Supported Living Webinar: Success Stories  
  
 Please stand by for real time captions.

THANK YOU FOR JOINING TODAY'S WEBINAR, WE HAD A FEW TECHNICAL DIFFICULTIES, TODAY'S WEBINAR IS SUPPORTED LIVING INITIATIVE. Presented by Jesse Smathers and Caitlin Bailey.

As many of you know, our business partner, Kelly Friedlander host the series, but last night Kelly and her husband met their new son, and both Kelly and baby are happy and healthy. Understandably Kelemete -- Kelly is not with us today.

Real? about the webinar, please write and post your questions in the comment box. If time allows, Jesse and Caitlin will address the questions at the end of the petition, we will respond in writing after the call. Today's webinar is being recorded and will be available after the presentation. With that, I will handed over to Jesse.

Thank you drew, thank you for filling in for Kelly, I'm sure she is excited about her new arrival. This is the final webinar that will be offered through the supported living making a difference initiative, we will provide an overview of electronic guidebook, the summary of efforts, a sampling of the video vignettes that will be part of the electronic guidebook, explore the dignity of experience section, and touch on a few of the important takeaways that will be included in the final report to the initiative.

The supported living, making a difference initiative has been made possible through a collaborative effort between the North Carolina Council on developmental disabilities, NCCDD, and the Medicaid project that assists Medicaid eligible North Carolinians, in skilled nursing homes to move into community-based living arrangements. The Council uses a five year plan to develop -- the assistance and Bill of Rights act 2000. To outline goals and objectives in specific activities to bring about change. The current five year plan effective from 2017 through 2021 was adopted by the 40 member council and approved by the administration under the middle disabilities. On October 1, 2016. Three overarching goals. Will one focuses on increasing financial security through asset development, for individuals with intellectual and develop mental disabilities so that they and their families have greater opportunities for choice, self-determination, independence and productivity.

Goal number 2, increasing community living opportunities for those with develop middle disabilities, ensuring that they be fully included, respected, valued and supported in the community of their choice. And finally, go three aims to ensure that more individuals with intellectual and developmental disabilities will lead and sustain self-directed lives through self advocacy Family advocacy and stakeholder leadership.

The supported living, making a difference initiative is characterized under goal 2 of the five year plan. Increasing community living options with individuals -- for individuals with intellectual disabilities. Requesting -- making a difference initiative in partnership with the national leadership consortium on developmental disabilities at the University of Delaware, and Caitlin Bailey has represented that agency. Relentless leadership, and as many of you know, the executive director in northern Virginia, closed their last congregate living arrangement 1994, serving 125 people with disabilities in their own homes, and community resources alliance, or CRA, and 4 service provider agencies North I, the ark of North Carolina, liberty corner Enterprises, first resource Center in turning point services, and community bridges consulting group, that is Kelly Friedlander and Bruce Smith's firm, then added them to guide webinar development during the first year of the initiative. The partners have worked to transition six people to their homes, their own homes, using supportive living supports that are available on the innovations home and community -- community-based services for those with intellectual disabilities. The learning community was developing offered learning opportunities at conferences, online through webinars, we've had meetings, to receive feedback from stakeholders, both in person and virtually, sharing successes and challenges, experienced by individuals that chose to transition to the supportive living model.

Initially it has collected data through surveys and interviews with participants, the initiative has strived to offer technical assistance -- education, opportunities, for professionals, and others in the community about supported living, and to it -- identify strategies for successful use. And systems, challenges and barriers, used in supported living. My co-presenter, Caitlin Bailey, will share more detail about the information gathered, the survey data, letter in this presentation. We applied for the initiative in 2016, and we started planning for the initiative in January 2017. The contract consultants participated in planning activities with the participating providers, the art, and see, liberty Enterprises, first resource Center in turning point. During the initial meetings, they determine the amount of support they would need for consulting professionals. Each agency worked with care courtiers and families to identify people interested in living in their own homes and supports, through the supported's -- supported living. Thus far, 37 people are being supported through the for -- 4 partner provider agencies, receiving supported living for's facilities -- services in their own homes, aware of two of the people that are planning to move into their own homes at this time.

