

National Disability Forum on Youth Transitioning To Adulthood And Preparing For An Age-18 Redetermination

>> Hello, everyone, and welcome to Social Security's National Disability Forum on Youth Transitioning to Adulthood and Preparing for an Age 18 Redetermination. I would now like to turn it over to Jeffrey Hemmeter, Deputy Associate Commissioner, Office of Research, Demonstration, and Employment Support at the Social Security Administration.

>> Thank you, James. Good morning and good afternoon to those of you on the east and west coasts. Thank you for joining us today. My name is Jeffrey Hemmeter. I am the Deputy Associate Commissioner for the Office of Research, Demonstration and Employment Support at the Social Security Administration. I have the pleasure of welcoming you to our 25th National Disability Forum Youth Transitioning to Adulthood and Preparing for an Age 18 Redetermination. On behalf of Acting Commissioner Kijakazi, SSA Executives, and everyone at the Social Security Administration, we hope all of you are well. Let me start with a few housekeeping items. First, I want to inform everyone that the National Disability Forum is a public forum and may include representatives of the press. So, any statements or comments made during the forum may be considered on the record. This virtual forum is being recorded and will be available on the National Disability Forum's website within four weeks after today's forum. Second, we have disabled the chat microphone and video feature for our attendees. If you dialed into this Microsoft Teams Meeting, please use your phone's mute feature. Third, we

are offering two accessibility features today. We have an American Sign Language interpreter, and closed captioning. If you would like closed captions, please go to your MS Teams toolbar, select the three dots titled "more," select the "language and speech" option, and select the "turn on live captions" option. As previously mentioned, there is no chat feature available for you to make comments. However, if you wish to ask a question of our panelists or provide a comment, you can do so via email at nationaldisabilityforum@ssa.gov, all one word, @ssa.gov. Again, that's nationaldisabilityforum@ssa.gov. Please include your name and your email question.

When submitting a question, please do not include any other personally identifiable information such as a Social Security number or address. We are monitoring the in-box throughout the forum and will share questions with the moderator as time allows. If your questions are not answered during the forum, we will make every effort to answer your questions via email after the forum or share them with the appropriate office. In a few weeks we will post the link to the recording on our national disability forum website at www.ssa.gov/ndf in the outreach section under today's tab 10-18-2023. As with all national disability forums, today gives you, our stakeholders, an opportunity to share your unique insights directly with us and policymakers within the agency. The NDF is not intended to be a means for reaching an agreement on an issue and SSA's participation is only for the purpose of gaining insight by listening to the panelists and their responses to your questions and comments. By sharing your thoughts and experiences, you will help us shape the future of Social Security by strengthening our disability policy development and contributing to our continued effort to address equity within our disability policy and practices. I hope you are just as excited as I am to hear from the expert panel about youth transitioning to adulthood and

preparing for an age 18 redetermination. The purpose of this forum is to learn from our panelists and you how SSA can improve programs for transitioning youth as they approach age 18 and a redetermination. During today's forum, we will focus on four topics: Youth transitioning to Adulthood; ABLÉ Accounts; continued payments under a qualifying program or Section 301; and determining capability and the need for representative payees. Mia Ives-Rublee will moderate today's panel discussion. After the panel discussion there will be an open question and answer session. And, again, anyone is welcome to submit questions for the panelists via the NDF email box, nationaldisabilityforum@ssa.gov. Mia Ives-Rublee is the Director of the Disability Justice Initiative at the Center for American Progress. She holds a degree in sociology from the University of Illinois and a master's degree in social work from the University of North Carolina at Chapel Hill. Ms. Ives-Rublee has a diverse and impactful career starting with her work in aiding individuals with disabilities and later transitioning into research and activism related to mental health, civil rights, and progressive causes. Her experience in community organizing, collaboration with various organizations, and involvement in political campaigns demonstrates a commitment to advocacy and making a difference in various spheres of public life. As the Director of the Disability Justice Initiative, she is utilizing a disability justice lens as she speaks publicly across the country about civil rights issues. To learn more about Ms. Ives-Rublee, our panelists, and SSA Executives, please visit the National Disability Forum website, click on National Disability Forums from the right-side menu, and select the "10-18-2023" tab. We would like to extend our sincere appreciation to Ms. Ives-Rublee and all the panelists for their participation in today's discussion. Ms. Ives-Rublee, we welcome you. The floor is yours.

