. So, it's, I cannot see it every day. I'm here where I lived. So, the services, some of the people with disability, they have a hard time speaking up for themselves. And we also, even though we have a disability, people will always have to support one another to have a voice.

Lindsay DuBois 1:07:57

Yeah, that, Oh, Hector, please.

Hector Manuel Ramirez 1:08:01

And I think I really want to think about it for uplifting that we have to really sometimes advocate for our own. And I think for me, one of the reasons that my family is important is because they backed me up and in those circumstances. Because, you know, I know what that is like to have services canceled or the retaliation for speaking up, and not really knowing where to go to speak up and having things done. It's something that we see. I mean, California where we have like lots of funding. We have like the leading disability agency in the country. But we still have cases like this on a, like a regular basis. You know, I think right now, for example, one of our leading advocates, National Disability Advocates, you know, Alice Wong, who just has been elevating so much work for the disabled community, she's nationally recognized. And a couple of months ago, she had to go into the hospital. And because her disability needs are, are higher for her, you know, and there was no services. And I mean, she's like an advocate. And the only choice that they gave her, she has her home and family, she just needed support. And she's even more support is like, here you have somebody who's nationally recognized and the only choice that she was given is to move into a boarding care facility or long-term care facility, because there was nothing for her to home. And this is California 2022. And I is like, and our community had to kind of rally and steel rallying, you know, to kind of like help, you know, here you have the leading disability rights advocate, and we all having to like advocate to help her sons like this. And I think that's just really kind of highlights the best the biggest state with the most resources, and you have this example of just how the system is really blindsided if sorry for the term but blindsided too. really the impact and the needs that our community has, and how there's really very little, if any place for our folks to go get help in a safe way. Because we're not at the table. It's nothing about its everything about us without us right now.



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Lindsay DuBois 1:10:16

Yeah, I hear all of you touching on the sort of constant advocacy, both individually, collectively as a community. And that's a constant presence. And I can imagine that that may sometimes feel like a burden as well to kind of have to repeat your needs constantly and feel like I should I be having to ask for this a lot, and certainly quite a bit of room for improvement in the system to make sure that that's not such a constant presence there. So, I kind of want to move to the next question, which is to think a little bit more about person centered planning, is one of the things that we heard from folks is, you know, that person centered plans, even though you know, they might be designed really well. And they might be really person centered, sometimes they are actually a barrier. It's just one more barrier to people having the life they want. So, I wondered if each of you could speak a little bit about how your services and your providers have, you know, supported your rights, and ensure that you have choice and control with your services, not just about those big things specified in your service plan, but even on that day-to-day basis. So, if we could start with Reveca, and if you could answer that for our whole audience.

Reveca Torres 1:11:39

Yeah, I have had some really great caseworkers over the years, and then some not so great. And they're, you know, they're there. Sometimes you see them more often. And sometimes it's just once a year when they come in, and they say, like, I'm here to do a reassessment. And, you know, it's, it feels like checking off boxes, and, you know, wanting to know, all of the very intimate details of your life that can sometimes seem very, very invasive. And then they go away, and they make a plan. And they say, these are how many hours you have, and you don't know how they got to that amount of hours that you need or are allowed to get services in your home.

Reveca Torres 1:12:31

So yeah, I think that

Reveca Torres 1:12:36

I've had, like I said, I've had some really good care workers or case managers that have really helped me, you know, get the right amount of care the name that I need in my home. And but yeah, I think sometimes what's what can be lacking is like, kind of knowing what what's next or, or somebody mentioned earlier, like, where's my care plan where you don't see it for many, many months? People, you know, and you're not really sure what's going on? And I think that oftentimes, you know, it's the caseworkers might have just a lot of cases that they might not get to you and but it's still like, I don't know, sometimes it feels like that shouldn't be an excuse, like, we need to be seen as like whole people and having all the information about our care and like, and what needs, what needs to happen for us to get the appropriate care. I'm not sure if that answers your question, but yes, absolutely.

Lindsay DuBois 1:13:34

And I know that Bathey, it looks like you're, you're prepared to share your perspective.



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Bathey Fong 1:13:41

Yeah, I think I have the same because over the years, it's been crazy in my life, because you know, I've been actually changing case manager some more, we're not supported some more supported the things that I want in life and even the homes that I've been living in some were not somewhere it but I learned during the years of to have a good life is to find the right people to support you, in your in, in my life. And I like the services that I have now, even though I have little bit services. But you know, one thing that I learned the past few years is like my provider, and my case manager and my circle support, get to hear how I feel in my life and to help what kind of good life that I want for my own. So, it really helps me to like to have a good services that I want in my life. So, it's, it's, it's for me, I have to be thankful that all the servers that I have now it's been working for me because it made my life happier than before.

