Customized Support – Designing Supports That Work, One Person at a Time

Beth Gallagher

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Hello everyone. Thank you for tuning in to Moms Fighting Autism in our Second Annual Autism Conference. We’re so happy that you joined us. The topic I’m going to be moderating today is "Customized Support – Designing Supports That Work, One Person at a Time" with Beth Gallagher. I’m your moderator.

Beth: Hello.
Nancy: Yes, hi Beth. I’m your moderator, Nancy Bernotaitis. There’s 2 ways to listen to tonight’s or to today’s webinar depending on where you are in the world. You can log in to momsfightingautism.com and the webinar is completely free. Once you’re registered, you’ll see a blue box in the upper left-hand corner of the screen. There you can click Listen In and hear the discussion via the internet and you can also click Ask a Question if you like to submit a question for a speaker.

You can also listen by phone by calling 949-333-4806. And our conference ID 168978#. All callers are immediately muted so don’t worry about us hearing you. We won’t be able to hear you. Later in our webinar, I’ll let you know how you can raise your hand to ask a question to our presenter.

We try to get to as many of the questions and the common themes as we can in the time we have allotted. If afterwards you have a question, Beth will be sharing her contact information with you so you’ll be able to ask her a question then.

When she slideshow begins, internet users can go to their blue box and click Slides to view the slideshow. It takes about 15 seconds to connect so be patient, they will connect. And once the slides are up, you can synchronize the slides with either your phone or with the webcast audio by clicking the button at the bottom of the slideshow. Be sure to mute your computer if you’re listening via phone so you don’t get an echo.

Nancy: Okay, so I will go ahead and tell you about Beth. Beth is the founder, owner and Executive Director of Life Works. Life Works was founded in 2004 after Beth moved to San Diego from Chico, California. Her work with people with developmental disabilities began just 2 weeks after graduating from California State University, Chico, in 1986 with degrees in Child Development and Psychology. While for over 2 decades her emphasis has been on creating personalized services, she began her career operating group homes for persons with behavioral support needs and/or medical concerns. The vast majority of her career has been focused on creating unique support situations for individuals with severe reputations.

Is there anything you’d like to add to that, Beth?

Beth: Well, thank you for having me today. I really appreciate it. Aside from my
career which stands about 25 years or so, I’m also a mother of 2 adopted children, and my youngest daughter is not neuro-typical. So she has the movement difference issues that we’re working with and so I’m coming at this presentation more as a professional but I’m also a mom. So I have spent most of my career working with people that have been labeled and kind of marginalized from the service system because typically, the behavior challenges or medical issues preclude them from getting supports from typically driven agencies.

So early on, I figured out that people that had differences that other people saw as challenging or not within their service code, they needed supports that were customized. And so for at least the 20 to 21 years or so, I’ve been focusing on figuring out how to do that and how to do that within a service system that exist in California. I spent all of my career in California. So I’ve done a lot of consulting for other places, other states, and agencies and stuff like that, but I’ve been only in California, so most of my experience comes from that.

What I know as a person working with person centered planning and customizing support is that for some reason even though to me, it’s makes 100% sense, it’s not generally absorbed by other agencies and it mystified me. And as a mom, it mystified me even more that people don’t tend to look at supporting people as needing to be individualized and customized only for that person, that especially when you’re working with people with different challenges, movement differences, autism, whatever it is, that the supports need to be only toward that person and kind of built from the ground up. And so that’s always been kind of a big ponderance for me. And so I’ve been trying to figure out why that is.

One of the things that I know for sure about creating supports for people with autism that actually works and are successful is that they have to be customized one person at a time. Person centered planning and all the tools that come along with that is the way that I go about doing customized work. I’ve learned from vast array of people who have been doing person centered planning, whether it be tools like MAPS and PATH which I learned from Jack Pearpoint and Marsha Forest from the Toronto area, or MAPS doing essential lifestyle planning, which I’ve learned from Michael Small and the learning community. There’s dozens of different tools that can be used in the classroom, in the home and residential setting and the workplace, whatever it is. I think that there’s many things that drives people away and my question is why are people not doing that.
What I know for sure about person centered planning is that there is innate or intense connecting with the person with the disability when you do person centered planning. And I mean real person centered planning, not just calling it person centered planning. It really needs to come from the heart, it needs to come from creating a support system around that person. It’s not just writing a plan in first person format. That doesn’t make a person centered. Person centered means that you’re collaborating with the person, you’re joining with that person, you’re partnering with that person to make sure that services are about him or her.

It’s about intense listening and what I mean by that is that people are listening with their whole body. They’re not just listening with their ears. They’re listening with their eyes, they’re listening with their body, they’re listening with being with that person, they’re listening about everything that that person does and it’s more intense than just listening with your ears. It’s being able to celebrate the things that that person has accomplished, being able to acknowledge that that person is a gift and that they have gifts that they can give to the community, that they are people that have things that they would like to brag about if they have the opportunity and probably haven’t been given that opportunity.

It’s about thinking outside of the box. And so if the plan is being derived from something that’s already set up and then you’re trying to fit the person into the plan, that generally is not going to work. So it needs to start from scratch. You need to start with nothing. And build the plan around that individual person. Therefore, any plan that you come up with is going to be completely unique. It’s not going to be like any other plan. Joey’s plan is going to be completely different than Betty’s plan, completely different than Jonathan’s plan. They’re all going to be different. If they’re the same, then you know that you probably haven’t done true person centered planning.

It’s about figuring out how to dream with that person. In my experience, most parents and most individuals with developmental disabilities have not been expected to dream. In fact, it’s been exactly the opposite. So sometimes, it’s actually learning how to dream all over again and figuring out how to allow that person to dream without squashing those dreams, making sure that if the dream is put out there, that anything that needs to happen in order for that dream to come true actually is done. So it’s about problem-solving and committing to that person every single time.
My slides when I came down to this format got a little bit screwed up so sorry about that.

So there are so many benefits of doing person centered planning that kind of demystify why people aren’t doing them. Oftentimes, people are not doing person centered planning because of not enough time, not enough money, that they feel it’s not necessary or whatever. What I know as a person that runs and you can see supporting people with autism and other disabilities, is that as an employer, I know that I want the problems to be solved before they ever happen. I want to cut ahead it off at the PATH.

If I do true person centered planning and really listen to people, in particular listen to the person with the disability but also listening to the parents, listening to the people that really know that person, I’m going to avoid all the pitfalls that what have happened had I not been listening or had I just put a plan into place and not consider those what those people had to say.

Oftentimes, what I hear from parents when we do person centered planning was their child is that is the first time that they felt like they were actually true stakeholders and what’s happening with that person. They’re given the opportunity to really collaborate with an agency, with the school district or whatever it is. And really be true partners so they’re working together, they’re aligning their belief system instead of working against people. You can’t do true person centered planning and not collaborate. They’re not compatible. So if you are truly doing person centered planning, you know that everybody is going to be on the same page. It’s not possible not to.