>> Thank you so much. I am so honored to be able to come here today to chat with you. I want to give a chance for each of our panelists to be able to introduce themselves, so I am going to ask Peggy McManus to come on and introduce herself.

>> Thank you very much, Mia. It's a delight. I am Peggy McManus. I am President of the National Alliance to Advance Adolescent Health and the Co-Director of Got Transition, which is a National Resource Center on Pediatric-to-Adult Transition. Thank you.

>> Thank you so much. And Raymond Cebula.

>> Here I am. Thank you, Mia. My name is Ray Cebula. I am on faculty at Cornell University with the Yang Tan Institute and am Director of the Work Incentive Support Center. And I'm also representing the National Association of Work Incentives and Benefits Specialists today.

>> Thank you so much for introducing yourself. And Jade Gingerich.

>> Good afternoon. I'm Jade Gingerich, I am Director of Employment and Transition Policy for the Maryland Department of Disabilities. Maryland has the only cabinet-level cross-interagency department at the cabinet level serving all individuals with disabilities and we are charged with improving the coordination and delivery of services so individuals can live, work, and thrive in their communities. I'm also the Former Project Director for the Maryland's Promoting the

Readiness of Minors on Supplemental Security Income. It's a real pleasure to be here. Thank you.

>> Thank you so much. And then Eric, can you come on and introduce yourself?

>> Sure. Thank you very much. My name is Eric Ochmanek. I am part of the National Association of State Treasurers ABLE Today Initiative. And we represent ABLE programs throughout the country and also work with the ABLE Savings Plan Network, which is the coalition of all ABLE program throughout the country. Thank you.

>> Thank you. And then last, but not least, Tom.

>> Thanks so much, Mia. My name is Thomas Foley. I'm the Executive Director of the National Disability Institute and the ABLE National Resource Center. We work exclusively on issues of financial and economic inclusion for folks with disabilities. It's a pleasure to be here. Thank you.

>> Thank you so much. So, I'm going to start with a couple of different questions and start with a couple of individuals, but if panelists want to come on and jump in, feel free to jump in whenever you want to. The first question that I have, you know, we're trying to talk about youth transitioning into adulthood, so how can the SSA improve outreach in education for children and families about the differences between childhood and adult disability? How childhood SSI recipients can prepare for the requirements of adult SSI, transitioning off of SSI,

and into adult workforce and addressing high-risk populations such as individuals aging out of foster care. I'd love it if, Raymond, if you can start.

>> Okay. I first have to say that working with transition-age youth, or kids, as I call them, is a wonderful, rich population. I mean, we can do such wonderful things with SSI kids. And the goal in my mind is not to make them SSI adults, as we often do now, but turn them into workers with disabilities. I think that's a much more successful outcome for everybody. Yeah, in my history, I have represented many kids who were seeking SSI. It's a different world. We're not talking about the ability to work. We're talking about the ability to function on an age-based level. Am I functioning as well as every four-year-old around me is functioning. And that changes a great deal at age 18. And the key, I think, to helping people prepare for those age 18 reviews are to involve the school systems most importantly. You know, I can't tell you how many reports from special ed teachers and well-meaning special education teachers who started writing wonderful, glowing reports about little Jimmy. He's doing so well. He's getting A's. And never said that Jimmy has a full-time aid. You know that it's a small classroom. That he has all of these other services. And for Social Security Disability purposes, I'm interested in knowing what Jimmy can do without all of these services. And when returning to age 18, you know, which is what we use as the adult barometer right now, we're talking about the ability to work. So, if we can get teachers and special education departments educated as to what this transition is, and I think parents as well, parents are key to this. Parents cannot continue to be afraid of this review. It's going to happen with or without them. With them it's going to happen better and be more productive. And along with that, parents need to know about the work

incentives because their kids can work. You know, and those paid work experiences that are offered by some school systems during the summer, or a week during Christmas break, are tremendous for both that student, for the family, as well as for securing information for the adult disability determination.

