**Transcript: CVI for the TVI The Alex Program May 18, 2021**

>> Cathy: Welcome to Perkins' learning, today is Tuesday, may 18th and my name is Dr. Cathy submit. Today, the program is the ALEX Program and one state's approach to building competence around CVI will begin in a moment. You may register to attend live at no fee or view

recorded webinars at a time and place that suits your schedule. The CVI for the TVI and other professionals webinar series is just one of the offers in our professional development program which includes publications, e-newsletters and online classes and self-paced studies. You can see our entire listing at our website, PerkinseLearning.org.

You can support resources for families and those who support them at @perkins.org and this will be available in a tutorial form, information will be available on the webinar page with more details. On today's call, we're talking about one program, designed to build competence

at a local level. This model will spur your thinking, toward how you can build a similar network of support in your area of the country. The ALEX Program, a program of Easterseals from central Illinois was born from one family's struggle for diagnoses, support and education,

due to the tireless efforts of the today matchup overfamily, the regional program was designed for the purpose of building competences in professionals and supporting families. Through ALEX Program for CVI, Easterseals provide the family in their area with high-quality service

the. Before we get started, I'd like to review a couple of things about the technology. To keep noise levels in control, we've muted your lines. A Q & A space is available at the bottom of your screen and we encourage you to post questions as they occur to you during the

webinar and we'll address them at the end, during Q & A. Hover your mouse at the bottom of the screen to open the tool bar, chat and Q & A are both provided here. You may decide to keep them open on your screen.

We're using the virtual meeting room for audio, you have individual control over your audio level, make sure your volume is on and turned up.

External speakers or personal headphones give the best audio.

Captions are available by locating the closed caption and full transcript toggle on the bottom menu within Zoom. This is being recorded and will be available on the Perkins website. Including the download of the slide presentation and transcript. Thank you for joining us for

this event. We appreciate your feedback and topic suggestions and now, it's my pleasure to introduce today's speaker. Dr. Mindy Ely and Susan Sullivan.

I've learned so much from both of them during the early childhood visual impairment alliance meetings and I'm excited to hear about their latest endeavor with the ALEX Program with CVI.

Mindy is a cofounder of the -- of the division of the association for education and rehabilitation for persons with visual impairments and along with Susan and melody coauthor of position papers roles and responsibilities of vision educators when learners have CVI. In 2020,

Dr. Ely partnered with Easterseals of central Illinois as they launched the ALEX Program for children with CVI.

Susan Sullivan is the Cerebral visual impairment lead of Easterseals in central Illinois and the finds of the neurological visual impairment division of the association for education and rehabilitation for persons with visual impairment.

Take it away ladies.

>> Dr. Ely: Thank you for that introduction, you introduced me and I'm the professor at Illinois state university and serve as the research lead on this ALEX Program for Cerebral visual impairment. So N -- my name is Mindy Ely.

>> Dr. Sullivan: Thanks, Cathy. My name is Susan Sullivan, I've served in the field (muffled audio). A project leader at the (indiscernible) house for the blind and currently at the ALEX Program.

We would like to welcome you and as stated, the ALEX Program, named after a young man, approved on the screen, who has CVI, his family fought for years to raise awareness and education and multidisciplinary support for this population. You're going to learn more about this

program in just a bit.

Today, what we're going to learn about is first, going to identify strengths and gaps of organizational competency. And we're going to define competency and high-quality for programs and service planning. And we're going to describe the elements of the ALEX Program as an

example of high-quality service.

>> Dr. Ely: To begin with, we're excited to tell you about a dream that Susan and I have had for many years, we're seeing it come to fruition and we see it as something that could happen in other states as well. Let's begin by talking about the need and opportunity related to

CVI in our states.

We've all known about CVI for many years and for several years, we have tried various strategies with students and I don't know about you, but I felt like I was isolated as I did all of this. I was the only TVI in my area and I had support, but few and far between, but the

colleagues I had, I didn't have enough time to talk with them, either whether -- enough time as far as frequency goes and just enough access to them to really get ideas to brainstorm ideas with my colleagues.

However, in the midst of all of that, I really felt like we did an okay job of serving students, but we always wanted to do better and so there was definitely a need around CVI to better prepare professionals to allow for collaborative growth and so we saw this program as a way

to do that.

