

The Future is Now informational webinar.

December 12, 2017.

3:00 p.m. CST.

The Future is Now Implementation Project Seed Funding.

JED JOHNSON: My name is Jed Johnson, and I currently serve as the vice-president of national programs and network advancement here at our national office of Easter Seals. On behalf of Easter Seals as well as the University of Illinois at Chicago, Department of Disability and Human Development, I would like to welcome you to today's webinar. I'll begin by providing webinar instructions. If you are connected today both by phone and webinar room, please ensure that your computer speakers are muted at this time. As a reminder we do offer live captioning. To access the live captioning, you would press control F8, once you are logged into the webinar room. For the duration of the webinar we will have all phone lines muted, to submit questions which can be done at any point throughout the session, you can either enter it into the chat box which is kind of at the lower left corner, or you are welcome to send questions to me via E-mail at Jjohnson@easterseals.com. I'll tabulate those and share those with our speakers at the end of the call.

At the end of the presentation, we will first begin by answering the questions submitted via chat and via E-mail. Then we will open up the telephone lines for additional questions. Note that during that time, all the lines will be active, so please mute your phone to ensure there is no background noise, or do not put the call on hold, as we will then

hear some lovely music.

If you didn't receive a copy of the Power Point presentation, please send an E-mail and we are happy to send that out to you. Without further ado, let me introduce our two speakers for today. Dr. Tamar Heller, head of University of Illinois at Chicago Department of Disability and Human Development and directs its University Center of Excellence in Developmental Disabilities for the State of Illinois. She's the principal investigator of the Family Support Research and Training Center, and the Rehabilitation Research and Training Center on Developmental Disabilities and Health both at University of Illinois at Chicago. She has a long commitment to research that helps support families and people with disabilities. Katie Arnold serves as the Director of Community Education for the Institute on Disability and Human Development at the University of Illinois at Chicago, Illinois' University Center of Excellence in Developmental Disabilities (UCEDD). She is also co-director of the National Resource Center on Family Support. In addition, another hat that she wears is that of Executive Director of the Sibling Leadership Network for people who have a brother or sister with disabilities. Both are co-authors of *The Future is Now* curriculum which they will share more about with you today, and with that. It's my pleasure to turn you over to Tamar Heller.

TAMAR HELLER: We are thrilled there are so many people that are interested in *The Future is Now*, and in this particular training. I want to give you a little context first about our center, that this is part

of. You will hear more about the background on *The Future is Now*, and the next steps that Katie will also go through.

A little about the Family Support Research and Training Center, it's funded by the National Institute on Disability, Independent Living and Rehabilitation Research. I'll share some of the goals of this center. First it's to design the state of science on family support. It looks across the life span, life course, and the process, abilities and aging. It's peer-to-peer family interventions (there are quite a few interventions that are part of the center) and to generate and implement a vision for policy and practice and family support through a National Family Support Resource Center. You will see they have a wonderful web page associated with the center. Another goal is to contribute to improvements in community living, participation, health, function and other outcomes for individuals with disabilities who are supported by family members.

As part of it, in addition to developing strategies and looking at policies, dissemination of information, there are several research projects. The first is a development of the strategic plan. The second is looking at promising practices in family support, and looking at what is out there nationally.

There is a project on family member roles and well-being in self-directed waiver programs. This includes understanding experiences, trends and needs in self-directed support programs. There is a project on family support in managed care and an intervention,

Parents Taking Action (a parent training program for Latino families of children with autism spectrum disorders). This is a general background. As part of that, that is what *The Future is Now* interventions and train the trainer is coming out of.

KATIE ARNOLD: Thanks for providing that background. Hi, everyone. I'm Katie Arnold. With that context, the train the trainer caregiver intervention project is part of the family support research and training center. Easter Seals is leading coordination of this effort, where we have identified three different interventions that have been effective with family caregivers, and we are going to be teaching organizations how to implement them. Intervention researchers, like Tamar Heller and I at UIC will be conducting the training and evaluation.

As I mentioned, we have three different interventions, over three years. Last year, we implemented *Parents Taking Action* in intervention specific to Latino families of people with autism. And this year, we are focusing on *The Future is Now*, related to doing future planning with family caregivers.

We are excited to be putting out this request for applications related to *The Future is Now* seed grant. We are going to be awarding three seed grants for \$5,000 each to community-based organizations, that provide services and supports to people with disabilities and their families. These organizations will learn and implement *The Future is Now* to help families plan for the future.

The application is available at:

<https://www.surveymonkey.com/r/futureisnowapp2018>

We will also E-mail this information out following this webinar if you haven't seen the application. There is also a MS Word version of the application available. Applications are due by 5:00 p.m. Eastern time on Monday, January 8 of 2018.

