

WEBVTT

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00:00:00.564 --> 00:00:12.085

By introducing the presenters for today's webinar I am Emily. I'm the federal programs director for the division of developmental disabilities with damage.

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00:00:12.535 --> 00:00:25.855

We have Leslie Bradley with the federal programs unit and then we also have Janine and Barbara Brent from nasties, technical assistant team today to help us out with the webinar.

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00:00:31.140 --> 00:00:40.469

We get started by sharing the objectives for today's webinar. We'll go over what understanding an waiver and the services.

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00:00:40.469 --> 00:00:44.039

Determining eligibility for an waiver.

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00:00:44.039 --> 00:00:53.009

Reviewing the waivers specifically today the Missouri children's developmental disabilities are most kids waiver and the partnership for hope.

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00:00:53.009 --> 00:01:07.349

Waiver and then we'll, we'll give an overview of the renewal process, which is understanding the renewal process and gathering input from stakeholders which is our focus today, is that that piece of gathering input.

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00:01:10.859 --> 00:01:15.954

So, what is a home and community based service waiver program?

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00:01:16.314 --> 00:01:26.034

It helps provide services to participants who would otherwise be an institution, a nursing home, or a hospital to receive long term care.

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00:01:26.310 --> 00:01:36.329

In the community wavers are funded through Missouri, Medicaid dollars and, um, federal dollars.

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00:01:36.329 --> 00:01:44.250

The Missouri state had approximately 64% of the cost is through federal dollars.

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00:01:49.560 --> 00:01:54.989

To be eligible for a, for the developmental disability waiver.

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00:01:54.989 --> 00:01:59.400

We must be eligible through the Missouri division of developmental disabilities.

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00:01:59.400 --> 00:02:03.780

Via Medicaid eligible or male, health net eligible.

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00:02:03.780 --> 00:02:13.284

Determined by the Missouri family support division, have a need for intermediate minute care facility for individuals with intellectual disability.

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00:02:13.794 --> 00:02:21.175

You must meet the federal definition of a developmental disability, which with 3 substantial functional limitations.

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00:02:21.419 --> 00:02:27.240

Have an active habit sorry? Affiliation name.

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00:02:27.240 --> 00:02:41.550

Reasonable indication that the individual needs, or requires an ICF level of care, unless those services could be provided in the community by a community home and community based service waiver.

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00:02:41.550 --> 00:02:53.520

The, or the level of care is determined initially and then re, evaluate evaluated at least annually are specified in the proved waiver.

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00:02:56.969 --> 00:03:10.919

Damage our division of DD has 4 waivers that we administer and that's the community community support waiver the comprehensive waiver and the partnership for hope waiver.

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00:03:11.634 --> 00:03:23.935

No, kids waiver. I'm sorry, the, our, most recent 1 was the partnership for home labor, which began in 2010, and then our Mo kids waiver began in 995 and those are the 2 that we will focus on today's in today's webinar. And.

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00:03:28.590 --> 00:03:33.270
Move on to going over what's.

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00:03:33.270 --> 00:03:40.500
Some information about the little kids waiver, and I'll pass it over to Leslie Bradley to share information about the most kids waiver.

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00:03:40.500 --> 00:03:44.580
Thanks Emily. Good morning. Everybody.

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00:03:44.580 --> 00:03:53.969
In 995, as Emily said, Missouri implemented its Mo kid waiver the targeted population is children with developmental disabilities.

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00:03:53.969 --> 00:04:05.099
The division currently has the capacity to serve 366 participants in this waiver and the last located waiver application was approved by centers for Medicaid and.

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00:04:05.099 --> 00:04:14.189
Medicare and Medicaid services or CMS effective July 1st of 2018. so the next wave of renewal will be in 2023.

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00:04:21.600 --> 00:04:27.238
Just a quick slide regarding important facts about the MO, kids waiver.

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00:04:29.249 --> 00:04:38.124
This waiver serves, as I said, 366 kiddos and does not have an annual cost cap. The child must be determined not eligible for any Mo, health net program.

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00:04:38.124 --> 00:04:50.213
If the child has no health net spin down or premium, the family must explain why this is a financial hardship and cannot be met. The child must be living at home with their family.

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00:04:50.213 --> 00:05:04.673
And under the age of 18 to be supported in the milk. His waiver and this waiver is not for children who only need low Health Net or state plan services, such as private duty. Nursing, private duty. Nursing is not a service to them.

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00:05:04.673 --> 00:05:13.043

His waiver and the child must be determined to have an ongoing habilitated waiver service need. Which we'll get to in the next slide.

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00:05:20.098 --> 00:05:34.949

So, as you can see, there are 15 services included in the milk, his waiver to meet the needs and flexibility of the participant supported in this waiver and those include applied behavior analysis assistive, technology, community networking.

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00:05:34.949 --> 00:05:48.629

Community specialist, which allows self direction crisis, intervention, day, hesitation, environmental, accessibility, adaptations, home vehicle, modification in home respite.

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00:05:48.629 --> 00:05:53.788

Individual directed goods and services individualized skill development.

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00:05:53.788 --> 00:05:59.608

Out of home, respite, personal assistant, which also allows for self direction.

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00:05:59.608 --> 00:06:06.988

Specialized medical equipment and supplies or adaptive equipment, support broker and transportation.

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00:06:08.579 --> 00:06:15.598

And I'm going to pass it back to Emily so she can let, you know about the partnership for hope waiver.

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00:06:19.043 --> 00:06:27.894

Thanks, Leslie, the partnership for hope waiver in 2010, Missouri implemented the waiver. The partnership for hope waiver is the county based waiver.

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00:06:28.314 --> 00:06:34.584

That is the result of a partnership between the Missouri association of county developmental disability services.

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00:06:37.079 --> 00:06:42.389

The division of developmental disabilities and the mental health net division.

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00:06:43.978 --> 00:06:51.509

This line gives you a quick overview of the partnership for hope waiver. It has 25 services.

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00:06:51.509 --> 00:07:02.728

Participants in this waiver have a cap of 12,362 dollars annually. The number we currently serve under this waiver is approximately 2002.

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00:07:02.728 --> 00:07:08.939

258 individuals we have up to 3415.

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00:07:08.939 --> 00:07:21.178

Participants that can be served in this in this fiscal year. So 3415 slots available. And this 1, this waiver also was renewing and.

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00:07:21.178 --> 00:07:32.428

July of 2023 this slide.