>> Wonderful. I was also wondering sort of how, what does that look like in terms of the individual transitioning? Like, what are the steps that folks have to do? And, Jade, feel free to also chime in.

>> You know, I think the first step is to get that notice. You know, and sometimes notices are terrifying. We're talking about an SSI child here which definitely means it's a very, very poor family and this is glue keeping that household together, keeping kids sheltered, keeping everybody fed. And it's tenuous. You know, lots of things affect SSI. So, I think it's true we need to educate parents that this is not -- it shouldn't be a scary thing. It should be something that they are willing to stand up and participant with. And that notice can sometimes be scary. It can be misinterpreted as a termination notice and the parents just, okay, throw up their hands. So, it needs to be written, I think, at a lower level than most Social Security notices are written so that people can understand it. And then this needs to be some kind of assistance. Maybe a special hotline. What do I do next? You know because that review is going --

>> But Ray --

>> Yeah, go ahead, Jade.

>> -- I think that I would actually sort of back it up earlier. So, I think that we need to be doing more at the point of entry onto SSI around the messaging with families to be saying we recognize that your current family income, and your son or daughter, has something that meets this criteria and we are going to make this award on the basis of this. But recognize that there are a number of adult supports and services that will be able to assist your son or daughter to be employed. There are work incentives. And so, we are providing you these things now, but anticipate that this shift and this redetermination will be happening, and we need for you to be helping to set higher expectations, helping them to become as independent as possible, and being prepared for and taking advantage of the opportunities. Because I think sometimes what happens is that driving mentality of, I'm afraid they are going to lose their benefits means that they don't take advantage of summer work, they don't do the things when they are being provided to them. And we need to make certain that that is being provided. But I also think we need to figure out from a broader systems change perspective, the schools don't often know who the kids are on SSI. And so, we do need to figure out how can we get this information over into the schools and the partners so that they know and could be making certain that as part of that transition planning at 14 or 16, depending on what age it starts, that they're sitting down and saying, hey, we know that your son or daughter is on SSI. And they're 16 now, but at age 18 you're going to get this redetermination, you know, and it's not something to be afraid of. So, we do have to figure out how we can better empower the schools with the information to ensure that they're providing the transition supports and information. And we need to be

messaging right from the outset, hey, this is going to be a short-term thing, you know, there's lots of supports. Everyone can work with the right supports and services and so be prepared and be working towards that as that goal for your son or daughter. Because, you know, staying on SSI over the age of 18 means that you are committing your child to a lifetime of poverty and I will often say to parents, look, I know you think that you are protecting and doing the best thing for your child, but I can tell you right now, the very worst thing you can do is to set them up to become an adult SSI recipient. It is far better to take your chances on all of these other things that are out there to support you.

>> Absolutely, Jade. And we have just -- we're in the process of making arrangements to meet with all of the special ed teachers and special supervisors and all of that, the whole special ed organization with the Department of Education in Ohio to let these teachers now how the system works. How does work by a student impact those families. Because oftentimes the work is not going to affect anything. It's just going to actually bring in more money, set this child up for an ABLE Account. It's, like you said, opportunities. And we need to show there are more opportunities available than becoming an SSI adult, absolutely.

>> Thomas, do you want to jump in?

>> Yeah, thanks so much. And I so appreciate what everyone has already said. So, you know, when I was 18, I was on SSI on the south side of Chicago, and, gosh, I love what others have said, you know, keep expectations high. Have that expectation of going to work. Because one of

the first things I was surprised at when I got on SSI was the S element. And I was on, you know, 18 a few years ago. And so, you know, Ray mentioned it, and I know we'll talk about it later, but ABLE Accounts, introducing kids and their family to the idea that they can work, and they can save that money for a better financial future. You know, maybe it's saving it for services, maybe it's saving it for college, maybe it's saving it for a car or a house. But, gosh, the message that you can save money, you can work and save money at 18 could be a gamechanger for so many people with disabilities.