The framework is set up right from the beginning in order to support the staff, in order to support the child, in order to support the family. And the person-centered planning is designed that way from the very beginning. So it provides a framework from which everything else is going to take place.

Some of the reasons why person centered planning isn’t being used, it takes too much time. This is what I hear from a lot of people. It takes too much time. We don’t have the budget for that. We can’t allow our teachers to be out of the classroom for an hour to do a plan about Johnny. There’s just no time for it. If every school district or every agency or every entity that’s supporting people understood that time that you invest in that child or that person that you’re supporting, it’s an investment in the future. It’s an investment, and making
sure that problems don’t happen in the first place. So if you take the time upfront, you’re going to save money in the long run.

I’ve actually done studies of this in my agency on payroll and I know for a fact that you will save money if you do this sort of planning with people upfront. So that should never been an excuse and it should never be an excuse that a person or a parent or an advocate, whatever put up with.

I’m sure you guys have heard of while the person doesn’t communicate traditionally, so therefore, he couldn’t possibly plan for himself and what that means basically is that it’s our role to figure out what the communication style is. Stopping at the idea that person doesn’t communicate is completely unacceptable.

So person centered planning can be done with the person who uses the most nontraditional form of communication. And not using traditional language or not being able to use facilitated communication fluently or things like that is not an excuse for not doing planning around that person.

Another excuse is we just don’t have time, we just need to get the annual done. We don’t have time for that sort of planning. That’s like saying, I just need to get my job done. That person’s life doesn’t really matter to me. We need to consider that the person with the disability is living their life and we’re just doing our job. So, that’s not really fair to say that we don’t have time for it or we just need to get the annual done.

Another excuse that happened is they say, well the person is doing really well so we don’t really need the plan right now. It’s like saying that “I’m doing really well right now. I don’t plan on having a future because right now, in April of 2011, I’m doing really well. So therefore, August of 2019 isn’t actually something that I’d worry about because right now I’m doing really good.” That doesn’t really make sense when we think about it how it pertains to our lives.

Dead and happy are incompatible but alive and miserable are unacceptable, so we need to consider that person centered plan, a plan written about somebody needs to be something that’s alive, alive and actually happening. So when you allow somebody to dream and create a plan for their future, the job of the person supporting that person is to make sure that that comes true. Don’t ask somebody to dream and then don’t have any expectation that the dream is going to be work done or move towards.
An example of a PATH, this is an example of my agency’s path that was done about five years ago. This is a PATH, is a person centered plan that is done graphically and it’s something that was derived out of business community probably 20 to 25 years ago where people do that course planning. So on the far right hand-side is the actual dream of the future and all the way through the documents from the far left-hand side through the circle part is the action plan that’s going to take place in order to make somebody’s dream come true.

So this is the, just like I said, this is done for an agency, this is done for my company back when we were fledgling and kind of barely keeping ourselves together. So this is more business planning but these are done for individuals, they’re done for agencies, they’re done for families, I do them for families all the time. It’s an awesome tool to use to help somebody really visualize what their future is going to look like. You walk away at the end of the session with an action plan labeling who’s going to do what and what timeframe you’re going to be getting that done.

This is an example of the PATH for an individual that I support who does some public speaking with me sometimes to present her PATH to people and show them what I’ve done for her best. Here is Tami’s PATH to describe. Tami is somebody who I know really, really well. I’ve known her for years. I thought that I had already had a preconceived idea of what her future plans were for her. And I almost tried to talk her out of doing a PATH because I thought I already knew what she wanted to do. When we started doing the PATH, she invited probably 15-17 people something like that. We started going on the PATH and I found out that her future plan was actually completely different than anything I had ever thought that she wanted to do. So she’s actually planning on purchasing a house. She’s planning on going to Japan to learn how to make sushi. She’s planning on doing some public speaking which all of these tasks was done about a little over a year ago and almost everything on it with the exception of finalizing the purchase of her house. She’s actually looking for a house right now and also the trip to Japan hasn’t happened yet but it’s happening in 2013. All of that stuff has come true and she’s made it all happen and none of these things with the exception of the bowling ball were things that I thought that she was going to put on her PATH.

Everything came out, it’s like giving the person the opportunity to visualize what their future is going to look like, giving them an opportunity to be heard, completely heard by people that mean something to them, you never know
what’s going to happen. So when people said that they know the person really well or that they already know what their dream is, it’s not actually the case. You never know what’s going to happen. So it’s really important that we allow for opportunities for people to be heard in a way that really make sense to them.

This is another PATH for a couple that I support. This is a wedding PATH for a couple that were then are just going to get married and so this is a way that they used for planning their wedding and making sure that their future look exactly like what they wanted.

So a future’s plan can be as big as what do you want your life to look like in 10 years to I am going to plan my wedding and this is what I wanted to look like. So a PATH would be a tool that you would use when your gut is telling you, don’t you stand there, do something. We have a future to plan here. Don’t you stand around waiting for it to happen if you want something to happen, put it out there. Once you put your future out there and your dreams, then it’s more likely to come true because it’s out there, people know about it, you’ve committed to it. You’ve put it into words and in most cases, you put it into pictures and it makes things more vivid. So when your gut is telling you, don’t just stand there, do something. A PATH would be a good thing to do.

Another type of tool is called the MAPS. MAPS are used more predominantly in the school systems and they were designed to support people, students in the school system originally. They’re used for a lot of different purposes now, but this is kind of the outline of a MAP and basically the difference between the MAP and the PATH is that this starts off more with the history of the person and things that have happened in the past that have brought that person to this place. It could be a health history or you know, a schooling history or whatever it is. It focuses more on what the person’s dream is but also in contrast, what is the person’s nightmare. And with that said, the action plan at the end of it addresses what you’re going to do to make the dream come true in addition to what you’re going to do to prevent the nightmare from happening which is oftentimes you know somebody, let’s say somebody is institutionalized and they’ve now moved into the community, the nightmare probably is that they would go back to the institution. So what steps are you going to take, what action plan are you going to commit to to make sure that institutionalization does not happen again.

And in the mapping, you’re going to talk about, dreams, nightmares, who that
person is, what that person’s gifts and talents are, and what that person needs in order to make the dream a reality. So a map would be, when you’re gut is telling you, don’t just do something, stand there. Which is in contrast, with don’t you stand there, do something.

So a MAP is more like you’re going to focus on where that person is now. It’s not completely about 5 years in the future, 3 years in the future or something like that. It’s more about recognizing where that person is then and where that person is now.

Now a different plan that I use a lot when I’m just trying to gather the best information on people, when I want to just slow down and get to know who that person is. As a provider, I’m making a commitment to partner with families around their son or daughter and making a commitment to partner with that person with the disability and I’m walking into the situation being the person who knows the very least about him or her.