And in recent years, we have seen an explosion of growth on the CVI front and that's really exciting and as far as, you know, in our ideas we felt like there were two really essential things that became apparent. Number one, those of us who had been studying CVI for many years,

had developed good skills. But many of us felt like there were some students that we just had hit a wall with. We couldn't -- we needed new ideas, time to brainstorm with colleagues and time to study, so we just needed more for some of the kids on our caseloads.

And we needed time to get that done. Time to tackle those tough cases.

So it seemed like sharing and providing a space for sharing, learning and growing would meet a need.

Then secondly, there were new people in the field, and they might be recent grads or for whatever reason, hadn't immersed themselves in CVI for the past 20 years or so and they also had need for growth and sometimes their needs were applying basic ideas that were available

through trainings. But what might really help this group would be mentor ship from those who were more veteran teachers and who had been studying CVI for many years.

So basically, we found ourselves in a place where we were ripe for growth and we, meaning as a state. We're ripe for growth in the area of CVI.

In fact, we felt like with support we could strengthen our workforce at a local level and maybe even grow to be CVI experts.

It's great there's information at a national level, but we felt that personal mentorship and support could help practitioners really change their practice and apply some ideas that were individualized for their needs so we could support one another at a state and local level to

meet state and local needs in assessment of students with CVI and then those ongoing support need that's those teachers had.

So quick one more time -- click one more time.

Another big hurdle for us was diagnostics, so we continue to have difficulty in getting diagnostics for kids. As you know, a diagnosis is important for services and searching out diagnostics at a national level is just not feasible for many families so we would like to help our

local doctors learn to diagnose children, just children who come into their clinics.

So kind of in a nutshell we see our -- our vision was all about partnership and growth.

Next slide.

Therefore, we saw solutions around communities of practice.

Such partnerships can help veteran teachers and the teams they work with so solve problems by hutting their heads together and in we do this, we can share what we're learning and everybody benefits and we also felt like new teachers could be mentored to become leaders and experts

and in so doing, we could build competence and confidence this nose enough teachers.

Next slide.

So let me tell you about this central Illinois family. The Camochos, who had a son named Alex and he had Cerebral visual impairment. They struggled to get a diagnosis and then struggled to find providers who really knew CVI and could address their son's needs so they decided to

act and raised funds for several years to address the problem and then donated the funds to Easterseals of central Illinois and Easterseals was able to conceive the ALEX Program for Cerebral visual impairment. And it just launched last year, kind of in the midst of COVID, so

that was -- that was a little -- put a little bit different spin on the plans, but they were able to launch and we were able to get things done.

We're going to show you this four-minute video secreted to announce that program. But it will also give you an idea of the vision behind it and then spend the rest of the time today, looking at the specific components of the project and those we believe will raise up local

experts through communities of practice.

And then there's several of these components we really see as a valuable model that could can copied in other parts of the country.

(video).

>> CVI is when the visual system has a hard time interpreting what is visually seen. It's nothing necessarily to do with the eye itself, but the unique thing about is it's an issue with the brain and the connections between the brain and eyes. Interpreting what you're seeing and

being able to file that and retrieve it and bring it back.

>> CVI is the only visual impairment we can help students improve the way they use their vision.

>> Teachers often get to be the first ones to see a child have a visual reaction and you'll see the joy on the parent's face when they realize my child is not blind. My child can see.

>> Kids with CVI can present in many, many different ways, but there's some things that we frequently see with kids with CVI. A lot of times, when the environment is really busy, they have a hard time using their vision and so we talk about visual clutter. Being something that

is difficult for kids. And interdisciplinary people approach to the evaluation and treatment and support of children with CVI is absolutely necessary. In order for children with CVI to have the best outcomes they need consistent strategies and supports across all settings and

environments because they're brain is trying to figure out what they're seeing and if you show them one object on a plain background to reduce clutter, and give them a minute, their brain is doing work to figure out what it is they're seeing. There's no one set treatment

protocol. There's -- it's important to have the individualized multidisciplinary assessment to identify what the child's individual needs and skills and the best way to provide the care to them.

>> I look at them as being a puzzle box and you have to find the right key to unlock the puzzle that can allow the child to learn. It give us you a sense of accomplishment when you see the child making progress.