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00:07:32.428 --> 00:07:46.019

You can see in this slide that the partnership for hope waiver is county based waiver and this map shows the counties currently participating with the division to provide services under the partnership for hub waiver.

47

00:07:51.899 --> 00:08:06.774

Some important facts about the partnership for hope waiver. It has an individual cost cap of that 12,362 dollars per person the county, and the division will pay half of the state match for the partnership for hope waiver participants.

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00:08:10.103 --> 00:08:21.353

The partnership waiver has a couple of services that are only provided under the partnership waiver and that's family, peer support, dental and temporary residential services.

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00:08:21.923 --> 00:08:30.774

The participant must be residing in the participating county and meet crisis or priority criteria to be part of the waiver.

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00:08:34.469 --> 00:08:42.298

Partnership for home waiver includes, um, 25 services, and those are applied behavioral analysis.

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00:08:42.298 --> 00:08:47.308

Assistive technology, benefits, planning and career planning.

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00:08:47.308 --> 00:08:55.073

Community networking communities, specialist, which also is available through self, directed option, community transition.

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00:08:55.344 --> 00:09:03.923

They have dental, environmental accessibility, adaptations or vehicle modifications, family, peer support.

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00:09:04.168 --> 00:09:09.119

Individual directed goods and services individualized skill development.

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00:09:09.119 --> 00:09:18.989

Job development, occupational therapy and personal assistant also available under self directed option. It includes physical therapy.

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00:09:18.989 --> 00:09:28.198

Pre vocational professional assessment, and monitoring by a registered nurse, licensed practical nurse or registered dietitian.

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00:09:28.198 --> 00:09:31.438

Specialized medical equipment and supplies.

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00:09:31.438 --> 00:09:39.058

Speech therapy, support, broker, supported employment and temporary residential services and transportation.

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00:09:43.288 --> 00:09:57.923

That was a quick overview of what's, what's part of the MO, kids and the partnership for hope waiver. And now we're going to go into the waiver renewal process, homeing community, based services. There 915 waiver applications for new every 5 years.

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00:09:57.923 --> 00:10:10.374

This past year we renewed the other 2 waivers the cop and CSW community support waivers and now we're gearing up for our partnership and hope and more kids waiver renewals,

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00:10:10.374 --> 00:10:13.014

which are set to renew in July of 2023.

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00:10:15.028 --> 00:10:24.719

The renewal process starts several years in advance of the renewal day, which which why we're starting already with this process in these webinars.

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00:10:26.124 --> 00:10:36.864

This next slide gives you just a quick rundown of the process, the way for renewal process. We start with our stakeholder input, which is what we are starting with in this webinar.

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00:10:37.193 --> 00:10:44.844

And then we move on to providing performance measure reports to CMS, to demonstrate our cost effectiveness.

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00:10:44.844 --> 00:10:58.553

And our waivers are supporting our individuals public comment, which includes an informal and a formal comment process. And then we, we review those changes and give them to mow Health Net.

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00:10:58.582 --> 00:11:00.624

To review those changes.

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00:11:00.839 --> 00:11:15.413

To our waiver application languages and then we'll have that submits the waiver application to CMS. And we have a question answer period with where we answer questions that CMS has for us on our waiver changes.

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00:11:16.283 --> 00:11:20.153

And to ensure that we're following CMS guidelines. And then.

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00:11:20.458 --> 00:11:28.619

Then we end with is way for approval and implementing the changes in the waiver language.

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00:11:31.048 --> 00:11:40.198

So, this next slide is to open up our stakeholder inputs portion of our webinar the focus for our.

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00:11:40.854 --> 00:11:51.234

For our webinar today, requesting feedback from stakeholders, individuals, families providers for the most kids and partnership waivers.

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00:11:51.624 --> 00:12:05.573

We want stakeholders to think about how the services provided in the waiver work for our individuals and our families, and how our services can be improved to better serve. Our low kids and partnership waiver participants.

73

00:12:06.894 --> 00:12:18.803

Right now I'm going to take time to introduce our guests with us today from the National Association of state directory, developmental disabilities or nasties as a part of this portion of our webinar.

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00:12:19.254 --> 00:12:30.803

We have gene Jeanine and Barbara brand from nasties. They're part of our technical assistance team and help Missouri and damage with our waiver language and guidance.

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00:12:31.078 --> 00:12:36.869

So, as I check the chat right now, for.

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00:12:36.869 --> 00:12:40.048

If we have had any chats yet, um.

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00:12:40.048 --> 00:12:43.739

Will go ahead and have Janine and Barb introduce themselves.

78

00:12:49.528 --> 00:12:53.278

Hi, uh, this is Jeanine. Just go ahead.

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00:12:53.278 --> 00:12:57.899

Oh, and my apologies that I am not able to be on video.

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00:12:57.899 --> 00:13:06.384

With you today, but I just wanted to introduce myself. I'm the director of, um, technical assistants and special projects that nasties.

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00:13:06.923 --> 00:13:18.474

We have been working with Missouri for a number of years now, and are really excited to be part of this stakeholder feedback session today. Please.

82

00:13:18.749 --> 00:13:29.609

Drop any comments or questions about anything with regards to Medicaid or the renewal of these waivers, and we would love to.

83

00:13:29.609 --> 00:13:32.844
Talk with you all barb. Yeah and I'm Barbara.

84

00:13:32.874 --> 00:13:47.724
Brent and you could see me talking way, but muted but and I am the director of state policy at and Janine had mentioned, we've been working with Missouri for a long time now on their waiver other policies and.

85

00:13:48.028 --> 00:14:01.499
Uh, different ways, so that they can support people disabilities in their families in the best way possible in your state. So we're here to support you help answer questions and they'll be here for whatever you need today.

86

00:14:05.038 --> 00:14:11.458
Thanks, Barbara and Jeanine, right now I'm not seeing any chats in the.

87

00:14:11.933 --> 00:14:24.384
Comments coming through yet I did want to offer if if you prefer unmuting yourself today to provide feedback or comments, please go ahead and do that.

88

00:14:24.683 --> 00:14:28.073
We have a smaller group on today and I think.

89

00:14:29.249 --> 00:14:37.048
We have the opportunity to unmute and please do we can handle chats in the.

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00:14:37.048 --> 00:14:44.759
To us to all to everyone, or if you'd like to unmute and provide some feedback or comments, please do that.