>> Thomas, I one hundred percent agree. Also, as somebody who transitioned off of SSI, I had no idea about some of these programs, and it is something that needs to be better, you know, broadcast to recipients and without sending it in this huge envelope of information that just gets very daunting to read.

>> Absolutely. And I think, Ray, it was you who mentioned it, you know, the work incentives of, you know, 1619B, I learned about the student earned income exclusion when I was, like, 40.

>> Oh, my gosh. Same.

>> Yeah, that could be just such a gamechanger for so many young people with disabilities because it's going to foster, it's going to foster effort, it's going to foster hope, and it's going to foster, you know, leading up to those expectations that we talked about.

>> You know, Thomas, I have to add, that along with the ABLE Account -- and I know your organization is heavily involved in this, and we depend upon that -- financial literacy is key here. Because if we have an SSI child it definitely belongs that child is part of an SSI family, basically. They're poor. These people may not have the financial skills necessary to even begin to save and now that we have the ABLE Accounts, that we have the students, the earned income exclusion that has been there for years, you know, there is an opportunity for -- I never thought -- I thought I would be retired and gone before I could ever say SSI recipients can build wealth, but they can now. And they can have a better life experience and have that now. But I think that the backlash from having a child who is beginning to save money into an ABLE Account is to see a family that is going to progress as well. And the entire family is going to benefit from the financial literacy skills, and the savings that come to a lot of us naturally.

>> Absolutely. And thank you for mentioning, you know, financial education, financial literacy, financial coaching. Man, I've been one of the lucky ones. When I was 15 in high school there was a financial education class, and it absolutely changed my life because it was the first time someone told me that the decisions, I made about money mattered. And it made me think that I had some control around my life, around my financial life, and that, to your point, I could build a better financial future, not only for myself, but for my family as well.

>> Thank you all. One of the things that I wanted to also sort of pull out as a thread is what about extremely vulnerable populations, like foster youth, do you all have any thoughts on how to better transition these individuals?

>> I'll give it a start. And, please, everybody, join in on this discussion. The foster care systems, you know, almost universally, are awful, you know. We have overworked counselors, we have kids that, you know, that are severely at risk just because of the lack of supervision, the lack of care, and all of that other things. And there are ways to do this, you know. The last time I resolved it was with a class action lawsuit. That's not a good way to resolve anything. You know, we need a foster care system that's responsive to SSI recipients. We have to stop sending kids home when they're 18, you know, with \$20,000 in retro and built-up SSI accounts, you know, and then let mom, yeah, now, deal with an overpayment. You know, foster care agencies, their staff need to be educated. They need to be educated on how the money should be spent. You know, it's not just a reimbursement for care, you know, there is a state agency that provides the care. We need to make sure that these individual accounts are below the resource limits, you know, and we need to make sure that that kid is also, while in foster care, taking advantage of the same things we have already mentioned, paid work experiences in school. You know, the same treatment for those. Those kids are really seriously at risk. And not only financially, but physically, and emotionally, and everything else. And they need to be treated better. And I think that that starts with each agency in the state.

>> But I also want to add that, you know, I think some of this comes from the very disconnect between poverty and disability, and that even within sort of the foster care systems and the Social Service system, they equate disability with inability to work; right? And so fundamentally, we have to start with shifting their understanding and perspective of what work can look like

and empower their staff with the shifts that we've seen on the disability side; right? When we talk about employment, first, we talk about individualized, customized employment, we know what the successes are. They haven't seen those successes. And I think that we really need to help them fundamentally shift their view that disability equates to inability to work and then equip them with the information and knowledge to be able to navigate that. Under Promoting the Readiness of Minors on Supplemental Security Income, we did a small project out in Western Maryland, with the staff, and kids in foster care, and their foster parents. And by having some targeted information, suddenly, you know, they went from sort of discouraging kids in foster care, to working to the kids working and getting that work experience and seeing what's possible. And I think that we really need to start to figure out how can we push what we know works on the disability side of the house over into the more heavily poverty-dominated pieces to help that mindset, to help them to be treating, viewing individuals in foster care with disabilities as being able to work and holding that as an expectation when they are working with them across the life-span.