>> If there's one thing I could tell someone, is not to ignore it. If you feel very strongly that something is there and someone is telling you it's not, maybe they're not the right provider. You need to find the next one.

>> Can you imagine as a parent or a grandparent or an aunt or uncle that you walk into a room and the child that you love so much doesn't recognize you? Or even aware you're there. And then all of a sudden through rehabilitation strategies and educational strategies that child

has now learned how to use their vision and you walk into the room and you get to experience seeing that child look at the parent as if for the first time. Or recognize their parent in a photo album. There's nothing more powerful than the human connection and every child and

parent or caregiver should have that right to have the opportunity for the most potential to have that connection with people they love.

And I think at the heart of the passion why we're doing this and why it's important, when you know that there are strategies that could help kids have that connection, there's nothing more powerful. Everyone deserves that.

>> There's never a better time to do that, right, than right now.

>> We're maybe starting small, but we're starting and it's going to be exciting to watch.

>> It's time to make the bigger impact. Beyond just what happened in the laws of Easterseals, it's time to make the impact for the entire community, there's an opportunity to help families and help children.

And to change lives.

>> Dr. Ely: Okay. So that was the community awareness video that kind of announced the start of. Program. Now we want to communicate to you, the different pieces of this program and let you think through how this might be something that would work in your state.

So the first thing that we wanted to do was we wanted to come alongside school teams and -- especially school teams that had kids on their caseloads diagnosed with CVI that needed support and they needed to -- they were team that felt like they had reached the end of what they

knew to do. Team that is just needed to brain storm new ideas.

So those that were already diagnosed and school team that is needed help. We wanted to come alongside them and brainstorm solutions to difficulties they were having, but couldn't really have an in-depth conversation without knowing the child and the child's needs.

So we began with an assessment.

So go ahead and click, Sue. Through the assessment, we get to know the child so we can come alongside the team and it drives the rest of the work we'll do with the educational team and makes our work with the team into a case study approach.

So that we can learn from one another based on that real case study and not hypotheticals as you do in a traditional training situation. So we really felt that -- we didn't want to be seen as the experts, but instead we had to know the case before we could help and brainstorm

through. So the assessment brings us up to speed.

And then secondly, we also wanted to use this time to be able to try out new tools so we were going to study different assessment tools. There's a lot of new tools that are coming out and we were trying those and we ourselves are learning right alongside the team. How the tools

might be beneficial and which students the tools may or may not be beneficial with. And with that, we think in the future when we'll be able to give some insight into how and when to use a variety of tools.

So the next thing is we also thought that we wanted to work on developing functional vision assessment and learning media assessment report formatting. Again, in our discussions and through some of the other project components you'll hear about in a few minutes, we're finding

out what is and not helpful for other members of the team and parents and for example, philosophically, we want our FVA's to be parent focused and we begin the assessment by learning the parents top three priorities and that becomes foundational as we craft the assessment itself

and we have been using the questionnaire that's available from the CVI, PIMD, that's the tool by Wollroth and Steendam and we use other things as well in putting that together and -- as well and putting that together. And what are they finding useful and what information is

helping them to build ongoing programming. That's what we're exploring.

And the other thing, our assessments are multidisciplinary, so we're using within -- in addition to the FVA and the LAM, we're doing speech and occupational therapy and it's a component that had stalled a little bit with COVID and we're trying to figure out thousand do it in a

different way given the formats that -- not needing so many people in one

room and things like that. And we were intending to work on finding ways to truly integrate the findings into a cohesive and interrelated outcome that teams could develop and use to develop cohesive

plans for the students and we're working on the details for that. But Easterseals has much experience through their well-established autism clinics and we're learning from them and what they've done in the past as far as autism and their multidisciplinary clinics and we think

our assessment findings will be able to consider the whole child as we learn how do that and better.

So while our assessment results -- they provide information about the child, they provide information to -- about the child to the family and to the team, that's really not our main purpose. We're assessing so we go can partner with the team each of whom touches more than just

one child. That team is -- they work with that one child that we're actually assessing, but they see other children as well so by coming alongside them and brainstorming through problems or brainstorming solutions they can then use those skills with the other children they work

with. I think of pebbles in a pond. Working, using the one case study to identify needs and learn and then that is going to ripple effect out to all of the other kids that that team is working with.

So together we're learning and sharing and together we're growing and then the purpose then is that the team is go going to take that learning to enhance services for other kids and that particular child as well.