91

00:15:05.274 --> 00:15:05.874
This is Barb,

92

00:15:05.903 --> 00:15:08.573
if you're not familiar with this platform,

93

00:15:08.634 --> 00:15:12.774
because we go to from zoom to web X to a Google,

94

00:15:13.433 --> 00:15:18.594

the unmute button and mute button at that on my screen at the very bottom,

95

00:15:18.744 --> 00:15:20.693
it's got a little microphone,

96

00:15:20.693 --> 00:15:22.433
and you can hit mute or unmute.

97

00:15:22.703 --> 00:15:26.514
So, maybe that would be helpful because we'd love to hear what you have to say.

98

00:16:48.269 --> 00:16:52.198
I'm not seeing anything, uh, in the chat box to the host.

99

00:16:52.198 --> 00:17:01.619
So, for and I'm not seeing the panelists.

100

00:17:01.619 --> 00:17:12.749
I was just going to ask if there were any terms or any questions about what we just presented on about the waivers or if anyone wants to.

101

00:17:12.749 --> 00:17:23.368
To ask us any kind of questions about that, a particular service, maybe that was mentioned, or maybe talk about a particular service that they receive and and.

102

00:17:23.368 --> 00:17:27.358
Any ideas are input about, um.

103

00:17:27.358 --> 00:17:34.798
The the services and how they're working for them, or how they could work better.

104

00:17:36.328 --> 00:17:39.388
Possibly I know we have some new services that.

105

00:17:39.388 --> 00:17:44.128
That Emily, and I talked about such as individualized goods and services.

106

00:17:49.199 --> 00:17:54.028

That one's new, um, recently, benefits planning is a new service.

107

00:17:54.028 --> 00:17:57.568

That was recently added to the partnership for hope.

108

00:18:05.608 --> 00:18:09.449

We have a new comment in the chat um.

109

00:18:10.884 --> 00:18:25.584

Andre says, I am my family navigator and with our without local board in St. Joseph, Missouri I work with families and individuals in our local community to provide information and resources.

110

00:18:32.788 --> 00:18:37.888

Good morning Leander. Would you like to come off? Mute and.

111

00:18:37.888 --> 00:18:41.459

And ask us a question, or provide us with any input.

112

00:18:50.578 --> 00:18:56.009

And this is Jeanine, I just wanted a comment that, um.

113

00:18:56.009 --> 00:19:02.578

Such an important goal uh, and I wondered if you.

114

00:19:02.578 --> 00:19:10.288

Input from.

115

00:19:10.288 --> 00:19:16.138

Is that you may not hear about today on the call, but would love to hear from you since.

116

00:19:16.138 --> 00:19:23.969

Um, you are obviously spending a lot of time trying to connect families with needed, supports and services.

117

00:19:34.709 --> 00:19:39.239

Leandro is looking for someone to help unmute her.

118

00:19:44.788 --> 00:19:52.409

Hello, can you hear me.

119

00:19:52.409 --> 00:19:55.588

Yeah, we can hear you. Okay. Hold on it.

120

00:19:55.588 --> 00:19:59.429

For some reason that there's a lot of people.

121

00:19:59.429 --> 00:20:06.929

Okay, give me a 2nd. Okay.

122

00:20:08.243 --> 00:20:23.034

All right, so we got the feedback may be because your computer audio is on and you may be on by another device. So let's see what works.

123

00:20:24.929 --> 00:20:28.439

Hey.

124

00:20:29.489 --> 00:20:33.509

Well, let's see, let me see if I can do it.

125

00:20:33.509 --> 00:20:40.858

Alright.

126

00:20:50.848 --> 00:21:00.388

I'm trying to which 1 which 1 let me see here.

127

00:21:02.638 --> 00:21:07.259

Is this better? Yeah, I think so.

128

00:21:07.259 --> 00:21:20.189

Yep. All right. I just turned it down there. Yeah, I work I'm a family Navigator in St. Joseph, Missouri. We work with individuals and families within our community and we actually, you know, we all get phone calls from all over the state.

129

00:21:20.189 --> 00:21:30.749

Um, you know, people asking about resources services, we also can help them with the intake process if they're not familiar with and talk and explain.

130

00:21:30.749 --> 00:21:36.088

What that process entails? Um, how, what targeted case management what the wavers are like.

131

00:21:36.088 --> 00:21:45.179

Um, if they would qualify for a waiver, so any new information that we get or any updates I always like to have so I can pass that along to our families.

132

00:21:48.419 --> 00:21:57.689

Are there any questions that you get about, the services that, that you hear, you know, often or maybe from time to time about.

133

00:21:57.689 --> 00:22:02.098

Things that state our stake holders would like to see changed.

134

00:22:03.118 --> 00:22:11.338

It just got I'm sorry. Um.

135

00:22:11.338 --> 00:22:25.769

Did you ask just to reiterate that what, um, some of the stakeholders of the families are interested in when they, when they talk with us. Okay. Um, a lot of it is, what.

136

00:22:25.769 --> 00:22:30.838

You know, basically, community based supports what is what is available for families.

137

00:22:30.838 --> 00:22:38.098

In Northwest, Missouri, we don't have, I would say, as much as say the Kansas City area, even though, you know, we're only an hour away.

138

00:22:38.814 --> 00:22:52.763

And a lot of times families are looking for ways for their loved ones, or the individuals themselves to have more supports within the community to be more active within the community and the resources to do that.

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00:22:53.334 --> 00:22:55.314

So, those are the, some of the things that.

140

00:22:55.528 --> 00:23:10.078

You know, that we've kind of, we see and we, we work with all age ranges. We work from pretty much birth to aging. We work with you and Casey, we use charting the life course framework.

141

00:23:10.078 --> 00:23:13.078

To help families so we have.

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00:23:13.078 --> 00:23:27.834

A variety of what people are looking for within the community. We see, sometimes we can see trends. Sometimes a lot of our are things that the families are needing are school related. A lot of times we see families that.

143

00:23:28.108 --> 00:23:36.628

They have an individual that has been that a loved 1 has passed away. They've lived at home with mom or dad and.

144

00:23:36.628 --> 00:23:47.064

Then they have, you know, someone who's in their fifties and sixties, and they've never been plugged into. They've never had any kind of support and they're kind of at a loss as to how can we help this person?

145

00:23:47.064 --> 00:23:54.233

Because their parent has passed away and we want them to still be able to stay in their home or, you know, have some independence. So.