The Future is Now curriculum was developed at UIC's institute on disability and human development, after seeing a need for families who needed to plan for the future, especially as parents age. The purpose of this project is that we want to build the capacity of new organizations to be able to implement *The Future is Now*, and help families plan for the future. While there are a lot of curriculums and resources out there to help families plan for the future, this curriculum is one of the only ones with evidence behind it showing proven outcomes for families. We want more organizations to be able to use this, and we want to collect more data to continue to evaluate how it's helping families.

The three organizations that are selected, you will each get a hard copy of the curriculum with a CD-ROM that has all of the materials on it. *The Future is Now* curriculum includes an instructors manual as well as a workbook for family members, and a workbook for individuals with intellectual disabilities. There are a lot of interactive work sheets. This slide shows some of those interactive work sheets, a lot of pictures to help people with intellectual disabilities think through different areas of aspects of what they want for the future. This is a person centered and family centered model.

The curriculum consists of six sessions. The first session is one where you will find someone in your local area that is an expert on legal and financial planning, to hold a training session about this topic to really get families to start thinking about planning for the future.

Most people think about legal and financial aspects first, and they want to know about special needs trusts, how to deal with transitioning of guardianship or alternative to guardianship and much more.

We have found that having a session on the topic of legal and financial planning initially is a draw, to bring families to come get a taste of the first part of future planning, and this is where your organization can then pitch for them to consider doing the next five sessions to dive in more and to develop a full plan for the future called a letter of intent.

This legal and financial planning session is usually where organizations bring in outside speakers with this expertise for about two to three hours, to present for about an hour or so and then open it up for questions from the families. Make sure to leave time for your organization to then share more information about *The Future is Now* intervention, and how they can sign up for it.

This would be more of a lecture style informational presentation, in a large room or auditorium, where you would invite many families to come, whether they participate in *The Future is Now* or not, and so it's sort of a kickoff. Then you will implement *The Future is Now*, and the curriculum has five specific sections in it. First section addresses barriers to plan for the future and the letter of intent. This really

helps families get started and gives them a sense of where they will be going. It works through some of their fears which have been barriers for their family to plan for the future, and talks about the benefits of planning and what their hopes and dreams are for the future. Next, a session is focused on relationships and supports. This is how to support the person with disabilities in developing and maintaining important relationships in his or her life. There is a session on residential and community living supports, another section on employment supports and a final session on goal planning, setting goals and identifying key people who will be responsible for certain aspects of the plan.

In terms of logistics of the curriculum, the goal is really to help families develop a letter of intent which is a roadmap about the future. It's really a living, breathing document that will continue to change and evolve over time. This helps them think about key areas that are important, gets them discussing those areas, and developing plans. The sessions are generally, though it can be adapted, two and a half hours each. Sessions are held around two to four weeks apart with approximately 10 to 20 families per group, per training group or cohort. Families must include at a minimum the person with disabilities and at least one other family member (though it's encouraged to have multiple family members come) including siblings, parents, other family members that the person with the disability wants to come be part of the plan for the future.

Some unique features about *The Future is Now*. The first unique feature

is related to peer support. People with disabilities and families learn a lot from each other throughout their time together. The training includes times for families and people with disabilities to meet in peer groups to discuss aspects of future planning. This is important because, for example, it allows people with intellectual and developmental disabilities to meet with their peers and problem solve. It also allows parents and siblings to meet separately and share their perspective with each other. Then there are times where everyone is together in a large group and can share their different perspectives, as people with disabilities, siblings, parents and other family members, with everyone in the group to learn from each other.

There is time between sessions where families have homework to do and they need to continue the conversation and think about things. In this way, they bring the information home to other people in the family that may not be coming to the training and they can involve more of their family in the future planning process.

A second unique feature is the inclusion of peer trainers. Having co-trainers as people with intellectual and developmental disabilities and family members is a really important part of the way the training is put on, and so, be thinking about that. Think about who you know at your organization that you could tap to be those peer trainers, at least one person with intellectual and developmental disabilities and at least one family member should be a co-trainer delivering the content.

The third aspect is the evaluation of outcomes, that this curriculum

has been evaluated. Tamar is going to be sharing some of the outcomes of the evaluation in a little bit and it really strengthens this curriculum to know that it has shown proven effectiveness for families.