So, I need to be prepared to say, you know what, I don’t know you very well and I want to figure out what is it that I need to know about you and who can help me get that information so that I don’t recreate the wheel. And I don’t want to spin my wheels recreating service plans that are going to fail you because that information has already been designed and we already know in most cases what has worked and what has not worked.

So, I’m going to gather the people together who know that person best in one place hopefully. It might be parents, it might be siblings, it might be teachers, it might be job coaches, it might be neighbors, pastors, who knows. It could be the guy at the 7-Eleven who knows him really well, I don’t know.

But that person generally will make the list of the invitation list. I am going to clearly announce to that group of people that I am the rookie in that situation and I am vulnerable, I don’t know anything about him or her or I know very little. It’s really helpful when somebody is able to say, although I might be recognized as the professional in the setting, I’m not the expert. So I think one of the reasons why planning doesn’t take place oftentimes between schools and families or residential settings and families, or day programs and families is because the professional, the “professional in the situation” has a hard time saying, “I don’t know what to do.” There is nothing more valuable than that. I don’t know what to do, I need your help. I need to partner with you. I need you to tell me what works and what doesn’t work and we’ll create something
together. And maybe what’s worked in the past hasn’t been super successful but if you don’t recognize these things, you’re going to fall into that pitfall again and again and again.

So the other thing that needs to happen during this planning is creating ground rules. Establishing procedures for gathering the information from people and be flexible. You never know what could happen.

The main person you want to gather information from is the person at the center of the plan. Now, even if that person doesn’t use traditional means of communicating, they’re going to have ways of telling you what’s going on. So preparing that person ahead of time for what the essential lifestyle plan is about, you know, letting him or her know what’s going to take place, letting him or her know also that it could be a little bit vulnerable that we’re going to talk about things that may or may not be necessarily pleasant but allowing that person to participate in whatever ways he or she can.

Probably one of the best learning around essential lifestyle planning and creating customized support is that it’s not my job to figure what the answer is. My job is to figure out what the next best question is, because the planning never stops. If I am having a lot of success with somebody and they’re doing fantastic, it doesn’t mean the planning stops. It means that there is another next best question about what comes around the band. What’s the next thing that’s going to happen for that person?

So I don’t want to come up with the answers. Answers are great, don’t get me wrong. I like being successful with people but it’s not about creating the answers, it’s not about finding the final outcome, it’s about really figuring out what is that next best question. And some examples would be oftentimes I see plans, I get brought into the planning for people a lot, and I’ll see things like these examples that I have on here.

 Probably one of these is more helpful? Justin does not have any friends. Or, Justin has difficulties forming relationships in a traditional manner because Justin uses Assisted Typing for his communication he needs support to build bridges with people initially. He also uses Facebook and e-mail to increase opportunities for lengthy and more challenging conversations.

Now which one of those is more helpful as a teacher, as a job coach, as a support provider, as a communication aid, as a whatever it is that you are?
There’s two sentences there. There are two comments about Justin and they both maybe true, but the next best question about Justin was why doesn’t he have any friends and how can I make that better? So just stopping at the fact that Justin doesn’t have any friends is not helpful.

Justin cannot brush his teeth. Now, this may or may not be true, but what we know about Justin is Justin cannot brush his teeth on his own. He needs total assistance with this task which may look like hand over hand or even at times just doing it for him. He may need to move around during this process and may appear to be resistive, but is easily redirected if the support person allows him time to finish and is not pushy. He needs time and space. Give this task some time to finish successfully. Don’t rush, it won’t work.

So as a person that provides personal care to Justin, both of these sentences are true, but one of them is a lot more helpful. So again, what is the next best question I need to ask to be successful with him?

Justin is hyper, or, Justin’s team must be made up of very active people. Couch potatoes will not do. He needs to be able to be on the go most of the time and being held back by a more sedentary team member is unacceptable.

So again, if I’m going to this situation and all I know is Justin is hyper, that might lead a teacher or a care provider or a job coach to just spin their wheels trying to figure out how to keep Justin calm down, how to contain him, but the reality is Justin is hyper. He’s got a lot of energy. Do something about it. Don’t require him to sit in the situation where he’s going to need to be contained. You know, give him access to places where he doesn’t need to be contained and have people with him that aren’t going to require that of him.

Justin is actually an individual that we support and Justin’s entire team, entire initial team anyway was formulated by the university I live in San Diego, and so San Diego State and MiraCosta College and a couple of other colleges as track teams, and so Justin’s entire team was sought out from the track team and the Sierra Club and those kind of people. So expecting Justin to sit and maintain wasn’t a possibility. We decided to figure out how to allow Justin to be who he is and that’s one of the adaptations that we did for him.

I need to change slideshows here. I hope I’m doing this right. Nancy, do you know how do I get to the next?
Nancy: Go to, go out of slides, go over to your left, and click on let’s try My Events.

Beth: My events?

Nancy: Then go back in.

Beth: Okay, and I’m...

Nancy: Control Panel.

Beth: Oh.

Nancy: Click Slides again, and it should give you a list of options.

Beth: Okay, I still got the first set of slides.

Nancy: I’m going to take control of it for a second.

Beth: Okay.

Nancy: Okay, when you get to that screen. Sorry folks while we figure this out, we have our presentation cut into two different sections because it is too long, so we’re trying to access the second set of slides. Oh, at the bottom, it says, Change Presentation.

Beth: Oh, okay.

Nancy: Okay, so go ahead and take over the slides again.

Beth: How do I take over?

Nancy: You click that Slides tab.

Beth: Slides, okay.

Nancy: And then it will pop out that, you’re going to take over.

Beth: Okay, and then.

Nancy: At the very bottom of the slides screen, there is a Change Presentation button?
Beth: Do you guys see slide 1 now?
Nancy: Let me look. Yes I do. Liberty Plan?
Beth: Yes, Liberty Plan.
Nancy: Here we go.
Beth: Okay, thank you.
Nancy: You’re welcome.
Beth: So, a liberty plan is a sort of customized planning tool that I created because a lot of the people that I support that, well not a lot, occasionally, the people that I support that have autism and have some other maybe some support issues that require some more unique intervention I guess, sitting through a PATH and a MAP or an essential lifestyle plan seem to be a little bit cumbersome and a little bit, what I was told by a couple of people is maybe a little bit intrusive or a little bit invasive.

A liberty plan is sort of like a PATH light. It’s kinda like diet path, sort of thinking. It’s designed to help identify strengths and previous successes and to capture brainstorming moments. So it’s a shorter meeting. It’s much quicker in pace and designed so that the person can participate to a pretty high degree.