146

00:23:54.659 --> 00:24:09.479

We kind of cover the gamut, so any kind of information and anything that I can pass along to them that says, you know, Here's a way that you can be supported within it to stay within your home within the community is always great. So.

147

00:24:09.479 --> 00:24:12.838

Good morning am I can I be heard.

148

00:24:13.584 --> 00:24:28.314

Can you guys hear me? Yes. Yes. My name is Candida. Crawford. I am a parent of a waiver recipient. I am his legal guardian. I have had to become his legal Guardian, and now I am the designated.

149

00:24:28.314 --> 00:24:42.203

Rep. my son turned 21 on December 12th and and we've had the waiver for a few years, but I found out things that was not communicated to me through my supports.

150

00:24:42.203 --> 00:24:53.753

I found out that the waiver that we have does not provide for what he needs and what he's always needed when we got on waiver services.

151

00:24:53.753 --> 00:24:57.473
We were told that, well, I was told that.

152
00:24:59.189 --> 00:25:11.124
Um, the waiver supplements, what? Um, the bureau was doing health and senior services, they did not want to duplicate services and I understood that.

153
00:25:11.124 --> 00:25:23.513
So we had to stay within lines and what the they were offering for nursing hours for his care. He has always had a nurse. He's never had a nurse's aid. He's always had professionals when I get help to care for him.

154
00:25:23.723 --> 00:25:37.733
And so when the waiver came in, it did help in senior services. They have always had a problem with turnover and agencies having nurses and so when the waiver came in, it would allow us to go outside of that.

155
00:25:37.979 --> 00:25:51.538
Situation to supplement where we weren't getting what we were approved for, but we're not getting through, um, helping senior services and we've always employed nurses. Well, he turns 21 and I notice that.

156
00:25:51.538 --> 00:25:54.898
Um, the, the reimbursement.

157
00:25:54.898 --> 00:26:08.548
Was awful low what I could offer a nurse, and the nurses were working for the agency. They would supplement and come in and kind of do extra hours for, you know, to make up for, on self directed.

158
00:26:08.548 --> 00:26:17.699
And so when you turn the maximum that I could pay a nurse was 19 dollars and 75 cents.

159
00:26:17.699 --> 00:26:23.848
I start investigating. Okay, this is not a comparable wage for a nurse. The nurses, you know, they already.

160
00:26:23.848 --> 00:26:33.659
Still underpaid, but they're really underpaid at 975 and if you were at least an lpn, but we had our ends working in our home. And, um.

161

00:26:34.074 --> 00:26:48.203

So, I went to the powers that be, I started out at the regional office with my service coordinator, and she wasn't aware, you know what it was then she, she told me I kept asking for months. Who do I talk to about this?

162

00:26:48.203 --> 00:26:58.284

The transition is going to happen. Who do I talk to? Well, there's really nobody to talk to you that, you know, the allocation team they do this, they do that, and it's already, you know, that's what we have. We have to use that tool.

163

00:26:58.769 --> 00:27:11.094

To, um, to compute what you can pay. So then I started then I just took it upon myself to call the assistant director. Lisa Tracy.

164

00:27:11.423 --> 00:27:25.104

Well, Lisa Tracy, and I had a very good conversation, because she told me the waiver that we were on did not allow for nurses. It was just medical. And when I questioned that at the beginning, they said, well, that's just what they call them.

165

00:27:25.104 --> 00:27:32.933

They don't call them nurses, they call a medical so all of this time, I'm thinking that this is going to be what I need. So.

166

00:27:33.209 --> 00:27:44.249

Um, here we are at 21, we don't have anybody to come in and they have also told me that I have to have a nurse manage the case.

167

00:27:44.249 --> 00:27:50.038

And, um, by that means, at least in our end.

168

00:27:50.243 --> 00:28:01.673

And but you don't have a wage for a nurse and so that's kind of contradictory. And I'm just trying to figure out how I can make sure that we are he's covered.

169

00:28:01.794 --> 00:28:14.064

He has nursing care, which is what he requires with all of his cares. And everybody has known that from day 1, I want to know how we can bring get a comparable wage to not only the nurse that's managing the case.

170

00:28:14.308 --> 00:28:22.469

And nurses to come in here and care for him.

171

00:28:24.114 --> 00:28:36.953

Anybody Dina, this is Emily and I know we've spoke on the phone, um, and I'm glad you could attend today to share your, um, your concerns and your feedback. I know.

172

00:28:36.953 --> 00:28:41.874

That's a struggle that you've been experiencing with the need for nursing care.

173

00:28:42.388 --> 00:28:47.669

And the desire to stay on our DD waivers for our services.

174

00:28:47.669 --> 00:28:53.759

And the right that you're allowed to pay for that Jeanine.

175

00:28:53.759 --> 00:29:04.169

Or a bar, or Leslie do have any, any thoughts on, you know, that's something that we can, um, as part of the stakeholder.

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00:29:04.169 --> 00:29:08.519

Process we can bring that concern up to our division.

177

00:29:08.519 --> 00:29:13.259

Along with other concerns that have run, brought up to us and there are stakeholder meetings.

178

00:29:16.888 --> 00:29:22.588

Yeah, and I guess for for us to understand, uh, uh, can be, uh.

179

00:29:22.588 --> 00:29:30.419

What waver is your son receiving support from? Right? The community support waiver.

180

00:29:30.419 --> 00:29:37.858

The community support labor? Yes. Before your family's receiving support through.

181

00:29:37.858 --> 00:29:42.509

Medically fragile liver, but that was not under the division. Correct?

182

00:29:42.864 --> 00:29:43.794

We never received,

183

00:29:43.824 --> 00:29:48.023

we never received supports from their medically fragile waiver when,

184

00:29:48.054 --> 00:29:48.473

um,

185

00:29:48.503 --> 00:29:50.124

when my son turned 18,

186

00:29:50.483 --> 00:29:51.084

um,

187

00:29:51.203 --> 00:29:56.243

we had a meeting with my service coordinator with the Bureau of special health care,

188

00:29:56.243 --> 00:30:00.233

needs this coordinator from the regional office and I was presented.

189

00:30:00.263 --> 00:30:10.374

And when I said, when I asked for options, I was told that there was the medically fragile waiver that we could transition to at 21, or we could stay on the community support waiver.

190

00:30:10.374 --> 00:30:22.824

So when I asked for the differences between the 2, they were very ambiguous. And some, and so they said that what I was told at the time well, it depends on what you need. And I said, um.