The learning community was launched with the statewide conference in March 2017. The today supported living, a shared living conference, held in Greensboro, attended by 282 people from across the state. The initiative partnered with monarch, Cardinal innovations and alliance behavioral health, those are other -- monarch is a provider agency, Cardinal an alliance, and -- managing their organizations. To bring David to bring a one day workshop called beyond behaviors in July 2018. Almost 200 people attended the event.

In October of this year, the initiative sponsored a closing conference, supported living, including everyone, and David was the featured

, Presenting a two day workshop called the importance of belonging. And we closed the event with that she closed the event with a talk and tired walking the fire road. And a people that had been living in their own homes, supported living supports, touching the hearts of everyone in attendance. Attendance for the event was around 100 people. Threw out the initiative conference, presentations focused on supported living. They have occurred at the North Carolina training and instruction, education conference, known as NC tied to, at the conference -- TIDE fall 2017, spring 2010, presentations about the initiative, featured at the annual conference, at ark -- ARC. The integrated care conference of the mountain area health education Center, in spring 2018, and the North Carolina provider counsel and annual conference in the fall of this year. The initiative has been featured and discussed at the Vaya health Summit and learning Academy in fall 2017 and again fall of this year. In all, through conferences and other presentations, the initiative has reached over 1500 people. Presentations about supported living in other community resources, at three state operated healthcare facilities North Carolina. J Iversen in Morganton, hospital Morganton, and the Murdoch center. And the CRA was the featured

. The presentations targeted social workers, and qualified professionals employed by the facilities. Member families and exploring supported living, attending the presentation at Murdoch center. Successes, challenges, lessons learned through the initiative, presented it 2 national conferences. 2018 national Association of counsel on develop middle disabilities, conference, and the 2019 national Council of executives, and CE, and summer 2019. -- NCE. Stakeholder meetings and 3 virtual meetings for stakeholders, the webinar series is offer the following titles, supported living 101, led by Trish Barnum, contracted with the division of health benefits, or North Carolina -- at the time, webinar entitled health versus safety, and risk versus liability, featuring Derek Dufresne, a webinar called supporting people with informed decision-making, presented by genre fail, with the national Association of -- professionals, person centered living, the connection, that was presented by Karen Luken, and the statewide data, visited by Michelle Barrett. The webinars featuring the WEAKEN North Carolina, first resource Center, and turning point services, so -- provider experience was supportive living, as previously mentioned, the vital webinar that will be shared through the initiative, can be viewed at any time, the councils webpage. That will be part of the electronic guide also, and all of the webinars, except one, were saved, because of technical difficulties, we lost one recording of a virtual stakeholder meeting. And the presentation of the webinars, over three were. -- A three-year period, we experienced three hurricanes, which changed dates on us a few times. 2 pretty severe hurricanes, Ashley. So change was a constant with regard to the initiative.

I would be remiss if I did not mention the coordination and support that we have had, thanks to our systems change manager, Philip Woodward, with other counsel initiatives that are intended to increase community living opportunities. From planning to action, integrated and collaborative care initiative led by Karen Luken, provided a webinar, the national support network development initiative, led by Gennett price, continuing to build on efforts with regard to the larger community, and the person centered approach initiative -- this initiative provided quite a bit of support. There is no doubt in my mind, that much of the survey data we have gathered has the assumption that supported living only works when the person receiving support has integrated healthcare, and either has or develops the national support network, and when we -- when a guardian is involved, the Guardian that uses supported informed decision-making instead of traditional best interest guardianship. Each of these topics addressed in some manner in the guidebook, which will be hosted on the webpage, that will be considered.

The supported living guidebook will be on the councils webpage, as I just mentioned, it will be shared with the seven local management entities, organizations that are currently in North Carolina. With the hope that they will link to the information for supported living on their websites. In some cases, the information on the page will link to specific information on the website, hosted by the North Carolina Department of Health and Human Services and vice versa, is intended to be a go to resource that will guide those in North Carolina, and -- based on their interests. The webpage will be divided into five categories, taking information easier to access for anybody who is interested. The five categories settled upon our foundational principles for everyone, information for people with disabilities and their families, affection for professionals to support disabilities, and provider agencies, and a section that outlines other resources. The foundations for everyone category will cover topics such as why supported living, what is the difference? Dignity of experience. Person centered thinking. Supported decision-making versus informed decision-making. And then how do I get started. For people with disabilities and their families section, it will have resources beyond the foundational principles, that really focus on families. Supported living, is it for me, an article about the right fit, keeping a great companion. And housing, and there will also be an article from a guardian, talking about the challenges moving a loved one from a congregant sitting into a supported living arrangement. Also sharing some of the positives that have been experienced. Affectionate targets, direct support professionals, to support people with disabilities, will have information that addresses the supported living mindset. Because it is different thinking than traditional service models. Cultivating community. Supporting people's access to money. Supporting the dignity of experience. And becoming the best support professional you can be. That section will actually you link to resources available on the national alliance for direct support professionals website.