So kind of the reason why I wanted to share the liberty plan was to make sure that it was clear that person centered planning and customized support and that sort of thing, there are billion tools that can be used to do that. But person centered planning isn’t a tool, it’s a theory and it really needs to be a mindset. So whether you’re using an actual tool that is professionally made tool or something that you want to train in to learn how to do and you can facilitate it really well, it’s not about that. Customized support and person centered planning as a theme of and a mindset or a culture really of how to support people and whether you’ve learned how to do a specific tool or not, allow yourself to take the risk of doing person centered planning. Really figure out how to listen to the person that you’re supporting, your child, your student, whoever, and really get in there and figure out plans that you can commit to, that you can help that person achieve.
So I think that sometimes, customized support and person centered planning don’t happen because people are afraid of the idea that you have to have specialized training and the previous tools that I showed you, the PATH, the MAPS, the essential lifestyle plan, that’s true that you do need to have some specific training. But what shouldn’t happen is not doing personalized support systems and individualized planning just because you don’t have that training.

Circles of support are another type of person centered planning. Circles of support are as basic as getting together with people that know that person really well and are committed to that person, have a vested interest that making sure that that person is happy and has a really good quality of life based on what they want.

Circles of support are just basically regular meetings driven by the focused person to whatever degree that they can. They are action-driven so they’re not just cocktail parties or you know cake and ice cream, they’re actually action-driven planning meetings that are driven by the person. So they’re best if they are casual and you know for everybody I think that’s true for how most people perform is that when things are more casual and less “professional,” people are able to get to the bottom line a little easier, gets less terrifying.

And the function of the circle can be as flexible as the person wanted to be. They could meet monthly, they could meet weekly, they could meet at a coffee shop every quarter, it doesn’t matter. There’s no set guidelines. It’s not like an IDT meeting, interdisciplinary team meeting that has to meet every strategic 6 months or whatever. It’s not something that is driven by the system. It’s not driven by making sure that you meet those Medicaid waiver requirements. It’s not about that. It’s really about figuring out how to create customized quality supports for people.

John O’Brien and Connie Lyle O’Brien have actually written quite a bit about the Five Valued Experiences. If you think about your life and what makes your life the quality that you wanted to be, it’s no different for you than it would be for somebody with autism. People want valued experiences. They want to have community presence. They want to be at their community and be a valued part of that community. They want to have participation in their community. Participation really is maintained by relationship. So it’s not just going to the grocery store. It’s actually creating relationships with the butcher at the grocery store, whoever it is that make sense for that person, the checker of the grocery store, the flower person of the grocery store, the relationships that makes
people’s quality of life better. It’s not about getting them to a ball game. It’s about the experience and the relationship that happen at ball game.

Valued roles and how people are seen in the community. What their reputation say about them? What people see in them as valued gift back to the community? When people can give back, by and large, when people give back, they feel better about themselves. I think that one of the key ingredients that we missed out in supporting people with developmental disabilities is that one of the keys to life is reciprocity, that is about relationships and that is about giving back to the community of our choosing, contributing to the environment around us.

Oftentimes especially for people who have been in the system for many, many years, reciprocity just isn’t taught and as people lose sight of the fact that they need to give back. Relationships are only real true golden relationships if they are reciprocal. You give and you take, you give and you take. If you’re constantly just taking, the relationship that ends up, the end product of that is not a healthy relationship. You could have a relationship with somebody if you only gave or you only took but it’s probably not a healthy relationship. There’s probably some dysfunction in there somewhere. So, real healthy relationships are only going to be when somebody learns how to give and take and so when I see agencies or people have goals of creating friendship but nowhere in there is the idea of teaching that person how to have reciprocated actions towards the person that they’re interested in and not in the relationship with. So, one of my goal is always to allow people the opportunities to figure out how to do reciprocity. It’s really important.

Promoting choice, allowing people to have true choice, not living the lives that what their parents want them to do. I want you for a second to think about what it was like when you were a teenager or a young adult and if by any chance you remember what your parents’ dreams were for you. I can remember my parents’ dreams for me and I’m comparing my life today to what my parents wanted for me and the ideal that totally different, markedly different. It doesn’t mean that I didn’t meet some of the criteria that my parents wanted for me but I want it better in a much different way. If I didn’t have the flexibility and the autonomy to do what I wanted, my life would be totally different than it is.

And so one of the things that I am grateful for is that I had the autonomy and the support to go ahead and do things my way and I made a huge, huge ton of
mistakes. But some of my biggest learning was that of these mistakes. And I think sometimes we don’t allow for that to happen. People are given the opportunity to make choices and then have consequences to those choices. There are mistakes made and then the learning never happens because the mistakes are made. So I don’t of course want to set people up to fail. That’s not what I’m suggesting but allowing people the opportunity to make mistakes on their own and supporting them through those mistakes on the other side, and supporting contributions with their unique gifts, figuring out what those gifts are and how they can use those competencies and those talents and desires to improve the community around them.

Some of the things to consider when doing person centered planning and customizing support system, never do a plan first on somebody else without doing a plan on yourself. The reason is because doing person centered planning and having your information out there in public can be very vulnerable and can be very intimidating. If you’ve never had that done on yourself, then as a facilitator of that plan, you have no idea what that feels like. If you don’t know what that feels like, then you’re not going to be a really connected facilitator of that plan. So it’s really important to whatever degree that you can to have some sort of person centered planning done on yourself around people who care about you and who you feel vulnerable in front of.

Whenever you’re doing a plan, you need to focus on the person being supported and make sure that they understand that you’re not going to put anything on the plan that they don’t agree to. So you may be asking them, if you can ask questions of the group around them but you’re not going to do that unless they say yes. So figuring out how that person communicates and to what degree that they want control over what goes up there and set is really important.

You want to match the plan to the situation so like I went through the PATH and MAPS and essential lifestyle plan and liberty plan and stuff like that. You’re going to want to match the plan to whatever situation comes up. That’s why knowing how to do a variety of plans and there’s many more future plans than just the ones that I had presented. There’s dozens and dozens of them. They’re all over the place. And you can create your own but matching the plan to the situation is really important.

Facilitating a future’s plan is an art form and it takes a lot of practice and commitment. So, it’s also intimidating for the facilitators so make sure people
know that you’re just a beginner or whatever.

Invite people who have commitment to the focus person, understanding that you may invite 15 people and 3 people might show but you know what, those are the right people that need to be there and don’t worry about it. Don’t get caught up on, grandma didn’t show up or dad didn’t show up or the teacher didn’t show up or whatever. Don’t get caught up on that. Whoever is there are the right people and the plan can still take place.

One of my favorite is bake it and they will come. I learned that from a friend of mine named Shafik Asante. He was from the Philadelphia area. He passed away about 10 years ago or so but he was a brilliant community builder and he always said that if you have food, this is the anxiety level of the people that are in the room and he has worked with gang members and really high anxiety situations and had time to success with the “bake it and they will come” theory and I have found through my learning that having food is always a good things. People aren’t looking to leave the meeting and so that they can go get their next or whatever. So it’s really important to keep people comfortable.