So we're again, not trying to be the experts, we're trying to come alongside and grow the skills and eventually across our state by coming alongside.

So then the other group of kids are those that are not diagnosed and what about those that need diagnostics. That component is one we anticipate adding this coming fall and we'll have a diagnostic clinic and we've partnered with a optometric school. We're working on the agreements for this, but this component will expand our scope to children not yet diagnosed and we plan to complete the FVA and the LAM simultaneously with the doctor and together learn from one another and this will inform work going forward. And, however, there are other benefits, since we're benefiting with a school, the new graduates go into their practices with experience in CVI diagnostics so this should build the medical workforce over time as the professionals go into practice across our state.

Okay.

Turn it over to you.

>> Dr. Sullivan: Okay.

So after the assessment has taken place, Mindy and I join together and write a comprehensive report and we share that report with the family and the entire educational team. One week prior to holding a virtual team meeting. So that virtual team meeting is where everyone comes

together, your favorite Zoom calls and we share that information and discuss the information and answer the families and other providers questions and we suggest strategies for intervention and really unite the team through an open discussion.

After the team meeting which typically lasts an hour to an hour and a half, it's a significant amount of time to spend with them. We open up the opportunity for tele support. We don't want to just dump a bunch of information on this team and say, hey, good luck! You know, take

it from here. We want to be there to support them going forward.

So this may be at the parent's home, it's virtual. Maybe at the parent's home, or maybe at a school with the school team. Wherever it is that the extra help is needed. Sometimes it's just for affirmation, you know, seeing, you know -- they're proud to say what they've done and

accomplished and my role there is just to acknowledged the work they've done and we're really seeing the TVI empowered to take the lead of that team in a way she didn't have the confidence before and we've seen it happen already and we're there to support the team -- not

necessarily the expert, but to support them and help them find more information or whatever they need.

And another arm is -- of this is that we're holding TVI case study forums and we started small with this part of the project. We started in east-central Illinois where we're located and threw out the invitation to all of our TVIs within the surrounding counties to join us one

evening a month for one hour and what happened is one TVI will present a case, that they're having issues with, and could use some suggestions, some ideas. Just some help. And it's been quite amazing. Again, we're in a virtual format. All in our own places, but it's been

fascinating to see the idea that's come from everyone. It's a very safe place for everyone to share the things that they have that have worked and things they may want to try. It's been wonderful for new TVIs, because you'll see at first, they're maybe a little quiet and maybe

nervous about sharing and don't feel they know or have as much experience as some others, but then they start to share and feel more comfortable.

We're brainstorming and sharing resources, webinars and all that all of you are doing, websites. Just a plethora of information. And also strategies. And things that have worked for one child, you know, maybe possibly work for another child.

So the benefits of that, I was talking about that, everyone leaves with new ideas of it's a safe place to ask questions and builds confidence in everyone. Not just the new people or those who didn't feel that they had a lot to offer, but those that, you know, consider themselves

very adept at working with kids with CVI, they're becoming more confident and it expands everyone's toolbox and we're all walking away with something new.

What we're going to do in the future is to grow this new forums. And one thing that's kept next successful is keep the groups small. We want to continue to do that, since there's only one me and one Mindy, what we want to do is empower some of the members from the initial team

to move out forward and expand the -- expand across the state and act as facilitators to another small group and Mindy and I can be there as support for those facilitators. Kind of like what Mindy said, with the pebbles in the pond, that ripple effect, this would be the same

thing. We're starting with a small core group, but as the group gains confidence and as they're ready to go out, those groups will continue to grow in numbers.

So here's some other components of the ALEX Program.

We have an emerging website with materials that we're adding all the time.

Trainings, and resources and we've done three live webinars so far and they're records and available at the website under the webinars. So we did CVI 101 for parents and did CVI 101 for professionals and we've just recently did the when's, why's and how's of multisensory

learning for children diagnosed with CVI. That one perhaps is not yet on there, stay tuned. It will be up shortly.

And we have the CVI video library. All of those -- you know, that -- you saw in the video we just watched. The stories are on the video library. Tells their journey and how they've acquired CVI and what they're learning and what is being provided to them. And we have

resources and many organizations you're working with have -- are on the resource page and we keep adding to that as we find more.