A few things for you and your organization to think about related to applying for this opportunity. Think about who will be the key point of contact. At least one staff person at your organization needs to be able to learn the training and then oversee the implementation of the training. You will need to be thinking about finding speakers, as I talked about earlier for that first legal and financial session. You will need to be thinking about space for the training sessions. Where will you hold it? How the space will work for the number of families you are going to be working with? Think about other logistical things. Whether you want to include food for families in the budget depending on the timing of the training session? When you hold it? How to find and train peer trainers? If so, possibly include them in the budget.

Those are just a few things to think about and you may have further questions when we open it up in a little bit. I'm going to turn it over now to Tamar to share a little more of the evidence of outcomes.

TAMAR HELLER: Okay. I want to tell you that when we developed *The Future is Now*, it was a project of years of trying different approaches. We had a whole advisory group of 8 different provider agencies, we also had families and we also had people with disabilities, all advising on this. We had tried different things that we had evaluated. Some things worked and some things didn't work. This effort seemed to be the most

effective way that we found. One of the reasons that we think this was so effective is because it deals with the psychological issues of families. It's very much about working out different issues in families and the chance that people with disabilities have to talk separately from their families, and then to do problem solving together. It also includes doing assignments in between sessions and having very concrete products at the end. I think that really helped make the difference.

The reason we say that it's evidence-based is because we actually did have, believe it or not, a randomized design, before and after. We looked at baseline and also a year later, so that is the scientific part of me talking. But the reason this is important is because it got recognized nationally as something that was evidence-based, which we know is important, especially if you want to get funding. It also got several national awards because of that research.

Let me tell you what some of the outcomes were. These outcomes that I'm telling you about are those things that were different between the intervention group and the group that did not get our training. One of the important things that happened was that people that didn't have special needs trusts developed special needs trusts. 24 percent who did not have one before developed one. That is a big deal. That takes lawyers and that is not a small thing. It involves a lot of talking with families and thinking about various aspects. It becomes very emotional, this whole issue of future planning.

Residential planning action. 64 percent who had not taken action did

so. That again is huge. Before we started, we found that 50 percent of families hadn't done any kind of planning or even talking about it. They didn't even talk to siblings about any of these issues. Mostly because it's very provoking to think about it so it takes skill in dealing with these issues. Almost every one developed a letter of intent. That was one of the goals so that is not surprising, but they did it and that is the important part.

The last part that I have on this slide, caregiving burden decreased. That was amazing to me because that is the first study I've been involved with where we actually saw differences between before they started and after. That's also comparing with another group. Sometimes you will see evaluations will say, "Did the burden decrease," and they will say "Yes." That is not the same as comparing between groups over time. I'll tell you the reason why it decreased. This is a nine item measure and one of the items says "I worry about the future." That, so many families worry about the future, even when their kids are little that is why caregiver burden went down a lot. They are not as worried about the future, because they have a plan in place.

Next, they also found that the daily choice making of individuals with developmental disabilities increased, according to the caregiver reports. That is because they learned a lot about the notion of self-determination. Also in the process of working out the goal planning together, they really developed more respect for the choices of the persons with disabilities. The individuals with developmental

disabilities reported doing more leisure activities and having fewer unmet leisure needs. That was one part that was important to them, especially these people are getting older.

There were other outcomes that I would say are systemic outcomes that came out of this. One is there was a group of individuals with developmental disabilities that developed a People First chapter as a result of participating in this training. I think we did a lot of raising of awareness of issues for families and for people with disabilities. Afterwards, other families led additional workshops and so the education continued on or other iterations of it. What I like about this project is that it's building the capacity of the organization. It's not just us coming in and doing something, but because it's a train-the-trainer model that you will be able to continue (as long as you have enough staff that is participating). I would suggest training more than one staff, because if you just have one staff, you might get turnover, and that won't be as good.

Also you may want to have some potential family members and potential peers also participating (who could in the future serve as a trainer).

One of the agencies adopted the letter of intent for everybody, not just the people that were in this particular project. It became a way of doing person centered planning across the entire organization. This very much fits in with all the governmental and funding edicts around person centered planning. Those are the principles that *The Future is Now* is all based on.

Also, on ideas of supported decision-making, this is very much a supported decision-making approach, thinking about the future.

We did a collaboration with the Illinois Department on Aging that was very interesting. Additional grants became available after this. That was some of the systemic outcomes that can come out of this kind of training.

KATIE: For this project, the three organizations that we select are going to be given the curriculum, as I mentioned. The curriculum is available, any organization can purchase it and many organizations have purchased it and implemented it on their own.