Casual is ALWAYS better than stuffy. And I’m a super casual person in a flip-flop and shorts kind of girl, but so maybe I might be saying this in order to back up the fact that I wear flip-flops to work every day, I don’t know. But I think casual is always better than stuffy. People are just less likely to share personal thoughts in a meeting that doesn’t make any sense to them and that those are bunch of suits sitting around that don’t know them and if you’re hanging out on the floor, eating Pringles and whatever. Casual is always a better way to go.

Believing in the process is critical and doing the plan just so that you can say you did a plan, this happens a lot and the funding system because they have regulations that they have to meet and so doing a plan is one way that they go about meeting those needs and then crossing it off the list if they did their annual event. But that’s not a waste of everybody’s time. It doesn’t work very well and it doesn’t work for the person that may meet their needs but that’s not any way to go about doing that.

Don’t ever do a plan if you don’t plan on helping that person follow through with the plan. Allowing somebody to do to dream something and put it out there to people and really get their dreams out in a vision and then putting it up on a shelf and not attending to it is probably one of the cruelest things that you can do to somebody. Imagine being heard for the first time and people
acknowledging that you had some dreams and some ideals about your life and then nobody working on it, that would be worst than never having the opportunity to dream I think. So don’t do it if you don’t plan on following through with it.

The common themes that come up in person centered planning that are confusing for people is that the person as the center of the plan is the authority of the direction of the plan. So it should not happen unless that person actually wants the plan being done. It’s not something that other people decide whether or not it’s going to happen. It needs to be done with the consent and the complete involvement of the person what the plan is about.

And the purpose of person centered planning is learning through shared action. It’s about walking together with people. It’s about collaboration. It’s about partnering and allyship. It’s not about a log or a document. It’s about gathering together and everybody getting on the same page. So, you can’t move in unison towards the same goal if not everybody is on the same page. So it’s about learning through shared action.

It’s about stimulating hospitality. You can’t be immersed in person centered planning and keep people segregated at the same time. If they’re not compatible, they don’t collude like that. So if you’re doing true person centered planning, the only option is an -- inclusion, full participation. There’s no way to do it any other way. So you know that if the person that you’re planning for is stills segregated, then the plan has not come to full fruition.

If true person centered planning is accomplished, then the customized support will just ooze from that. A customized support will drift off of the plan once you figure out where you need to go. The customized support will come out of that.

The other thing is that person centered planning and customized support, is not for the faint of heart. So, if you’re a little oozy and a little uncertain about how to support somebody, you might want to take heed before you do person centered planning. It really tests your stands and your ethical standards and your values. You will absolutely have emotional and visceral reactions to some things that happen.

I’ve had a lot of very interesting experiences through person centered planning that I did not anticipate that have happened on a truly tested where I stand on certain things. So I want to share couple of experiences with you.
This is a gentleman named Alan. He grew up in a group home since he was about 6 years old. He was never successful in a group home because of his individual support needs. He has autism and he has the following challenges: He has pica, really irregular sleeping patterns like sleep maybe 3 hours a day and then catnap during the day in 15-20 minute increments; really significant food allergies; a seizure disorder; no real solid means of communication; extremely loud noises that other people has said are obnoxious and disturbing and interrupting and that kind of thing; a history of running away daily and several times daily usually, so they call it AWOL behavior or whatever; and he is assaultive occasionally when tasks are presented to him.

So we did some person centered planning for Alan. I spent a lot of time with Alan and his team and try to figure out. So this is the guy, what are we going to do to be successful with him. He is one of those guys. He is very, very hyper, very active. He is just kind of stimulated all the time. We could try to contain him and I’m sure that wouldn’t improve his quality of life. So we got together people who cared about him. And there was a couple of people who didn’t like him very much actually in that group but I didn’t know it at that time.

So we came up with some adaptations that would allow Alan to have a better life. He has awake staffing arrangement all time. So previous to that, he was in a group home where the staff were able to sleep at night, and of course when he would wake up, they consider that to be disruptive. So now the staff are awake all the time and it’s not disruptive because they’re awake anyway.

He lives in a home out in a country with miles before a major road where he can just run as much as he wants to. He lives alone. He has alarms on his doors to alert the team members when he leaves his home. So they’re not alarms to keep him in. They’re alarms just to like if they’re in the laundry room or something like that or in the bathroom, the alarm goes off, they know that Alan has left the house. So the intention is that Alan’s team follows him and they go running with him.

They’re working on the best means of communication. He still has a very, very slow process but they’re exploring different methods. He is currently using a letter board and looking forward to his first iPad but he doesn’t have yet but it’s in the works. His whole team are people who love to run, love to be active.

When he moved in to his new home, they took out all over the plants around
the entire house and a landlord helped them with this and they put in a huge herb garden. So the things that are there now are mint and parsley and licorice and stonecrop whatever that is, grape plants, onions, and dandelions, so he is able to eat his garden because his Pica before was he would eat things that were not healthy for him and he would get sick, really sick. So now he’s able to go out in his garden, in his yard, run around and eat the stuff that’s out there and he doesn’t get sick and he loves it, and he’s actually much, much healthy than he was.

They replaced his windows in his home with plexiglass because he would break the windows just to hear them crash, and now, he doesn’t do that anymore because they don’t break and so he’s not getting the the visceral response to that.

And now he’s working for the U.S. Department of Forestry planting trees and he happens to be in the department where they’re planting some sort of shrub that’s edible so he eats part of the plant while he’s working. That’s not an issue anymore. I can’t remember what it is that he’s eating but it’s kind of, it’s a plant that you use to stave off fires. It’s a very succulent plant in its good form. So he’s happy, he works probably 10 hours a week. He looks forward to going to work. He’s excited about it. And he works with part-time, and part of that work is also done with a CCC crew which is people that are younger than him and he’s kind of a mentor to these younger kids. They’re all below the ages, I think 25 or something like that, and so, and they see him as a mentor so he’s also doing some community activism or he’s teaching these young kids about autism and he loves it. So that’s Alan.

Oh wow, the O at the top of the page is unusual, I cut off his name but this is Carlo. Carlo lives in an ICF facility in Northern California in his teens and his 20’s and I think the early 30s also. Carlo and his team had a horrible time budgeting and getting, and keeping Carlo employed. Carlo is a self-described lazy man and he is a spendaholic. He knows that he’s lazy. I’m not outing him right now. He describes himself as lazy. He hates to work. He is just somebody who just isn’t interest or hasn’t found anything that he’s interested in working yet.

Carlo also has autism. He doesn’t communicate in traditional means. As you can see, he is a very handsome man and again, he’s lazy, really seriously lazy. So it’s really hard because he is spendaholic. He spends money like it’s water and we’ve been trying to figure out ways to allow Carlo to have control over his
money but he doesn’t have very much money because he doesn’t work so he’s on social security income only and loves to spend it but he’s an adult so we can’t really, he doesn’t have a conservator. We can’t really keep his money from him. So it’s a huge quandary. This is one of the various where my values came into play because my inner self was telling me to control his money and my person centered self was saying this is Carlo’s decision and he needs to have some consequences and figure this out.