Lindsay DuBois 1:15:39

Yeah, thank you for sharing, Bathey, it's great to hear that they're, you know, from what you're sharing it sounds like they're working really well for you now, but there was a lot of work on your part to, you know, get the person centered supports you needs. Thank you for sharing that extra work. And I asked you to kind of share your perspective about how services and providers have supported your rights and ensured you have choice and control and maybe some examples of that.

Hector Manuel Ramirez 1:16:07

Well, yeah, actually, the best staff that I've had, she was so good that she gets fired for it. Because she taught me how to advocate for my person-centered choices. I wanted to go home to my family community, and everybody really, in their best interest, they wanted to keep me independently out in the community. And I wanted something different. And people felt that I was going backwards. I don't know, that's really what it felt like. And this particular staff, I think, for me, was helpful because she really kind of helped me understand not only what, how things could be, not how they should be. And so like, she kind of like, move the curtain so that I could see how things worked. And that was when I really had a better understanding of, you know, how I what I needed to do to try to get the things that I needed. And so, I realized that, you know, she explained to me my rights, which was like, wow, okay, thank you, that was like, really, really good. And she explained to me, I've tried many, many questions, and how to how to really enforce those things. That, to me has been like one of my biggest kind of services, because I used to be very non-confrontational, and we just go along, and now I'm more willing to really speak up, and not worry about the tone that I'm using, you know, because I'm why we're doing it. But then I also understand, understood that, you know, sometimes just following a chain of command doesn't always work. And I thought, that's how it worked. And sometimes you have to do kind of systemic work, or systemic adversity advocacy to get the things that we need and infer that she lost her job. Because I wouldn't, I wouldn't stop advocating, you know, for that, after that. She was a great woodworker and had really, really fantastic folks. And some that I was really glad to go away. You know, I mentioned the experience with my brother, but I think at home, you know, I had two other because I never get to, I've never get to choose who comes in. And I had two cases where we had to



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return individual separate individuals with different faith backgrounds, then they would come into my home and one of them was from a Catholic place and in for a family, there's generational trauma with the Catholic Church and survivor as well. And that was a very difficult thing because she thought that it was appropriate for her like to pray for us or things like that. And my me and my family were very uncomfortable with that. That was one example. Similarly with another one. You know, I think it's really has come back to individuals that necessarily that don't know how to do the basic job, but how they do it, the cultural context of it. You know, it's like, we all like to eat right? We all like hamburgers. We all like different types of hamburger. And we go to different places for them for a reason. And I think, you know, that that's one simple way of kind of explaining sometimes, you know, you want you want to, I don't know, like a McDonald's hamburger and somebody wants you to go eat, you know, Burger King, and that's all they haven't, but you want. I don't eat fast, but I shouldn't say that. But you know, just trying to kind of make it kind of put it in those terms. Let's make sense. Nancy, they said correctly. Yeah.

Lindsay DuBois 1:19:48

Thank you. And I think that was a great example. But obviously not the outcome that you want when someone does a great job of supporting the rights and ensuring that people who use services have choice and control and then they lose their job over it. So, so I hope she was able to be she, I think you said she was able to continue working, but maybe for an organization that had some of those values, because those are exactly the types of people that that we need more of in, in this space so we can continue to improve services. So, for our final four minutes here, of the panel, I wanted us to do a thought experiment where we sort of imagine what it could be. And you'd kind of started to talk about this XR when you said, you know, not what it should be or what it's supposed to be, but what it could be. And I think that's an incredibly important kind of thing to think through. You know, there's a lot of things that probably could be changed to make the system better reflect Person Centered supports. But I'd be curious to hear from each of you, you know, what, what you would change? So, Hector, can I ask you to share first what you would change?