191

00:30:23.969 --> 00:30:28.048

I need what my community support waiver has given me, but.

192

00:30:28.253 --> 00:30:37.314

Let me know if the medical graduate, but they said, well, they're medically fragile waiver only covers nursing hours and maybe diapers your community support waiver.

193

00:30:37.703 --> 00:30:48.203

Um, it's a little bit more, um, they cover my home modification, which I'm aware of, because that's how we got our handicap accessible van. It covers a whole modifications equipment.

194

00:30:48.384 --> 00:30:57.743

Um, some, some supplies, if needed that are denied by Medicaid and what else? Um, and it is going to supplement.

195

00:30:58.078 --> 00:31:11.159

You're nurse, I mean, it's gonna, it's gonna cover your nursing. Totally. It wouldn't cover. It was a supplement before, but now you can get more. This is coming from my service coordinator and so I said, okay, well, well, then.

196

00:31:11.663 --> 00:31:26.453

I need to choose the community support waiver versus medically fragile waiver. We received hours under the healthy children and youth program before before he turned 21. well, at 21 that's over.

197

00:31:26.453 --> 00:31:33.653

And so we just, we're going to transition everything just to do straight self, directed through the community support waiver.

198

00:31:34.618 --> 00:31:44.278

But now I'm finding out that that waiver is not comprehensive and it's kind of contradictory because if there is if they're saying that.

199

00:31:44.278 --> 00:31:55.709

Um, because we are not with an agency, we have to have a nurse manage it, but then they're telling me that this waiver doesn't call for nurses. But that's only the only thing that only, um.

200

00:31:56.153 --> 00:32:09.653

Discipline in healthcare, the children has had throughout this home at home. He's always had nurses. It was a letter of medical necessity that was given when we 1st came on human support about what his needs were what?

201

00:32:09.653 --> 00:32:22.673

The doctor, you know, wanted the, all of the cares in his plan of care is all delivered by myself or licensed nurses. Now, all of a sudden to realize, now, when I really need it, um.

202

00:32:22.949 --> 00:32:26.308

More than ever, because I don't have the.

203

00:32:26.308 --> 00:32:37.558

Helping senior services portion I don't have anything now and we're relying on our waiver. They're telling me that that's a waiver that doesn't.

204

00:32:37.558 --> 00:32:41.249

Doesn't have a nurse product or a rate for a nurse.

205

00:32:41.249 --> 00:32:45.449

But but it tells me that I have to have a nurse to manage the case.

206

00:32:45.449 --> 00:33:00.233

And nobody is going to come in here and manage the nurse that is willing to do it because she's worked with us before she is in our in, with a BSN, a bachelor's, a nursing and to ask her to take 975.

207

00:33:01.769 --> 00:33:07.469

To put her license on the line to make sure this case is running. That's not.

208

00:33:07.794 --> 00:33:16.614

Good well,

209

00:33:16.614 --> 00:33:17.933

for Janine and I,

210

00:33:17.963 --> 00:33:24.923

we would have to understand that specifics a little bit more than I think we could do right now.

211

00:33:25.199 --> 00:33:32.608

We can certainly have some discussion with the division about, uh.

212

00:33:32.608 --> 00:33:38.999

You know, the differences in what would be best for you and your son.

213

00:33:38.999 --> 00:33:52.949

Around the medically fragile waiver versus the DD waiver and it sounds like you gain some things from 1 and lose some things from another. But what's in the best interest of your son?

214

00:33:52.949 --> 00:33:56.969

And, you know, what are the other possibilities.

215

00:33:56.969 --> 00:34:01.828

I've been talking to people about this since.

216

00:34:01.828 --> 00:34:12.233

September, I finally spoke, like, I spoke with Emily I haven't spoken with the head of self directed. Um, that's, uh, I think, what is Tanner? I haven't spoken with.

217

00:34:12.264 --> 00:34:23.574

I've got several messages, but he refuses to call me back, but everybody tells me that well, you can go, but you can go. You can change way because you don't have to stay with community support. But why should he have to lose.

218

00:34:23.818 --> 00:34:27.088

What is being offered under that waiver?

219

00:34:27.088 --> 00:34:41.998

And I, and that's what he needs, he needs home modification. We're working on something now, trying to get some things to get him moved into a different part of the house and we will lose all of that. We'll lose those things that.

220

00:34:41.998 --> 00:34:46.559

Were working for us because.

221

00:34:46.559 --> 00:34:52.739

The waiver won't it just doesn't come and I don't understand how it doesn't cover it, but then they require it.

222

00:34:52.739 --> 00:34:59.909

So that's my and I have been talking to people. I've been talking I've talked to Lisa Tracy, I've talked to everybody, nobody.

223

00:34:59.909 --> 00:35:04.559

Number 1, they won't even acknowledge the fact.

224

00:35:04.559 --> 00:35:18.028

That is kind of not making sense to have to require a nurse, and they not have a product to pay a nurse, you know, to can pay the wage. And so nobody's acknowledging that. But is clear that.

225

00:35:18.028 --> 00:35:25.829

It's some language that needs to be, and if he's always had if they always had in the records, what he needed.

226

00:35:26.123 --> 00:35:38.364

Why would they? Yeah, I just the communication is what I guess I'm trying to bring out our service coordinators are not informed. And when you, I like I said, I didn't wait until the last minute.

227

00:35:38.393 --> 00:35:49.463

I've been working on this since he was 18 years old, and I just found out on December, 13th or 14th that this waiver does not cover nurses.

228

00:35:54.114 --> 00:35:59.603

Just found that out and so I've been asking what can be done we really need to stay on the waiver.

229

00:35:59.724 --> 00:36:11.094

We would like to, but, you know, because you're asking us to, to provide a nurse, we have I have nurses lined up to come and help my son, but they, they just really can't go as they can. They.

230

00:36:11.699 --> 00:36:15.148

They were paying these more.

231

00:36:15.148 --> 00:36:20.608

To care for him it's the same page. It's Medicaid so how communicate can't pay them.

232

00:36:20.608 --> 00:36:32.753

I don't want, I don't get, um, extra money or anything for taking care of Calvin. So I was I I asked if the nurses could be paid what they were being paid through Medicaid through the agency 25 dollars an hour that's 6 more dollars.

233

00:36:32.753 --> 00:36:35.873

5 dollars in 75 cents more or 25 cents more and.