So, over a long period of time, we try to figure out how we could get Carlo engage in employment that he liked, that he would be motivated about and it just wasn’t that there was, it was just really challenging. So in the picture, he’s an extremely handsome in his 20’s. He was like a chiseled Greek god, just very, very attractive. He loves being naked, very much, enjoyed being naked, predominantly naked most of the time if he had his way.

He lives in a university town. He prefers to not work at all but if he’s going to work, he needs to be in very, very short increments, and by that, I mean like 5 minutes, 10 minutes, now it’s up to maybe half an hour but he’s really active too. He doesn’t use traditional language so a job where he needs to speak is not going to work. He’s also very loud so he needs to be in a place where he can be loud if he wants to be. Any ideas what his job might be?

Nancy: Tell me it’s not a stripper.

Beth: Well, he’s not a stripper, but you get in very warm. He is a still nude mode in the art department at the University of Northern California. So he models for the art department and gets paid to do it. And so he does still nude modeling about 9 days a semester and gets paid fairly well, I mean for an hour or two of work and he asks for it now where he loves having that money and knows that he understands, I mean that he would be naked 24/7 if he had the opportunity. But there’s not a lot of jobs for him that work and when he was asked by a team member, he was in the art department if that would be something he’d be interested in, he listened very intently and when they told them about what kind of contract he would have, he listened very intently and everybody thought oh he’s not going to understand what this really means. But Carlo did understand and does very well. He actually getting a bit older and isn’t quite the chiseled god that he was before, so he’s looking for new employment. But this worked for a very long time and he might be nearing time, I don’t have very much contact with him anymore because I moved but he might be nearing retirement age now but that was a very successful job for him for a long time and it didn’t
require him to be anybody that he wasn’t. That’s a job that made perfect sense to him.

This is the gal that I currently support. Jamie was denied customized services in California because of a variety of reasons, mostly because she has autism which, you know, we were like, and so what’s wrong with that. Her reputation that preceded her when I first got her collateral packet was that she was too dangerous and she looks pretty dangerous. I mean that picture she looks fairly scary. It would take too many specialized trained people to support her. She needs too many staff for her to be successful so they were saying that she needed a 2:1 ratio and that she just, it just wasn’t possible financially. They couldn’t afford it.

And that nobody was listening to Jamie’s dreams. Her dreams were really unrealistic and that nobody, everybody said that her dreams were really outside the realm of being typical and why would she want these things. And so we took a look at Jamie’s dreams and her dreams were to go to college. Pretty normal. Live in a house of her own, an apartment or a home. Okay, that was my dream too when I was at her age. Have a cat. Have a job that makes a difference. Work with animals. Hang with her friends. Get married. So I think what freaked everybody well was the get married part. Everything else was just like oh, it will shoot, you know. There’s no way she’s going to get married. There’s no way she’s going to college. There’s no way she’s going to be able to live in her own home.

When we started doing planning with Jamie, I couldn’t figure out what the part was about her being really dangerous and needing so much support. It just seems like once you listen to Jamie and told her the circumstances of her dream and what could make that happen, she seems pretty straightforward and that you know, some adaptations needed to happen, that there wasn’t out of the realm of possibilities.

So we created some adaptations for her that allowed her to reduce her anxiety and her need for 24/7 support. She is another person who is really, really hard to budget for, and so what was happening with all the budget plan that we had for her was that, she is the person who needed to see what she had and so we created an envelope system where she could see literally how much money she had for week. It would put into a categories within the envelope system and then once that money in that category was gone, then it was gone until the next week when she went back to the bank. And so, once we created the
envelope system, she’s been on budget ever since. She’s never gone over.

She would have lot of anxiety over who was working with her or what’s her scheduled was for the day. So something as simple as just writing down her staffing schedule so she can read it. Nobody had ever done that before and she was 24 at the time. That just seemed very bizarre to me.

Jamie is somebody who does not do well with down time. She needs to have something kind of scheduled for her at least an option to be scheduled for her all the time. And she can choose to do it or not but if it’s scheduled for her, she knows she has an activity to participate in.

She needs intentional long preparation periods. It takes her, she is on Jamie time, and if you’re anticipating that you need to rush her for any reason, that’s just absolutely not going to work. So she needs a long time to prepare for things. She needs a lot of information and she needs just a transition time that is probably at least twice, if not three times longer than other people. So okay, we gave her an intentional long period of preparation.

In the beginning, she needs 24 hours support for safety because she didn’t understand, she didn’t have very good safety skills so she just needed to be taught at. So we’ve been working on that for about 3 years.

She needs a healthy diet. She eats a macrobiotic diet and she knows that for her if she doesn’t eat healthy, her mood and her behavior are really affected negatively. So she eats really healthy, take vitamins, sees an acupuncturist, all that kind of stuff.

Honor Jamie’s priority. She needed to know that she was being heard and that what she said matters. She also needed to have regular team meetings with her entire team in the room at the same time so that she know, she would know for sure that they were listening to her.

So she has had tons of success in the last three years and we’ve been supporting her for about three and a half years, I guess. So she works two different jobs. She now works for the school system as a paid kind of an office aid and she started out with one to one job coaching and now she has a 100% generic support in the office that she works in because she doesn’t have anybody go with her to work at all. She has about and that’s actually 8-10 hours of alone time per week is that she probably gets much more than that,
more like 20 where she is alone. Prior to that, she had somebody with her every waking moment, every sleeping moment, every moment of the day she has somebody with her.

She’s making many more decisions with less and less help. And she consults her team instead of depending on her team so she asks them for advice instead of waiting for them do it for her.

She is much more responsible for life decisions like budgeting and cleaning and she’s understanding consequences of those actions much more regularly.

She handles relationship issues with other people much more maturely and she is doing reciprocity on an active level.

She has her cat Emily living with her. She’s working on having an adult parent/child relationship with her mom and dad where prior to that her mom and dad which I’m sure many of you can understand where seen as the case manager and the therapist and the nurse and the staff person. Oftentimes, the parents are put into roles that other people can’t even imagine, that they’re able to have a regular adult child relationship because that’s never what they’d live through. So she’s working on creating that relationship with her mom and dad and it’s going really well.

And Jamie’s life has changed in the last two years, three years dramatically. Her main goal when she started hanging out with us was that she wanted to have a relationship. She wanted to get married and so she got married to her soul mate, one of the pictures, but she got married to her soul mate, Tim, in November of 2010, this was last year. Tim is a gentleman that we also support and they are the most amazing couple on the planet pretty much as far as I can tell. So she actually met her dream when they met. Tim’s dream was also to get married and a lot of the same things that she wanted was the same thing that Tim wanted and I actually set them up. I’m not bragging or anything, but I am actually a really good wedding planner. Another kind of support that we provide, just kidding.