And we also have our wife. Which I have list there had. It's easy, just do a Google search for the ALEX Program. Easterseals. Central Illinois and you'll be able to find it.

So as we conclude, we really would like you to consider, is there an agency in your state that could partner in providing financial assistance, management, marketing support, to start a similar program where you live? You just -- just asking you to think outside of the box.

Mindy and I were working with Easterseals for a long time, trying to figure out exactly what we wanted to do and it's become a true partnership for us. And so that was really our purpose for coming here and speaking with you all today, was if we can do this in Illinois, we're

really hopeful that this can become a mission in some other states and we can all support each other and learn together and grow together.

So I wanted to thank you for attending and then we may have questions. I'll throw it to Cathy for that.

>> Cathy: Okay.

So now we're ready to begin the question and answer portion of the webinar. If you haven't done so already, post your questions in the Q & A box and thank you for sharing your knowledge on this important topic.

We really appreciate it.

Does anyone have any questions?

>> Dr. Ely: One thing I'll emphasize is, I just -- I think that mentorship is such an important piece to seeing changes in practice. And so that's -- it's an underlying piece to every single component of all of those pieces that Susan was talking about. Mentorship is a

big part of what we're trying to do.

>> Cathy: I don't think we have questions at this point.

Hmm.

>> Dr. Ely: Okay, well, thank you very much.

>> Dr. Sullivan: Thank you for attending and Mindy and I are open to discussing this opportunity with you if you would like to know a little bit more. I know that the -- be able to reach us and whether it be email or at a conference or wherever, we're open to discussing and

sharing our ideas with hopes we can find smaller compact ways to help the family so families don't feel so isolated and feel the need to travel so far that things are in their own (indiscernible).

>> Dr. Ely: I see someone asking in the chat for our email addresses. I'm going to put mine in there.

>> Cathy: Thank you, there are a question about -- can you talk again about the areas of expenses. So if someone did want to pursue this in another place, what the expenses look like.

>> Dr. Ely: Yeah, so Easterseals is the fiscal agent. There's some administrative expenses, but we've sought out grant funding and have been successful in gaining some grant funding and then Easterseals itself did some fund-raising and that was our -- that was our initial cost.

Obvious, the Camacho family gave the seed money through the work they did for five, six years prior to launching it. but our program has several different components and so the expenses are a little bit more than F than if you just decided to partner with other teachers and do

the case study forms. Zoom is free. If teachers gather, they could do that at very little expense. That's a piece I think can be replicated at no cost.

This coming alongside and helping a team figure out assessment, there's a little bit of cost to that because someone has to give of their time to do initial assessment and the ongoing support and writing the reports and things. but I think there's ways to mentor one another

without a lot of expense. Or just picking a piece and really raising limited funds to focus on that one piece.

Sue, do you have anything to add to that.

>> Dr. Sullivan: No, I actually was reading the chat question.

(Laughter).

>> Cathy: Let me do that!

(Laughter).

>> Dr. Sullivan: There was another question --

>> Cathy: Someone wanted to know if anyone could -- across the nation could access the support website with the resources for families and professionals.

>> Dr. Sullivan: Yeah, everything on the website is accessible and free, the webinars, and you can get on to the list to -- once you register for one webinar, we send that out to everybody. So it's kind of like the webinar we're doing, it comes live at one certain time, but then

is saved to the website and you can watch it at your convenience.

So we're hoping that will continue to grow.

>> Dr. Ely: And part of that will be -- so some of the things we're doing with the assessment is we're testing out lots of new things that as a single teacher you might not have time. And what we're hoping to do is put out that information. I hope within the next 12 months, we

put out the protocol we're using for assessments. And actually that gets into -- and I'll give you a little peek that that. What we're looking at is looking at a functional vision assessment, a learning media assessment and a look at the expanded core curriculum. And ox sill

tall lobe and ventral stream and dorsal stream and what did we just learn that those, and what recommendations can we pull from that for improving visual efficiency and what -- efficiency and what we can pull from that for across the day accommodations and then the learning media

assessment, Sue, that's the piece you focus on. Do you want to talk about what you're doing in the learning media assessment portion?