234

00:36:37.588 --> 00:36:42.449

No, just to continue the services, so he's not lacking for care.

235

00:36:48.893 --> 00:37:01.434

Well, I think you ladies, I guess, you know, it's dumped everybody in. Well, I'm so sorry that, um, Ken. Dana, this is Emily. Can you? Yeah. Can you put in words what you would like to see changed?

236

00:37:01.673 --> 00:37:05.574

I know you mentioned communication because you worked hard to.

237

00:37:06.239 --> 00:37:16.949

To do that upfront and then felt like you didn't have the right information when it came down to the end. You also have mentioned being able to keep your nursing services.

238

00:37:16.949 --> 00:37:26.938

At the rate that you had in with DHS, so let me be completely honest and transparent here. Um.

239

00:37:26.938 --> 00:37:31.798

I have not had a nurse in my home working with my son in 9 months.

240

00:37:31.798 --> 00:37:39.478

I've been doing this all by myself because of the shortage because of, um, just different. Um.

241

00:37:39.478 --> 00:37:48.659

Challenges that I know that is everybody is facing across the board the hospitals, the agencies, everybody, there's a nursing shortage. There is.

242

00:37:48.659 --> 00:37:52.378

A lot of different components that.

243

00:37:52.378 --> 00:37:59.938

Are lacking, or or out here, that makes makes us lack nurses that are available. So.

244

00:37:59.938 --> 00:38:13.793

I, you know, I knew this was the year for transition and I knew that a lot of times nurses, I have nurses that will work with us and because they didn't like the agency or how that runs. They went volunteer hours sometime.

245

00:38:13.974 --> 00:38:28.224

And so I've been talking to them over the last 6 months, you know, we turned 21, and we'll go straight self directed and then in self directed. I don't have to do an agency. I'll just have to have a manager, and I'm like, would you be willing to come to work or kill bond and you don't there? And they were like, um.

246

00:38:29.099 --> 00:38:42.869

Sure, she was like, oh, yeah, this we were going to make the same money and everything, and I don't have to deal with the agency and I have to deal with just, um, in our end, she said oh, yeah. That that all that red tape is, you know, cut out and I was like, okay and so.

247

00:38:44.094 --> 00:38:57.114

I, when I was talking to my service coordinator, I said, well, you know, brighter days are coming. I have nurses that are going to come in here and work. I found an, an R, in that's work with us and she didn't mind because she knows, calvin's care.

248

00:38:57.414 --> 00:39:04.045

Um, and, uh, she doesn't mind coming in and managing the case. She said she'd even work some hours.

249

00:39:04.199 --> 00:39:17.784

And so I said, so, I said another required is just to be paid for 25 dollars that they've been, you know, being paid. And so when Caitlin said, well, no, you have to you can only pay 975. that's the max. And so I started researching and so I would like.

250

00:39:19.650 --> 00:39:33.414

So, I'm not asking for them to make, you know, like, the that works that works with us. Sometimes in her real job, she makes 55 dollars or 57 dollars an hour. We're not asking for that and she's not asking for that.

251

00:39:33.414 --> 00:39:41.635

And when we sit down and had a real conversation, she said, kinda, it's more about I want Kelvin to get some help. But then you got to, it has to make sense.

252

00:39:41.635 --> 00:39:51.204

She was like, they want me to put my license on the line for everybody that works here and want to pay me 975. she says, that's just that's just not going to fly.

253

00:39:52.014 --> 00:40:02.215

And she said, I want to be honest with you, she said, for me, it's really not about the money, but it's about what I, what I am responsible for. And so I've asked my service coordinator.

254

00:40:02.215 --> 00:40:15.835

Could she please give me a list of duties and responsibilities for the R in that's managing the case? I still haven't got it, but it doesn't matter because we still don't have a rate to pay her.

255

00:40:15.835 --> 00:40:23.034

She's not going to except 975 and neither of the other nurses that they agreed to come in here. So when I'm thinking, okay, things are gone, I'm looking forward to.

256

00:40:23.034 --> 00:40:37.074

Okay, he's entering 21 and we don't have to worry about the agencies and this and that and, and I've recruited these people that have worked with him before and had been loyal. Like I said, they will come and donate hours. They'll say I know you haven't had anybody do you want to go take a nap?

257

00:40:37.074 --> 00:40:48.474

I'll come over here and I'll let, you know, and they're licensed and I don't the brighter days are not here. I'm still struggling. I have not I still haven't had here or help consistently. We just got to the hospital for 12 days.

258

00:40:53.130 --> 00:40:59.130

Um, and I've come home by sun. Um, excuse me.

259

00:40:59.130 --> 00:41:13.409

He has Christine skin. I work my tail off in here every day taking care of your making sure he doesn't break down. He is a total care. He doesn't move. He's dead weight. He has a chart we go into the hospital.

260

00:41:13.409 --> 00:41:21.269

3 days later, he's probably D*** and they released to me with no nursing help to dress his wounds.

261

00:41:22.289 --> 00:41:25.590

They caused that and so.

262

00:41:26.094 --> 00:41:40.735

I'm sorry, for getting emotional because that's still fresh because I was struggling to do just as basic care because he has a tracheostomy. And when I told the doctors, I said, you know, I hate to say this because I know what you're going to say.

263

00:41:41.094 --> 00:41:43.255

I said, I don't have.

264

00:41:44.635 --> 00:41:58.764

I don't have the manpower to care for his wounds properly and they was like, well, have you made him and now they start asking questions. I said yeah, I said, well, what, you don't understand. While I have him turned up and I'm dressing these wounds.

265

00:41:58.764 --> 00:42:01.614

I'm cleaning and dressing who's managing the airway.

266

00:42:03.090 --> 00:42:12.179

And they were like, oh, yeah, they don't think like, and I'm thinking about everything and I'm not trying to say that. And so, you know, what was offered to me.

267

00:42:12.179 --> 00:42:17.070

Well, we, we can find Kibana a bit in the nursing home until the heels.

268

00:42:17.574 --> 00:42:30.175

That was what what was offered and I declined and I can wrap my son home and I'm trying to figure it out, but it would sure help if I could get nurses in here to help me. Because I do the heavy lifting.

269

00:42:30.355 --> 00:42:37.554

It's not that I want somebody, you know, so I can run off and go do whatever. I've been here committed for 21 years.