For this particular project, along with the seed funding you will also be getting the on-line training from our organization. You will also receive ongoing technical assistance and support from UIC as you implement *The Future is Now* with the families at your organization. In terms of goals and expectations, we want you to commit at least one staff member or project coordinator to learn the training and coordinate the effort. As Tamar mentioned, if you are able to commit more than one staff, that can really help build the capacity at your organization and help the various turnover at your organization. Also, to be able to attend the on-line training that we have scheduled. Tamar and I and other team members here at UIC will be doing these trainings with you via webinar. You will need to recruit a minimum of two peer trainers. Like I mentioned earlier, including a family member and a person with disabilities to help implement the trainer, recruit a speaker to host the kickoff legal and

financial training.

Recruit a minimum of six families of people with disabilities. Attendees must include the person with the disability and at least one person considered to be a family (and the definition of family can be up to the person with the disabilities). Whomever they consider to be a family member. Although a number of family members are welcome to attend. We have suggested that we really want ten to 20 families as part of each cohort. We know that there is often some drop-off of families and so recruiting a minimum of ten and up to 20 is preferred, so that you actually complete the training with at least six families and then implement *The Future is Now* curriculum with the families, complete and submit quarterly reports and provide evaluation information, and attend every other month teleconference calls that we will have after we do the initial training. This is an opportunity to continue to provide support to your organizations.

In terms of the time line for the three organizations that receive the grant funding, we anticipate it to look something like this. We are proposing these dates, February 9, 16 and 23, to do the training via webinar with your organization. We encourage you to have one to four people from each organization participate in the on-line train the trainer that we will conduct. Each session will be about two to four hours. After we select the organizations we will nail down the specifics of this. There will also be some tasks to be completed in between. Also, after receiving the train-the-trainer, your organization will then

implement *The Future is Now*, conduct those six sessions at your site with at least six families. It will likely take a couple of months after the training for you to then be recruiting families and preparing for the training. We are thinking that the training would likely be starting in April or May and going through September or October of 2018. This is flexible. This is something that we would like you to think through and in your application to put what you are proposing. Put what will work best for your organization related to the time line in your proposal submission.

So that's kind of an overview. We are pleased that there is so much interest. Now I'll turn it over to Jed so that we can open it up for questions.

Jed Johnson: Perfect. Thank you. It is now time for questions. Please input your question into the chat feature and we will read those back. Or you can send me an E-mail at Jjohnson@easterseals.com. Once we respond and share those questions, we will open up the lines and hopefully we won't have any background noise and folks will be able to ask questions.

I'll start out with one question that came in via E-mail. The question is, "Our organization does not provide direct services in the form of adult employment, residential services, etc. The organization provides technical assistance, training, resources, tools and materials, all in an effort to build capacity of people with disabilities and their families. On the application itself, it appears that Easterseals/UIC

is only looking for a direct service organization. Is that correct? Or would service include training, technical assistance, etc?

KATIE: Thank you for the question. Your organization would be open to applying. This is not only for direct service organizations. An organization like yours that provides training and even if you do not provide direct service, that is fine. If you have the capacity to conduct this training with families of persons with disabilities, then you would fit the criteria to be selected.

JED: Thanks, Katie. We have a number of questions that came in via the chat feature. The first one is, Katie, could you clarify or confirm that the application will be sent via E-mail in a Word document?

JED: I can actually respond to that. Applications can be submitted in one of two ways. We do have the on-line form. So if folks want to use the on-line survey monkey tool, they are welcome to enter their application information. In checking the other day I saw that we already had five applications successfully submitted. I will go in episodically and check completions and confirm to those folks that are submitting on-line applications to let them know that it has been successfully received. The other way is via an MS Word version. As Katie pointed out, that went out with other materials for today's webinar. So, if people would prefer to submit a Word version, MS Word version of the application, (Note: you will need to conform to the same character limits). You are welcome to submit an MS Word application. Those can come in to me at Jjohnson@easterseals.com. Again I'll confirm submission and receipt of

that, and acknowledge that to you and all those then will be reviewed after the due date of January 8. Here is another question that came in via chat.

JULIE: That question is, What are the verbal requirements for participation? If we have nonverbal or minimally communicative adults, is the curriculum designed to include them and their families?

KATIE: The curriculum is designed to include the person with the disability. If there is some way that the person can communicate what they want, then they could also participate in it. They just won't necessarily participate in the interviews with people with disabilities portion. What is required is that the person is there, and be able to at least express some kind of preference.

Even completing the work sheet. It will be fine if a family member supports the person with disabilities to think through and complete some of the work sheets. So, somebody is nonverbal but can indicate their preference for different things. That type of participation is what we have, the families that have participated in the past.

JULIE: Wonderful. We have another chat question here. That is, can you clarify what acceptable budget items would be? A full-time equivalent would not be covered by the \$5,000, but could this be an in-kind to the project?