The agency category will include information about setting the agency's culture. Person centered staffing practices, person centered individualized budgeting, finding the right partnerships, supporting dignity of experience, again, this is a common theme throughout all of our work. And other considerations for the agency. The other category will list different resources, such as technology's role in individualized work, accessing other public services, food stamps, like those kind of things. Housing resources, practice planning and intervention. The information, documents, resource links, etc., will be submitted to the Council as the final product for the initiative, it is our intention that the community will continue through efforts hosted by the North Carolina Department of Health and Human Services, specifically Medicaid, and innovations labor stakeholder groups, and the national support network development initiative.

So that is the overview of the electronic guidebook. We are going to transition now into a sampling of video vignettes, the video vignettes will be at the forefront of the foundational principles for everyone section of the webpage that I have been talking about. Ultimately, there will be at least one video from each participating provider agency. I will mention them again, they have been a great asset throughout these three years. The WEAKEN North Carolina, first resource Center, liberty corner enterprises, and turning point services. There will be a compilation video that shows several people living successfully in the immunity through supportive living. -- ARC North Carolina. The final videos will not be ready until the end of the year, and when I say we, the stakeholders that have provided feedback. Showing people using supported living successfully, encouraging people to consider supported living is an option.

We are going to start by seeing a video that features six people that attended the supported living conference, in October, Brittany, Deanna, Gavin, Nicole, Richard, Selena and Sam, all of these wonderful people were great, doing a really great job at the panel and answering questions, hopefully our technology will work and we will be able to watch this video.

[ video playing ]

[ Indiscernible - low audio ]

I really enjoyed it. I can focus on myself. Another people living there.

[ Indiscernible - low audio ]

[ Indiscernible - low audio ]

[ video playing ]

For quite a long time.

And --

He enjoys his time on the horse lawn.

Feeding the horses.

Making a lot of positive progress.

[ Indiscernible - low audio ]

My name is Brittany, I work here at the regal arms, skinning tickets, directing the patrons to which theater they need to go to.

I love working actually, I work at the hotel.

She does an amazing job, always friendly, smiling, saying hello.

I do laundry. And other things. Working there, it is a great community, I love hotels.

I am really proud of everything I have done. Giving me the support that I have needed. And proving to myself that I can do what I wanted to do.

I work hard and I feel good about it.

I know I can do it, it is worth it, and I can see about getting it done and living on your own.

Okay, that was the first video we had, we have three more, we don't have all of the ready yet. That was the compilation video. And I hope it warmed and touched your heart like it does mine. The next video. It is going to be of Nicole. We were able to show the close video in the conference in October, I think it was the only one we were successfully able to show on the first day because of technical difficulties, and I have known Nicole and her mother for many years. And when I saw this, you will see in the video, a section that shows that one of her dreams is dancing with Jesse, I told Nicole was -- that all she had to do was ask me. She was? to point out that her boyfriend was named Jesse, and it wasn't any desire to dance with me. A couple days later during the panel, she actually let everybody know the audience that the Jesse on the list was not me. [ Laughter ] Without further ado, we will watch this video.

I love it, I can dance, I can sing, I can write. Facebook actually, and about my adventures, -- I wrote a book.

This is when you first got your old one.

I'm Nicole, and North Carolina, I am like anybody else, I have dreams.

I've learned a lot working with Nicole, she surprises me all the time, very capable. I always hoped that she would have that.

She is just stepping up, she kept trying, she kept wanting more, and it made it easier and easier for me to get out of her way and let her do what she wanted and what is possible.

She likes the direction her life is going right now.

I love working actually, I work at the Doubletree Hotel.