270

00:42:39.474 --> 00:42:53.425

And there's not, there's not a plan for him now that he's turning 21 you guys, this is only the tip of the iceberg, the nursing, the change. Everybody is all changed and nobody wants to work with Medicaid for adults.

271

00:42:54.179 --> 00:43:02.039

And he's in an adult now. Yeah, it's been so many challenges the time he's supposed to be.

272

00:43:02.039 --> 00:43:14.550

I'm supposed to be really happy and and just just grateful that he's 21. they told me he wasn't going to live to be 2 weeks. You guys he's 21 and I'm crying every day.

273

00:43:14.550 --> 00:43:19.860

For the last 3 months because of all the changes just because he's still here.

274

00:43:19.860 --> 00:43:23.250

And I just don't get it and so I.

275

00:43:23.905 --> 00:43:37.735

I don't know, I just probably shouldn't. Yeah, but I appreciate you guys listening like Emily like, I told you, but I'm just not getting any answers. We've been dealing I've been talking about this for the last 3, 4 months.

276

00:43:38.340 --> 00:43:42.389

Just trying to figure out what, and I'm here now and.

277

00:43:42.389 --> 00:43:45.480

I don't I still don't I can't get the help that I need.

278

00:43:47.400 --> 00:43:51.989

I can't get the help so, um, I understand that.

279

00:43:51.989 --> 00:43:59.519

This platform for it was for, but I was told, I was given this information and this is the 1st time I've ever been invited. Um.

280

00:44:00.534 --> 00:44:09.505

To come on when you're talking about waivers. I would've loved to have been a part of the process when the community support waiver came up for renewal or, you know.

281

00:44:09.534 --> 00:44:17.454

Um, but this was the 1st time, because I was like, well, how do I know when this and Lisa Tracy sent me the email and she and so I made a point to come on.

282

00:44:17.849 --> 00:44:31.019

But I just needed some help and just to see if there were some answers as to what besides okay. Just cut all that off and just go back to the, um, medically fragile way to go transition to the medically fragile labor. Um.

283

00:44:31.019 --> 00:44:34.530

I don't know why he has to, you know.

284

00:44:34.530 --> 00:44:42.090

Not have what he needs comprehensively.

285

00:44:48.385 --> 00:44:54.775

Thank you, thank you can't Dana for sharing. Honestly, this is that's what we were.

286

00:44:54.804 --> 00:45:05.755

We were hoping for input and and that is sometimes not good input as far as the struggles that you're experiencing and your son is experiencing.

287

00:45:06.449 --> 00:45:12.300

So, we appreciate the input. I know you've been working hard for your for your son.

288

00:45:12.300 --> 00:45:16.559

Advocating for him, getting what he needs and you're tired.

289

00:45:16.559 --> 00:45:22.980

Okay.

290

00:45:27.085 --> 00:45:32.335

You guys that don't complain I sit here and day after day and do it and I,

291

00:45:32.335 --> 00:45:37.974

thank God every day for the strength and he gives me for me having a peace of mind that I can do it then I really,

292

00:45:37.974 --> 00:45:38.275

you know,

293

00:45:38.275 --> 00:45:39.235

we were in the hospital,

294

00:45:39.264 --> 00:45:42.804

and I really I don't consider myself special.

295

00:45:42.835 --> 00:45:55.795

I don't consider I'm just doing what I need to do a mother lemon or kid right and these nurses, they were just falling all over me. Oh, my God. Look at his teeth. They're so good at looking at scanning mom.

296

00:45:55.795 --> 00:46:05.784

You do this by yourself you don't have any yet and I'm looking at them. Like, they're crazy. I'm like, I was like, I was starting to get irritated. Okay. Why are we still talking about kill bomb being clean and so.

297

00:46:06.059 --> 00:46:09.300

1 of the nurses came and told me she was like.

298

00:46:09.300 --> 00:46:13.679

You really don't know. Do you and almost like know what? And she said, like.

299

00:46:13.679 --> 00:46:17.190

You have an incredible individual. She was like.

300

00:46:17.190 --> 00:46:26.010

You have for 21 years, and he doesn't have this. He doesn't have that. Even the kids that are taking care of. Well, they.

301

00:46:26.010 --> 00:46:36.989

Have problems because of things that are not being done right? And she says, I, she said, so you have to know that. You're incredible. And I'm like, and I'm sitting there thinking, like.

302

00:46:36.989 --> 00:46:41.969

People just don't do this for their kids. I mean, people don't do what needs to be done and I know.

303

00:46:41.969 --> 00:46:49.829

I'm sure there's kids like myself, but I'm like, this is his need and this is what we have to do so it's just.

304

00:46:49.829 --> 00:46:54.780

I never ever thought about it like that, but it gave me a sense of.

305

00:46:54.780 --> 00:46:59.369

Dang, I'm pretty bad with this. I mean, I'm really I'm doing this.

306

00:46:59.369 --> 00:47:09.985

And so it, it gave me a little piece of encouragement, because sometimes I do feel like, you know, the more I do the more I do, you know, am I doing better for him? And I am I right and keeping him in my house.

307

00:47:10.255 --> 00:47:14.994

But Kelvin is thriving and they were, you know, and so they really gave me.

308

00:47:15.510 --> 00:47:19.949

Um, a different way to look at this.

309

00:47:19.949 --> 00:47:25.800

I didn't think, I mean, I just didn't think that I was anything special. I didn't think that.

310

00:47:25.800 --> 00:47:36.750

Um, you know, everybody's not getting this, all the kids like him, or are not getting this. Well, I know there are some kids that are neglected and, you know, those things, but I just didn't know that. And.

311

00:47:36.804 --> 00:47:51.744

As hard as I've worked as hard as I worked, and I don't complain I'm not calling the 8 when we didn't we worked with I didn't call the agencies. And how come I don't have a nurse every day I didn't call because guess what?

312

00:47:51.894 --> 00:48:05.784

If I don't have a nurse, I gotta do it and that's what I learned a long time ago. The nurses are not guaranteed, they're scheduled or whatever, but they're valuable. And so I had to learn everything I needed to learn about my son. And so I've done that.

313

00:48:06.864 --> 00:48:12.025

And from what they say, I'm really good. I've done I've done a justice.