>> Dr. Sullivan: That's a big passion of mine, over the past few years, I just feel strongly that we have not in the past really challenged the kids with CVI to become readers and learners and look at -- learners and look at literacy differently perhaps, but it's still really

important so I really try to encourage the team to, one, make sure they're exposing all -- all sorts of media opportunities for the kids. Sensory, auditory, touch. And as well as just looking. And then to give them ideas of how to incorporate all of that into their day. And

to pay attention to which form they're using. As we do with kids with ocular visual impairment, but to point that for kids with CVI. And it's been quite amazing to see just with the kids we've already done, how pairing the tactile with the vision really cements that

understanding and so as we said, we're learning as we go, and building these schools so we -- as we're learning what questions we forgot to ask or what we should have asked, we know the next time, ask that, bring that out.

And we also are inviting the TVIs from the previous assessments to join the forum so that the other folks can learn what it is they learned through the assessment as well.

And then, the expanded curriculum, I think gets overlooked for kids with multiple disabilities and there's a way for every one of those components for this population. So we address that with every report we write and each team.

>> Dr. Ely: It's really a matter of using the tool, the assessment tools that are out there to drive our conclusions and our programming. So when gathering data and then putting it into a formats that useable for school teams across the different disciplines.

You know, one of the questions I see has to do with what are we still struggling with. I will say that this whole child, this multidisciplinary piece, I really, really am hoping that as we continue on, we figure out some efficient and good ways to really take the data from all

of the different disciplines and pull that together to -- for a cohesive educational plan.

And so that will be a piece that we're working to figure out. And as we have more experience and as we get these brainstorms -- these TVIs together to brainstorm and see what works with different teams, and what doesn't work with different teams, I think we'll have more

information on that. Another thing that we're really hoping to problem-solve as we go forward, how best to come alongside doctors for diagnostics and our FVA and LAMs, how they can these partner and how we can help one another and what can we communicate to one another and

that's another big mountain for us to tackle.

>> Cathy: I have a couple of questions too. One is --

How long on the average do these -- for each child does it take to collect all of this and does -- do the assessments connect with the individual child or do you do the same assessments on everybody?

>> Dr. Sullivan: That's a great question, actually. We do have a whole list of materials that we gather, we require them to have all of this information at least a week before we even see the child. So we collect all of the school records, the O.T. reports and the functional

vision assessments that the TVI has done and doctor reports and one of the most helpful things we collect is videos, we ask for videos from the family, from the school, daily living skills of them. Traveling if they're mobile.

What else? We -- and also work samples. If the child is doing academic, we want a writing sample of them and all of that stuff, so we have a care provider who collects all of that information for us and a week before the assessment, she gives it to us so Mindy and I have a week

prior to meeting the family to delve into all of that information. We do questionnaires and that's one thing, Cathy, that's different for each child. Because we base the questionnaire we give the parent, the TVI, the classroom teacher, based on what we know about the child.

So some questionnaires are based on more kids with multiple disabilities and season are more appropriate for kids who are more (indiscernible). And there are things that are different for each type. And we're really focus on what we know about that learner.

>> Dr. Ely: And I think over time, we will probably get a little bit more efficient at figures out how to -- how to craft the assessment, so right now, we're spending a lot more time than a teacher would have, right, to spend on one assessment. Yesterday, we assessed a child who

was higher academically than the kids that we had done previously and really changed the way we did the assessment and we learned a few things. And, you know, that -- I think in the end, I think of those categories that were put out, the category one and category two and

category three, one being kids with multiple disabilities and CVI. Two being those with some cognitive delays and CVI and category three kids with limited other disabilities if any and CVI and I think we'll find different approaches that will work with those different categories

of kids. Not that it's -- it will still be individualized, but you need some efficiency if you're going to be a TVI and honestly do this, right? We need to efficiently be able to grab our toolbox for that child and that's what we're hoping to kind of figure out as we go along.

Again, because we want multiple tool, lots of data.

>> Cathy: Great, thanks.

So any questions from anyone out in the audience?

No? Anything else you ladies want to say before we say good-bye. Thank you so much!

>> Dr. Ely: No, thank you for the opportunity. It's an exciting time to be doing this work and I look forward to seeing where we're able to -- you know, we in the field are able to go in the coming years.

>> Cathy: Absolutely.

>> Dr. Sullivan: Thank you very much.

>> Cathy: All right, so thank you to all of our participants for joining us today. We hope you found this webinar to be informative and hope to have you join us for future webinars.