She does an amazing job, always friendly, smiling, saying hello. I love her.

I do laundry, and other things, and working there is a great opportunity, because I love hotels.

[ Indiscernible - low audio ]

I have my own dreams in life, and it is really about living my dreams.

This is a video that is going to feature Gavin, who is being supported by liberty corner enterprises.

My name is Gavin, 28 years old, and North Carolina.

[ Indiscernible - low audio ]

I have had a history of -- [ Indiscernible - low audio ]

Games, board games.

I have had a job now it Burger King since July of this year. -- At Burger King.

I love working with them. I really do.

[ Indiscernible - low audio ]

Really good for him.

I'm like his grandmother, we just help to support him to be independent, and he does a fantastic job.

I'm glad to take myself away from conflict.

It was a year last night, he has not had any incidences like that, he supports himself.

Liberty corner has helped me come a long way. And -- [ Laughter ]

A wonderful feeling to know that you are helping someone. Fulfilling their dreams.

Able to get the support that I needed. And prove to myself that I can do that I -- what I have been wanting to do. I'm really proud of everything that I've done.

I need to share little bit of information about Gavin, Gavin has been in his own place about a year and a half. He has had a great difficulty living in group home settings, and Gavin isn't receiving supported living services, with liberty, he is receiving supported living through long-term community supports, in lieu of service via the and see Medicaid to get approved, and it has a supported living component. We included Gavin in the videos, because supported living is more than a service, it is really the culture of an agency. And the agency that works with Gavin, liberty corner enterprises, they made the decision to move away from property ownership, they are in the process of divesting all of their properties and just focusing on providing services to people in their own homes. As part of this initiative, and with the determined leadership from the executive director, with consultation support from Lynn Siegel, liberty corner closed one of the kinder get living settings, and they have plans to do the same with the two remaining group homes, and part of the reason that Gavin became a candidate for long-term community support, he is on the waitlist for innovation, but he was living in the group home that liberty corner closed, and we had to find a way to help support him, and we did that through that option we had.

And again, supported living is not just a service destination, it is a cultural concept. So next, we will take a look at Sam's story.

[ Indiscernible - low audio ]

You're my daddy. [ Laughter ]

I could be your daddy. [ Laughter ]

Sam started working about a year ago. He was just full of energy and really excited about the possibility of working here. We thought we would give it a try, and a year later, here we are, he is still a wonderful worker.

I do many things, and doing the dog washing.

His energy is contagious, he is so positive, he is always happy and he brings a smiling face.

I love it. I love it.

I can tell.

[ playing guitar ]

My disability is -- I went to school with the same disabilities that I have. So it is a little bit of a challenge, but I move forward.

[ Indiscernible - low audio ]

They help me with support, and with the goals that I have, and trying to achieve the goal.

[ Indiscernible - low audio ]

I really like hanging out with my friends. On my own, I want to give back to the community.

Everything about Sam makes me smile. He has a YouTube channel, where you can see his music, and during the panel discussion at the conference, he was so energetic, he was asked by an audience member what his parents that about moving out on his own, and he said his mother was fearful about it. About the move, not sure how things would go, and he said his dad was like yes, he's finally moving out. You can imagine how the whole audience responded to that. Sam also did one of the planning meetings in November in 2018, he lives in the Raleigh area, and he is just light so much. -- Liked.

Over the past three years, we consistently have seen that one of the greatest challenges in supported living is cultural. You probably heard me saying experience a few times, the dignity of experience, our guidebook will try to tackle it through a few thought exercises. In preparing this webinar, Caitlin and I thought it would be best, and based on the information that she has gathered, discussing some of the information from the guidebook, on the topic of the dignity of experience would be a good thing to do with our limited time. To have the opportunity to attend the shared living conference in 2017. Participating in a brief exercise with Lynn Siegel, she had conference attendees reflect on their own lives, to understand the value of experience. We used a worksheet to define values, attitudes and beliefs. The value is anything that you value for what it is for its own sake, and it's pretty easy to change the value. And attitude is a viewpoint composed of your physical, mental and emotional habits. Attitudes are difficult to change. And a belief is a strongly held commitment developed over time through the integration of values and attitudes. A belief is most difficult to change. Exercise that we did with Lynn, it became clear that a lot of the things that we do we take for granted, a lot of the things we do involve alcohol, risk, involve money. And many of the things that we do involve significant others. And often we don't afford the same opportunity to people with disabilities. That we work in a service delivery system that has, over the course of time, developed believes that prevent us for supporting people in the least restrictive way because of past practices. And some of our current practices. Some people with the best of intentions see people with disabilities as unable to change, grow, achieve, and as a result, we wrap them in bubble wrap and some ways. We are slowly changing these beliefs through laws and just culture is changing because of those laws, and people are being included more greatly. However, we continue to use and defend segregated structures based upon the outdated beliefs that I've mentioned. These outdated beliefs are a huge barrier because of the amount of money -- we must constantly be checking ourselves away deal with people with disabilities to make sure that our beliefs are not being transposed on the people we are supporting.