314

00:48:12.474 --> 00:48:12.804

I've,

315

00:48:12.864 --> 00:48:18.385

I've not putting the burden of him on a nursing facility where he wouldn't survive,

316

00:48:18.715 --> 00:48:22.014

but I keep him home and I do,

317

00:48:22.735 --> 00:48:24.144

especially since Coby,

318

00:48:24.324 --> 00:48:26.005

I have not been out of my house,

319

00:48:26.005 --> 00:48:28.675

except for a doctor's appointment since April 12.

320

00:48:31.139 --> 00:48:43.139

I don't go to the grocery store. Somebody else has to pick my produce and their horrible at it. So I don't even order produce like that anymore.

Um, so I make the sacrifices for him.

321

00:48:43.139 --> 00:48:47.280

And I don't complain. This is he's my son.

322

00:48:47.280 --> 00:48:50.579

But I, there is a system that is supposed to be set up.

323

00:48:50.579 --> 00:48:55.949

To give me help and it's failing me right now, because he's 21 years old.

324

00:48:56.844 --> 00:49:03.085

And still here still viable, the DMV company that, and we haven't even gotten a new DMV company. This is crazy.

325

00:49:03.355 --> 00:49:13.554

The company that we're trying to get with told me that they had to do a verification through Medicaid and then they said, well, we have to do a prior authorization for his feeding.

326

00:49:14.155 --> 00:49:20.184

I said for his feeding for his intro supplies, he said, yes, and it could take a few days and I said.

327

00:49:20.489 --> 00:49:27.690

So, what is Medicaid expect? See, this is not anything new and so I'm supposed to stop treating him at 21.

328

00:49:28.860 --> 00:49:34.739

And so whatever the authorization comes back, and if it comes back is determined on what they would, um.

329

00:49:35.664 --> 00:49:48.025

On how, if they would extend to them and, because that's mainly what we need from this company. Now, we have 4 different companies that don't really want to work with Medicaid. They kept saying that, well, you know, he should be getting Medicare when he turns 21.

330

00:49:48.025 --> 00:50:01.135

no, Kelvin is not eligible for Medicare. He's not eligible, and I had to keep telling these people that because 1 company accepted us thinking kill mom was going to be on Medicare and they accepted this and I thought it was all good and grant. And then they sent me a letter in the mail.

331

00:50:01.135 --> 00:50:13.914

Didn't even call me sent me a letter in the mail that they are, are not able to take another Medicaid patient. If Kelvin had Medicare they literally said that to me. So I have a 21 year old son.

332

00:50:14.909 --> 00:50:19.409

With limitations with his insurance for things that we have been doing.

333

00:50:19.409 --> 00:50:25.590

I mean, yeah, so I just don't know. And this is just and you're right I'm tired.

334

00:50:25.590 --> 00:50:37.585

That of hearing that, because he has meditated, he's 21 that he's denied this, or deny that Medicaid denied his wound supplies for the wounds that he got in the hospital.

335

00:50:37.585 --> 00:50:49.914

They denied the supplies who has heard of that. So, now they have to go through an exception process and I'm, like, really? So yeah, but.

336

00:50:50.670 --> 00:50:58.889

I'm tired, but I keep on going wherever, you know, God gives me the strength, you know, I'm still going to do it today.

337

00:50:58.889 --> 00:51:05.880

Is not going to be another day because Calvin deserves better. He deserves me to do everything that I can.

338

00:51:12.690 --> 00:51:26.909

Thank you Dana for sharing and we truly appreciate you coming to the webinar and, you know, in communication after this webinar if you know, with your with your comments.

339

00:51:28.289 --> 00:51:31.679

Okay.

340

00:51:31.679 --> 00:51:41.369

We are coming to the end of the hour if there's anyone else who wants to provide feedback or in the chat or on on mute.

341

00:51:41.369 --> 00:51:46.440

Often, if that would be, we have a couple minutes left. Um.

342

00:51:47.545 --> 00:52:00.414

I just wanted to share some resources for for these waivers that we've talked about today the, we have a waivers fax sheets, kids, eligibility requirements and partnership for hope. Summary.

343

00:52:00.414 --> 00:52:02.965

That's available on our website.

344

00:52:03.059 --> 00:52:05.244

And then also,

345

00:52:05.724 --> 00:52:15.414

please feel free if you have feedback or comments that you didn't share today or you think of after this after this webinar and want to share,

346

00:52:15.835 --> 00:52:20.514

please send those to the D mailbox at mail.

347

00:52:20.789 --> 00:52:34.829

At damage dot Mo dot Gov and you can address those to Emily or Leslie Bradley, and just mention it's feedback or for the waiver renewal process and we'll get those will get forwarded to us.

348

00:52:34.829 --> 00:52:45.599

So, I want to thank everybody for attending today. Everybody who shared and provided us feedback. Um, we're taking these notes down.

349

00:52:45.599 --> 00:52:50.519

They are things that get brought up to our division for discussion.

350

00:52:52.769 --> 00:52:56.099

And we can use these lessons.

351

00:52:56.099 --> 00:53:00.570

This information is lessons learned as well for our staff and our out there.

352

00:53:03.690 --> 00:53:13.289

So, I appreciate your time I want to thank Leslie and Janine and Barb for joining us today and being part of this discussion and everybody who attended online.

353

00:53:13.289 --> 00:53:24.059

The recording of this presentation will be available online as well on our website. Um.

354

00:53:24.059 --> 00:53:28.260

Cat, you can remind me what's available and where it's at. If you.

355

00:53:28.260 --> 00:53:32.789

Thank you, um.

356

00:53:32.789 --> 00:53:37.679

It's the transcripts and the recording and the PowerPoint itself will be, um.

357

00:53:37.679 --> 00:53:44.760

Attached to the webinar that's on our main, um, division DD webinar site.

358

00:53:44.760 --> 00:53:53.610

So, if a person wants to get that, just go back to the page, um.

359

00:53:53.610 --> 00:54:01.199

And go where the webinar, and go to the Webinars and type in 2020.

360

00:54:01.199 --> 00:54:07.050

2, I mean, you'll see it, it'll say 2021 2022 and it should be attached there.

361

00:54:07.050 --> 00:54:17.880

You'll see it at the bottom, it'll, it'll show the description and everything that you saw when to attend this meeting and then below that, you'll see it as an attachment.

362

00:54:21.449 --> 00:54:25.260

This should take it should be there within the week within a week.

363

00:54:25.260 --> 00:54:29.909

Okay, thank you. Thank you. Everybody and go by birthday.

364

00:54:29.909 --> 00:54:33.588

Thank you.