>> Yeah, and, Jade, I think that we need to recognize that a Social Security standard disability is very difficult. It's not a light standard. And that we need to stop seeking success by removing people from the rolls. And that every child we get working to their maximum capacity, even if there is still SSI payable, is a success. Social Security needs to recognize that, Congress needs to recognize that, and everybody listening needs to recognize that someone working at 20 hours a week at their maximum capacity is a success story.

>> Absolutely.

>> [cross talk]

>> I'm sorry, I saw Eric pop up on screen. Do you have something that you want to pull in?

>> I do, Mia. Thank you very much. This is part of the fun power of technology and how we are all able to communicate together. I have a message from the ABLE Program Administrator in Maryland, her name is Betty Ann Mobley, and she wanted me to mention for the group that the State of Maryland actually has legislation that requires conserving funds for foster youth to be available upon transition, and ABLE Accounts are actually listed in the statute to be one of the vehicles for the money to be able to be saved and then passed on. She also then wanted me to see if Jade wanted to add on anything to that since apparently their offices are down the hall from each other, or maybe their buildings are across the lawn, but that's one of the things that was just mentioned to me by the ABLE program in Maryland. I wanted to pass that on.

>> Well, and so one of the things, though, we have a master IEP tool in Maryland. Not all of the local school systems use it, they're not required to, but they're required to ensure that that online IEP items are included in that. And we have been systemically sort of building out what some of those pieces are. Like linkage to post school services. And I know that some discussions have been, you know, is there a way that we can ensure is that online IEP process, you know, the discussion of ABLE Accounts. But again, this is where knowing who the students are who

are on SSI would be really beneficial because then we could target information to them, you know, through the schools, you know, as they are going through this online IEP process. But I think that we really need to start to think systemically how are we putting these pieces and how are we getting the information to the people who need it, and we can track it back and it's not just sort of hoping that somebody picks up a piece of paper or that information but that we can track that, yes, this information has been received. And then, you know, what are we doing to ensure that not only have they received it, but they have been able to understand, internalize, and act on it, and how can we measure that action has occurred as a result of that information.

>> One hundred percent, one hundred percent. I want to talk about one other community that I think is important to talk about during transition age which is for individuals who have very complicated medical histories, and so they may be worried about losing Medicaid. Many states make SSI an automatic eligibility requirement for individuals who are on SSI. So, I would love to hear from folks on sort of what would your suggestion be to those individuals who are concerned about their children losing access to SSI, including things like home and community-based services and supports.

>> Well, I would hope that every state has a Medicaid buy-in. And those of you that haven't, I'm happy to talk with you because that's really critical; right? Being able to have earnings, increase your earnings, and not risk losing the very benefits that oftentimes are how you are able to work and generate earnings. So, so I would hope that Medicaid buy-ins, if they are not in your

state, I'm happy to talk with you further. You know, Maryland does have it, we call it the Employed Individuals with Disabilities Program. But that is a critical piece to not losing that health care.

>> Peggy, you just got on, I'd love to hear from you.

>> Yes, thank you. Yes, I think that it is really interesting to see how much is done to inform individuals about when they become in, come into Medicaid. But very little is done in terms of when they are exiting or when they are potentially going to lose coverage. There have been a lot of protections starting to build in with the COVID, et cetera. But in terms of this, one of these provisions is called the "ex parte" provision, which allows the Medicaid agency to rely on other sources of data, to not make the individual have to reapply on everything. And that provision can be extended to SSI, but it is my understanding that it is not been widely used. So, the kind of informing people much earlier, about the age 18 and what that means in terms of Medicaid is really important. And also, for many of them, they will, then lose their benefits under the early and periodic screening diagnosis and treatment program, which is really important particularly for a long-term care services and supports. So, I think earlier education and more administrative sharing of information between Medicaid and SSI would be of great help.

>> Thank you. And Raymond?