So I mean, basically what the thing is about person centered planning and customized support is that all of the ingredients need to be available. You need to have opportunity for interactions. You need to have confidence. You need to have exposure. The more exposure you have, the more confidence you have, the more opportunities you have and it’s just a vicious cycle. If all three of
those are not present, then the success and living a customized life or a life of your very own is going to be less successful. So we believe in creating opportunities that allow for people to express themselves in a way that they may not have been able to do that before.

So that basically is, and I have some references here, people who I’ve learned a great deal from that I would be remised if I did not include them but references, the Inclusion Press, the Grove, Capacity Works, and elpnet -The Learning Community, all incredibly valuable places to learn from if you’re interested in that. So I don’t know if there’s questions out there or...

Nancy: Okay, if you’re calling on the phone, you can raise your hand to ask Beth a question by pressing *2 and I will see your hand raised then I will connect the two of you together. In the meantime, I’ll go to the questions that have been coming in through the website.

Beth: Okay.

Nancy: Carol from Houston asks, she said, “There are dozens of future plans out there. What is it called if we want to Google it?”

Beth: Oh, I would probably Google persons that are planning or personal future’s plan and see what comes up, but I’m not sure that I’ve ever actually done that. But that would be where I would start. You might also want to, depending if you’re talking about a child in school or in adult school plans, school future plans, play around with those kind of words and see what comes up with that.

Nancy: Okay. I was curious, who summons you to help these individuals?

Beth: I’m sorry, who what?

Nancy: Mainly, was it the group home?

Beth: Oh, with the individuals that I presented about or anybody?

Nancy: Yes, that you worked with, that you presented about.

Beth: Alan is a guy that I was consulting with a group home company that is in Northern California, I was consulting with them and I had known Alan for years and years and years and then so, they were having some problems and wanted
to bring me into to see if we could switch things around. Carlo is a guy that I was connected with the agency during the presentation that I had done, and after the presentation, they asked me to do some consulting for him. And Jamie is the person that I support through my agency currently, Jamie and Tim both, and they were referred to me by, in California it’s the Regional Center System which is the Department of Developmental Services so they referred her to my agency for support.

Nancy: Is Lifeworks a place where individuals with disabilities can go to or you’re consulting. Do you go them?

Beth: Both in a nutshell, but Lifeworks provides customized supports to people so we have people that we do case management for, so we do all supportive living, independent living, customized employment and micro enterprise that kind of stuffs. So all of the supports that we provide to people who are on a regular basis referred to us and we have contracts with. Those are all customized support situations one on one. And then we also do consulting to agencies and families and school districts and stuff like that. So both, but Lifeworks is generally a support agency. You come to us for ongoing support.

Nancy: Are you separate from the disability…developmental disabilities for the state or the county?

Beth: No, we’re funded through the state, through the Regional Center System to the Department of Developmental Services.

Nancy: Okay.

Beth: We also do some private fund, private pay funding but 99.9% of our revenue is from the Department of Developmental Services.

Nancy: Okay. Alright I’m sorry. I see the little spider web now.

Beth: I get it. Yeah.

Nancy: We had a question come in from Melody in Louisiana. Melody says, “I’m a 15-year old with a high functioning Aspie sister and a high functioning Aspie father, and my brother is also extremely high functioning. How do I find good support?”
Beth: Where are you from again?

Nancy: She’s from Louisiana.

Beth: I am not familiar with what occurs in Louisiana around support systems but I would look under the Department of Health Services or Human Services and generally that will lead you to whatever it is that the system in Louisiana that supports people that provides supports for people individualized like that. I’m not familiar with the Louisiana system. I’m sorry I can’t because they are called something different. Department of Health in Human Hygiene or Department of Mental Health or you know, Department of Social Services, I’m not exactly sure what Louisiana calls it. But also, your doctor should be able to refer you to the system and you know then you can check people out. I think any time you’re looking for support that you need to interview an agency to find out if it’s a good match because with the Lifeworks looks at anyway is when we’re committing to somebody, we’re committing to that person for life and it’s almost like we’re getting married, you know, I’m not going away from you even if things get ugly. So we need to be able to make sure that we are, that we have the same philosophy and we can work together. So I think it’s important that you interview whoever it is that’s going to be supporting you in whatever way. I wish I had better information about how to find those people but I hope that help a little bit.

Nancy: Yeah, I think it probably pointed her in the right direction. I’m going to generalize this question from Elizabeth in San Lorenzo. If you have somebody on the person centered planning team who really isn’t supporting the plan, how can you deal with that, say its appearance?

Beth: I’ve been there many times. One of the ways that I try to nip that in the bud is from the first second that I’m with those people, whether it’s from the invitation or the first very minute that we’re together in a room, I make it really clear that I’m not here for the parent, I’m not doing the parent’s plan, I’m doing the individual’s plan and they might be really different from each other and, but my job isn’t to support the parent at this point. My job is to draw out the information from the person and figure out how we can all get on board. Now if the parent can’t get on board, then sometimes, they have to leave, or they have to not participate. That’s really hard obviously for a lot of really obvious reasons. But I think, nipping that in the bud from the very first second like, when I’m creating the invitation list, I’m, for the most part, not go into the parent for that invitation list because the parent probably has ideas about who
they want to come but that may not be the idea of who the person wants to come. So, it’s really important that boundary be set right away. And sometimes it can get kind of hectic because the parent is usually the person that has a lot of say so in what’s going on in that person’s life, so I think the very best way about it that any literature that you give that person, any discussions that you have with that person, it’s always, always, always 100% of the time, the person’s plan. And they’re invited to it as though they were an equal participant as everybody else that’s being invited to it. They have no more power and no more say-so than anybody else. The person drives the plan and if they aren’t on board, then they cannot participate, that’s fine too.

Nancy: Okay, suppose you have an individual who doesn’t express desires, dreams, wishes, is it still helpful to create a person centered plan?

Beth: Oh yeah, even more so probably. Even more so, I think that person is probably the person that hasn’t been heard the most usually. And so, you know, it’s obviously more challenging for sure to do a planning with somebody who doesn’t express themselves in a typical way. My experience is that if you’re really listening to people, even if they’re not speaking, if you’re really listening to people and they really get that you’re planning for their future, that they will participate in some way, that sometimes will blow your mind. But if somebody is not participating and doesn’t, isn’t expressing any dreams or any desires or whatever, then maybe they are not ready for a plan, that’s true too. But it doesn’t always mean that. Sometimes I think we misread that as being not ready for a plan and what it really means is I don’t know how to say what I’m trying to say and so it just takes more time to us. It’s kind of like if I was trying to do a plan for somebody who speaks Hebrew and I don’t speak Hebrew and they don’t speak English, I’m not going to expect them to learn English. I’m going to try to figure out how to understand his language, whether it’s through an interpreter or whatever. So I need to figure out what it is that they’re saying, whether it’s through sounds or typing or body language or whatever it is, that’s my role to figure out how to do that. So, you know, I’m sure you’ve all heard not being able to speak is not the same as not having anything to say, but it’s kind of the same premise. Our role is just made more complicated but it doesn’t mean stop. It just means again, figuring out what the next step question is and how to get that information.