Hector Manuel Ramirez 1:21:05

Thank you, I think, definitely. Well, I think what we're doing right now it's picking up, it's one of the things of having more opportunities for people to be heard, to be understood, to be validated and recognized for their experiences. And but I think, like I've known that this systemic change goes from the top down, and I think really gathering data that is centered, you know, by the people that use the services, in a, with an equitable lens to have diverse representation is important. Because it comes down from the top down, you know, really having regulations and guidelines in place, that are very well developed, develop by the people that utilize the services. And I appreciate, I really do appreciate our policy folks and our researchers, I really, really do. But I think, you know, really centering the work that they're doing around, you know, the beneficiaries from Parkland, having them be part of the design, having them that had significant input into those regulations to how it's being implemented down. Having us along with the process is very important. And I think, recognizing the significant impact of not only having, like, first sources, which is what we are, you know, you gather the data from ours, you go



write it, and then you tell us what you write about later. Like, it's a different type of approach. So really having, you know, the beneficiaries included, seek intentionally, you know, with a purpose from the top down is very important, you know, so we can improve the services, we don't need to go back to that horrible normal that we had before. The pandemic has taught us so much. It's, we owe it to all the people that we've lost, and I think continue to lose to really try to make the system better. If not, for them, then at least just as much as we can for families and ourselves. But it's something that it's something that that really is a cultural thing. You know we've lost over a million people, and many of them, you know, couldn't be saved had they had supports when they needed them.

Lindsay DuBois 1:23:16

Yeah, absolutely. Bathey, could I ask you if you could change the system somehow, or what you would do to make home and community services more person centered if you were had an unlimited budget and everything you needed?

Bathey Fong 1:23:34

Are you talking to me?

Lindsay DuBois 1:23:35

Yes, Bathey, if you would share your perspective?

Bathey Fong 1:23:37

Could I have the question again? Sorry.

Lindsay DuBois 1:23:37

Yeah, that's okay! So, just thinking about kind of what Hector had mentioned around not necessarily what it should be, but what it could be, and not what it is, but what it could be, you know, so if you were to create, you know, reform, or change the system to make it better reflect Person Centered practices, what would you do?

Bathey Fong 1:24:01

For me is, I want to see more people to have a good life and to actually have, you know, a better community because since COVID, everything has changed for people with disability. You know, I feel like we need to have more freedom for them since COVID. has changed a lot with their life and you know, and services has been changing and then always I mean, yeah, Bring back more, more life. Good life for people with disability.



Lindsay DuBois 1:24:57

So, like, I know we're new barely enough time. But Reveca, can I ask if there's anything that you would change or many things that you might change, so that the system is really better designed?

Reveca Torres 1:25:10

Yeah, I'll have to agree with both Hector and Bathey and what they said. And but I also want to add that like, something that stuck out to me was what if there said that someone sort of opened that curtain to show him that he had a voice and same with that he, she found her voice and I think there's a lot of opportunity for, for support, not even not only like, you know, dollars at the at these programs for research and for supporting the services, but like, supporting those who are receiving the care supporting the direct workers like we there's a lot of turnover because they aren't supportive, they aren't getting good benefits, they aren't getting, you know, good pay, and so they need to be supported and empowered as well. So, do the caseworkers who may be burnt out from doing this work? Like, there just needs to be more support at every level. Because, like, if we're going back to prison centered, all of these people are humans and people in different roles that do need the support in order for all of this to work successfully. Great to also, I'd love to also somehow tap into this power of like mutual aid, like you said earlier about, you know, how we helped, you know, Alice, supporting Alice wanting to like, get them the stuff that she needed, like, we have a lot of power within our community and how can we harness this like mutual aid power to?

Lindsay DuBois 1:26:51

Yeah, excellent points. I know, we need to wrap up now. So, I just want to express my tremendous things to Hector, Reveca and Bathey. You know, again, I reiterate how much I think research needs to do more to really understand as you did after the kind of the experience of folks, I think you said first, I can't remember exactly what how you coined it. But yes, yeah. So just thank you again, for sharing. I think you have presented a lot for us to think about as we move forward with this work.

Bevin Croft 1:27:32

And this is Bevin. Thank you, Lindsay for facilitating this panel, and to Lindsay, Tonie, and team for introducing us to Hector, Reveca, and Bathey. And for all the wisdom that you've dropped today. We are just thrilled. And you're getting lots of things in chat as well because we've all I think, really benefited from this conversation. A post webinar evaluation poll has popped up. And we would be ever so grateful. If you could please just click through and answer the six questions on this poll before we say goodbye. And just as a reminder, we are you know, in a state of continuous quality improvement here at end caps, and so we're always open to ideas about how we can improve our webinars how we can make them more accessible. And we're also open to ideas and requests for future webinar topics. So, get in touch with us if you'd like and stay in touch and we will keep the conversation going. Thanks to everyone have a great evening or afternoon or morning depending on where you're from.