One of the exercises that we will outline in a lot more detail in the guidebook under foundational principles, is a guide on self reflection. It is an activity for staff, guardians, anybody working with a person with disabilities. And the person providing support, to be able to group -- question their own attitudes and beliefs, to be aware of their biases, so that they know whether they are trying to influence the decision that the person with disabilities is making. Questions such as what values, needs and interests are nearly universal, down to what is the risky activity the person wants to do. These five things are for the staff and Guardian to consider.

We also move into the idea of past reflection of a rainbow of experience, given by Trish Barnum in her early development of the manual, or the guidebook, and after reflecting on our own thoughts, a person supporting an individual disabilities has to really evaluate, the on illegal activities, or things that can't be reimbursed through Medicaid, how and when a person should be able to complete it -- an activity, the questions that support staff, guardians, anybody working with an individual, to be considering when they are helping them and supporting them to do things, whether or not the activity is dangerous for anyone. And what I have a strong concern about, with anyone, what I have strong concern, down to if I was denied the same experience, I would feel like my life was a complete. It is from red to green, it is a guide for the people reserving services -- receiving services. The person discussing it with the person, and doing the best not to push their beliefs onto that person. This becomes a real challenge when you are supporting someone and you are worried about the health and safety. As primary pieces. These are things that we have been touching on and encountering throughout the entire initiative. And this is just a piece of what is in the guidebook. So what we have been able to show you, giving you a summary of our efforts, we felt like it was necessary to just share with everyone what has gone the last three years, because a lot is happen was supported living, and sometimes you have to step back and just appreciate that. There is a great book, things to be desired, 1952, one of the lines is enjoy your achievements as well as your plans, everybody who has been involved in the initiative over the last three years, there's been some achievement. Still plenty to do but there has been some achievement, and we wish to highlight those.

Taking a look at some of the things that will be on the webpage, that will be available in years to come, and of course the videos, outshine everything else. You got to see a sampling of those. There will be a few more.

Then we touched a couple of activities or exercises, or resources that will be available on the page, and give you an overview of things to expect. Now we will shift gears and Caitlin is going to share some of the important takeaways that we have learned, and will be summarized in our report, so I will pass it off to you, Caitlin.

[ no audio ]

Standby for just one second, I am working with Caitlin to figure out why her audio is not working, give us one moment.

Okay.

[ Pause ]

This is one of the great things about technology, we can be on three different parts of the planet trying to present this information to you, and then you always run into technical difficulty, I hope everybody was able to hear the videos, because that was the first challenge.

[ Pause ]

Sorry about that, Caitlin should be getting some audio just one second, I think we found it, she will be able to speak with the group in just a moment.

[ Pause ]

Hi, this is Caitlin, can you hear me?

We can hear you.

Oh wow, I could hear you guys the entire time that I couldn't hear you the entire time so I kept starting and restarting, I will very quickly talk about some of the evaluation that we did, so I really appreciate the opportunity to be part of this initiative, because it incorporates such an intensive evaluation that we modeled off of the coproduction model of evaluation, I think the best way to describe the coproduction model is by understanding the principles of about me, most impacted by the initiative, sharing their expectations. And to talk about what we should measure, very early on in the project or in year one, and based on what we found from them over the next couple of years, we continually evaluated those factors to see how the initiative was doing. To support people.