Nancy: Okay. What is the youngest and oldest individuals that you helped create a person centered plan for?
Beth: Oh, well, I’ve done plans for pre-schoolers. I’ve done plans for families who were pregnant, so I guess that’s probably the youngest. And the oldest, a couple of years ago, I helped a person with autism who is in her 70’s who is dying and her plan was about how to make, how to figure out how to do her support the best to make her, she had cancer, and so how to figure out how to make the end of her life the best she could make it. So I think she was like 74, something like that.

Nancy: We have a caller that would like to ask you a question. Let me unmute them and it takes just a second for them to connect.

Beth: Okay.

Nancy: Hi caller. Did you have a question for Beth?

Caller: Yes, I have son who is 6. And we did soccer last fall, and he didn’t like it. And he really improved over it. And now, spring baseball is coming, he doesn’t like to go to school. But he is to go to school. He just likes to stay at home. Where do I draw out the line between what is good for him and what he needs to do and what we need to do to open his world because it’s really kind of – on opening his world and he made phenomenal progress. So how much of that do we keep doing them? Where do we, you know, baseball is too much, we’re not going to do it.

Beth: Well, I think it’s all about these opportunities and the engagement. I think that sometimes where we get stuck is that, the individuals that were around show some resistance and so it gets easier to just avoid creating the opportunity. So I’m a big a proponent of, you know, I wouldn’t necessarily force anybody to go do something but constantly creating opportunities where socialization and activities that he might become really excited about are created. So, I don’t, I mean, without knowing your son, I don’t know how far you would push him, but I wouldn’t give up. It sounds like may be there’s some reasons why staying at home and that kind of thing seems like a better choice for him. Maybe it’s just more comfortable and maybe it’s just the place where he can chill out and relax and you know maybe he’s 6, so maybe he just doesn’t learn the skills that allow him to be comfortable in the community yet. So creating those opportunities where he can have little many successes over and over is just going to make it much easier for him to be successful in the future. But I wouldn’t give up on that kind of stuff. Grow on whether it was soccer or baseball or whatever. Figure out what one little thing that he really loves to do
and then grow that. You know figure out, sometimes what I do with people is just do it think tank. If somebody likes, I don’t know, skateboarding, what kind of things can you do around skateboarding but allow him to have more opportunities. So it’s not just skateboarding in a driveway. You can go to the skate park, you could take him to you know the board walk and skateboard, you go to skateboarding shops. So just figure out what ideas it is that he really likes and grow those ideas.

Nancy: Thank you Paula.

Caller: Okay, thank you very much.

Beth: You’re welcome.

Nancy: I’m sitting here wondering how you do a person centered planning on a fetus.

Beth: It was the family’s plan, but they knew that their baby had Down syndrome and so they were trying to plan for the future so that was kind of sarcastic but it is true, I didn’t do the plan for the family who were I think maybe 8 months pregnant with a little baby boy. So and it really helped. It helped them to kind of get focused.

Nancy: It was interesting.

Beth: I learned a lot.

Nancy: Sandra from Honolulu asks, “Do clients need to be California residence to take advantage of your services and if so, is there a national association where they could find planners like you in other states?”

Beth: Good question. As far as the services that we provide for people living in their own home and that kind of thing, currently we’re vendorized with the state of California, but we do have some private paid people. So people who want to live in San Diego, I mean, I’ll come down a little if you want me to. I mean that would be horrible. We do private pay and as far as planning services, there’s people that do person centered planning all over the United States, all over the world really, and there’s different places that you can find those people and I’m trying to think Michael Schmoll I think has a list on The Learning Community website, I think it’s learningcommunity.com and then Inclusion Press also has a list of people who do some stuff on there and that’s on inclusion.com. So it
depends on what you’re talking about. If you’re talking about direct support services, then we do those on San Diego County only at this point. But if you’re talking about person centered planning, we do that all over the place, so if I understood your question correctly.

Nancy: Yeah, I think so and you had mentioned before that you do private pay, is it cost-prohibitive?

Beth: We charge the same as what the state charges. It’s just there’s certain people that don’t qualify for services like for instance, people who don’t qualify for regional center services which is services for people with developmental disabilities, they may have mental health issues, or they may slip to the cracks for some reason they don’t qualify for one or the other. We also have looked into providing services for people with disabilities that maybe or that are veterans of the war or have disabilities that occurred after the age of 18, that don’t qualify for some certain services that currently pay us. So, there’s different situations where the private pay would come into place. But as far as person centered planning, that’s just a consultation service that we have that is not paid for by the state.

Nancy: Okay, you understand PATH a lot better than I do, so this question will probably make sense to you. Carol from Houston asks, “Hi, my child is elementary age with the PATH MAP. Could she, meaning you, explain the columns of now and what does stronger mean?”

Beth: Okay. I do understand that. On a PATH, after the goals and the dreams are created and a strong visual image is kind of put up on paper and figured out what that person wants, the next step is to spend a little time figuring out what is going on now for that person. And the intention behind doing the now is to create the drama effect or the dichotomy between where that person is now and where they really want to be. So, it’s kind of create tension and create a motivation to get where they want to go. So that’s what the now is about, we generally don’t spend a lot of time in the now because it really is supposed to be just a snapshot of my life now looks like this, versus in three years I really want to be here. And so creating that tension between the two.

The stronger category is the next, or the two categories over actually, and stronger is about identifying the things, the actions, the whatever it is that’s going to help that team of people leading that person to that dream, what is going to keep those people motivated and driven to get there because I’m sure
everybody has been in a situation where they’ve come up with an idea or a plan and then as soon as the meeting is over, everything is folded up and put away, and then nobody addresses that again until the next meeting when it’s like, so what did we get accomplished. Oh yeah, I totally forgot to make these phone calls, or, oh I forgot to write that paper, or I forgot to connect with so and so. The stronger part is what’s going to keep your motivation on fire, what’s going to keep you going and keep you going in the right direction and not stop, because again the worst thing that you could do is allow somebody to dream and then not give them opportunities to address that dream or to follow that dream. So stronger is about keeping you on task.

Nancy: Speaking of being on task, it’s time for us to wrap things up here. But Beth I wanted to thank you so much for participating with us today. And is there a way that folks can contact you directly if they have questions?

Beth: Yeah, I have a website and all of my contact information is on the website. So, my website is www.lifeworks-sls.com.

Nancy: Okay, thank you for sharing that with us, a lot of e-mails, mine included.

Beth: Good.

Nancy: Thank you very much. I want to let our participants know that if you want a transcript to this event, please join our Spectrum Gold Club, we’ll send you a copy of the webinar audio and transcript plus 29 other webinars when you join. Also, tell us what you think.

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