>> Yeah, hi, Mia, it is me again. You know, we can't forget 1619(b) either, you know, a program from Social Security. This program started in 1987. So, it has been around with us for a long time. And as soon as somebody is at work and earns enough to cash out their benefits, so that they become an SSI recipient eligible for zero, they continue their Medicaid coverage. And it is all based on state-to-state thresholds, but some of those thresholds are in the 40 and \$50,000 range. The one thing I love to talk with kids and parents about is the fact that you really need to work hard and a lot to lose your Medicaid. And even if we lose it after 1619(b), then the state buy-ins kick in. You know, so it is going to be real hard to lose your health care, you know, short of missing out on a disability review that determines that you're no longer disabled.

>> Thank you. Thomas?

>> Thanks, Mia, Tom Foley. Just another opportunity to mention you know this is a great place to mention ABLE accounts, because again while someone is working, as they go through 1619(b), maybe transition on to a buy-in program, all that time you know at present rates, they can save up to \$17,000 a year in an ABLE account and not have it count as a countable resource.

>> Right. Wonderful, thank you. I think we have talked a lot about sort of communication. How do we get this information out? Particularly on specific programs that SSA provides to all recipients, but are really, really helpful for folks who are transitioning or are looking to get, looking to be able to start working. So, I would love to hear from you all on, you know, there is

several different programs that we have already somewhat talked about. But would love to hear from you about how we can communicate this. Because as Tom has mentioned and as I have mentioned, you know, some of this information is not getting out to the correct people in the time, in the time that they actually could utilize it and benefit from it. Programs such as the Ticket to Work Program, earnings limits, work incentive policies, and other programs. So, I would love to hear from you all on what, what are the best ways to communicate this information?

>> I'm happy to go first, Mia. I'm sure there are other things that folks can provide. This is a little bit of an advertising piece for the U.S. Social Security Administration also. So earlier this year, through the ABLE programs and our initiative ABLE today, we hosted one of the largest webinars we think as far as ABLE accounts that had ever happened. A lot of those because the partnership and the collaboration with the U.S. Social Security Administration. So earlier this year we had over 1,900 live attendees on an ABLE SSA webinar. And since then, we have had over 2,000 people watch the video, of the webinar recording. And so, things like that where the Social Security Administration can partner with the administrators of the ABLE program, really help to lead a national initiative to be able to push things off of national channels, but also then use the state agencies and the ABLE programs themselves to partner with disability groups and people across the disability space on a local level. So, I think if there is ever an opportunity to partner again, on information, I know we all love webinars and we probably all sit in a lot of webinars every single day including the one right now, but they are informative ways simply

because the fact that there is an option to watch it live, or also see that recording following when people have more time.

>> Mia, I would like to also suggest that having more of your materials in plain language would be really helpful. I know we, we looked at the AJ Team brochure that is put out for about the AJ Team Redetermination, and it was at a 13th grade reading level using the Flesch-Kincaid Test. So, I mean that is, that is just one example. I also think the, having an organized outreach effort to case management programs, whether they be in mental health or in developmental disabilities or child welfare, or the Title V programs for children with special needs, and again the special ed. programs, would be really wonderful. And we have done some interviewing of a program that is supported by SAMHSA called the SSI Outreach Access and Recovery Programs called SOAR. And they work in underserved communities to help gain access to SSI benefits. And again, I know that the agency is very committed to working on marginalized communities, and so again that is a model that I think they work very hard on training case management staff. And to the extent more can be done like that, using that model, that would be terrific. Thank you.

>> You know, Mia, I think we also have to look at populations that are remote. You know, I was, I spent most of my life in Boston where the Internet was fully taken for granted, and cell phones were fully taken for granted. I'm in New Mexico now. I live twelve miles from the state capitol building, and I have no access other than using satellite for Internet. Comcast doesn't come here. Let alone going a mile down the road when you start getting on to Pueblos, get out to the

Navajo reservation. There are enormous populations that we are missing. And how we do that is beyond me. I think that you know some of the suggestions for the questions that we saw ahead of time looking at faith-based organizations, looking at anybody you know on the Navajo nation who may have an Internet connection, that is not too remote from people to gather people together, we have to turn Internet cafes into Social Security information centers. You know, and we need to address those populations on their own terms. You know, it is not going to be very helpful for me to go to the Navajo reservation and talk to them about Social Security. And so, we need to get into those populations and educate their own, so that they can then pass on the good words in a much more effective and culturally appropriate way.