So we interviewed people who were thinking about [ Indiscernible - low audio ] services, family members of people who use these supported living services, and stakeholders from each of those four agencies, that Jesse mentioned, that were providing these services as part of the initiative. And within those agencies, we interviewed people in support rules, people who are working in -- across the agency and middle management, and including the agency. And so each year, developing a report highlighting the successes, and some of the lessons learned as well. In the third year, we compiled that information into what we learned, and strategies supportive of the -- hopefully people can use this information with supported living, or when they think about how they are going to evaluate it within the agencies providing services, with their families, do understand better what are is -- what it is and what makes a great.

One of the highlights in one of the things we learn, particularly those throughout the initiative, and the time that we have left, and give time for questions. Stretches going to share two things with you, and just say for more information, like what I'm going to share, these take a look at the report that is almost ready to be disseminated. So that you can also learn everything that we learned as well.

The first thing that we learned from people using services, was that when people were -- the services needed to be flexible, and when services were flexible, people were using supported living services, the flexible services, people not only controlling, or feeling like they were control over the services in their lives, but also services and agencies really working to adapt to the person's needs as they change, as they changed over time. For instance, in the initiative, a specific question, saying that [ Indiscernible ] previously, that what you want to do with your day, having so many choices in their lives, they kept looking for validation, is that okay, are you okay with the decisions you are making, things like that. And really demonstrating that they were going to be flexible, she was much more confident in the decision she was making. And the direct support professionals were able to adapt that with her, providing a lot less validation engine -- really just following her lead by the end of the year.

We heard about the flexibility in a couple of other cases, one person said that flexibility for them meant that they didn't come into their home and told them how to set their home anymore. And he saw the video with Nicole, who also said that she expected her services to be flexible, which meant that at the time that I met her, she said that she was feeling a little down and needed a little bit more support. But she said the moment that she got another boyfriend, she was more up, she wanted her services to adapt to that, to get out of her home and her life so she can have more free time and a little bit more space and privacy with her boyfriend. So I did not get to interview her this year, but it looks like from her video, her supported services have been able to adapt to that with her.

Finally the one of the lesson that we really learned from people who were using services was that successful supported living services work when people who are providing support, believe in them. Supported living was really successful for people when more people had opportunities to fill and said yes, then said no. And as Jesse said, because they were afraid of it. For instance, in the first year, interviewed me, she was in the video briefly, at the time of transitioning into supported living services, she was looking forward to more people believing in her, living in a transitional apartment at the time, and interested in learning to cook, she had a hotplate in her apartment, because she said she had to essentially prove that she wasn't going to burn down her apartment with a hotplate, before she graduated up to an oven. And in her conversation, you could really see how that affected Britney, because she felt like under the services, she wanted people to believe in her, and give her the space to try things, and maybe making rice, something like that, she could live on her own. And later she was a lot happier with their services, as people learned with her to be more flexible and believe in her and her life. [ Indiscernible ] successful. Strike that was a really short overview of some of the lessons that we've learned. And the report will have a lot more information for you going forward.

[ Pause ]

Jesse, I will turn it over to you.

Okay, I had to take my phone off of mute. Drew, have any questions come in while we have been presenting this information?

Thank you for your presentations, there is one written question, and it reads as follows. When will the resource manual be available, and where can we access it?

The intent is to send all of the information for the manual to the Council no later than end of first week of January, we may meet that date, we have a spreadsheet we have the topics I mentioned in the resources that will be linked to that and we will be sending all of that information to Philip at the Council, and he will share that with the agency that manages their webpage. And based on how they usually move pretty quickly, I think that the whole page should be available on the Council's webpage no later than the end of January.

Perfect, thank you.

We do have one participant, Courtney, if you think you have time to take a question, I can unmute her line.

We will take the question, yes. Answers are not guaranteed. [ Laughter ]

Okay, Courtney, can you hear us? Courtney, if you have a question, your hand was raised, you are unmute it, if you want to ask your question. All right, I will go ahead and mute Courtney again, she may not be available. With that, those are all of the questions that we have received. As stated, we will be passing this webinar back over to Jesse and Caitlin to be able to archive and share it . And with that, unless there are other closing comments, we will go ahead and end today's webinar.

I think everybody for their patience with us today, -- thank everybody. And working with us for the last year, and have a holiday season, an enjoyable holiday season.

Great, thank you, and everyone have a good day.

[ Event concluded ]