KATIE: Yes, thank you for that question. The budget items are flexible. It's really what you and your organization feel you could and should use the money for to be able to implement this curriculum. There

is no limitation on it. It's really up to you and what you think would work best for your organization. The \$5,000, you are correct, is not enough to cover a full FTE. It could be used to cover a portion of somebody's FTE. But that could also be provided in-kind. It is important to really show us who you are committing to this project, who is going to be working on it, how much of the money will be used for those people or other items that you think are needed, and how much will be in-kind or you will be using other funding sources to supplement, to be able to make this happen.

JULIE: Wonderful. Another question from the chat field, what will the reports consist of?

KATIE: The reports are really to assess that things are going well, that you are on target. There is nothing super detailed. These are designed to find out from you how many families you have recruited at a certain point, and then how many families you have worked with so far. We will be having check-in calls with the organizations regularly as well. It's just going to be the basics of sharing information about how things are going, what is working well, what is not working, so that we can get that information and feedback. In addition there will be an evaluation piece. Tamar will share what that will entail.

TAMAR: The evaluation portion hopefully will be useful to you also because you will be able to see for yourself so you can have a report that you can talk about the program and the accomplishments. What we include is, in the beginning some evaluation of where your organization

is in the process. A checklist of what you have done, what the capabilities are, what the confidence people have in working in this area. And then in the end, we should be able to see what you have accomplished as part of that and what has been some of the outcomes where for the families that participate. We will be pulling all this together so that we have also data on how effective the program is using the train-the-trainer model.

KATIE: We see this as a collaborative learning process for the organizations involved and for us as well. The goal is to help you learn the curriculum so that you can implement it and support you along the way.

JED: Thanks Katie. Thanks, Tamar. We did have a couple of questions about, related to eligible organizations. We had a question that had come in, "Would somebody working for a state government or a state agency be eligible to apply for the mini grant?"

KATIE: Yes. A state organization is welcome to apply. We will be looking at all the different applications that come in to make our selections. But any organization that feels they have the capacity to implement the curriculum with families and really help families learn how to plan for the future, is eligible to apply.

JED: Great. This is another one with a specific situation for an organization. Would a collection of rural communities who do not have ready access to supports for persons with disabilities be considered? This would be coming through a church, who reaches out to families in

several communities in their particular state. The church itself does not offer supports to people with disabilities or intellectual disabilities.

KATIE: Yes. Again, any organization that feels like they can learn this curriculum and implement it with families is absolutely eligible. Having creative models with different partnerships like that could be interesting.

I think that just in the application process, be sure to explain why you think you have the capacity to implement the curriculum. That is really what we are going to be looking at to make our selection about which organizations to choose.

JULIE: We have two additional questions. The first is a funding question as well. We currently provide one-on-one futures care planning services to individuals with disabilities and their caregivers. Would you consider an application from our organization, so that we would be able to compare the success of both methods and compare and contrast them?

KATIE: Yes. It would be interesting to learn about other approaches to use in contrast with *The Future is Now*.

JULIE: All right. The other question here is, for organizations that have a long history of providing various topics but not this specific curriculum, would that be considered a positive or a negative?

KATIE: Please share that information in the application and we will take that into consideration in our selection. I don't know either way. I think it's just information that if you feel is relevant, related to

your capacity as an organization, or a group of organizations, or a partnership to be able to do this, then feel free to share that in the application process.

JED: Great. I don't see any more questions that have come in to us via E-mail or the chat feature. So we will now unmute all the lines.

CALLER 1: How many organizations have implemented this training currently.

TAMAR: Okay. I can't answer exactly how many, but I can tell you that we have currently done the training in at least ten states, if not more. It was also done in Europe, in Switzerland. We have sent out many, many curriculums. So it's hard for me to tell you exactly how many. The study had 40 people in the intervention, something like that. For the research, it was done all over the State of Illinois. It included rural and urban areas and it was done all over the state. Just to give you an idea of that variable.

TAMAR: Since there are no more questions, we look forward to getting all the applications.

JED: If you do have questions, feel free to E-mail us, our contact information:

Jed Johnson: jjohnson@easterseals.com

Tamar Heller: theller@uic.edu

Katie Keiling Arnold: kkeiling@uic.edu

JED: Perfect. As I mentioned, I will acknowledge when applications are received. I'll send out an E-mail. We will also, once the

transcriptioning is completed and we have the recording, we will also email both.

We appreciate your joining us. Have a wonderful rest of the week and we look forward to seeing those applications come in.

(end of webinar at 3:54 p.m. CST)

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