>> And while I hover this at -- sorry, just going off of what, what you're talking about, we know that the Pew Research Poll, that was done in 2021 showed that 62% of adults with disabilities say that they own a desktop or laptop, which means that, you know, almost half of the individuals with disabilities don't have either a laptop or a desktop or a hand-held smartphone. And so, and we also know that disabled people are much less likely to have access to the Internet. So, all of those are very, very important things to think about. Tom, I know you jumped on --

>> Oh, thanks, Mia. Yeah, I wanted to, you know, faith-based communities, I think is a huge opportunity to be able to service message particularly in rural areas, just wanted to agree with Ray on that. But just a couple of other thoughts. I don't know, I haven't been to a Social Security office in a while, but there used to be TVs in the waiting rooms, so you know, videos on work

incentives, videos on ABLE accounts, and what they can do. You know, it is, it is getting people at the right moment where they might be open to hearing a message like that. And we would be happy to share this with everyone. We are currently working on a transition age toolkit with the Department of Education's National Technical Assistance Center, around ABLE accounts, you know, particularly for you know transition age youth. But I'm sorry, I can't remember who said it, but somebody mentioned you know getting, catching people where they are at. And I know this is a little outside of the box and not everyone has access to the Internet. But but there are you know disability, young disability influencers out there. And I just wonder if there is any way that Social Security could partner with some of these influencers, you know, to tell people about the employment opportunities, to tell people about work incentives, to tell people about ABLE accounts. Because man, some of these folks have millions and millions of followers, and, you know, I have got kids and I know the way you reach them these days is through social media and influencers.

>> That is a great idea. I also wanted to -- Oh, Peggy, you had -- you wanted to add something?

>> I'm good, Mia.

>> Great. Excellent. I also wanted to hear from you all about other populations such as individuals who maybe English isn't a first language.

>> So, I think that a lot of this comes back to building relationships with communities, because there is a mistrust. And I think we need to acknowledge that. And we need to then be partnering and building that trust with the different communities, providing information in a way that, that works for them. So, I have done some work with some Hispanic communities in Maryland, and you know they are very articulate about the fact that a translator is not, just a translation of something is not helpful to them. In part because their population has varying reading levels and so forth. They need somebody who can not only help them to translate the words on the page, but to ask questions and to be able to navigate and to really understand those words in a way that works for them. And so, I think that our entire systems when you think about it are really predicated on, we push information out, we expect you to come to us, on our terms, nine to five, Monday through Friday. We need to be much more flexible in terms of what we communicate, how we communicate it, when we communicate it, and that we also ensure a consistency and accuracy of information that is being communicated and build those relationships with the communities, like the influencers. I mean, I love that, Thomas. You know, those influencers are the people that we should be getting the information, the hands of. You know, it shouldn't be coming from those of us sitting in government. We need to build the trust, build the relationships, and then, and then work with them and get their input into, is this information being useful or do we need to reframe it or redo it in a way that works better for your community? What questions are you getting so that we can change it? It needs to be an interactive process, not a sort of push out and just expect that that's going to change the outcomes.

>> Great, excellent. I think -- oh, Eric, do you want to jump in before I go to the next question?

>> I just wanted to say, thanks to Angela and Dane. We actually built an ABLE ASL Resource which is a presentation that uses ASL as the first language. It is not me presenting with somebody on the side, or on the corner doing ASL interpretation, it is people who are deaf and/or hard of hearing, who are actually using ASL as a first language. And I want to just state that the power of what the comment of I think Jay just made, providing, and communicating in ways that people want to receive. The number three webpage that is visited on our website after the Social Security webinar, and the listing of all ABLE programs in the country, is actually that ASL presentation. There is many people in many disability groups that support the deaf and hard of hearing community, that is registered with them. And so, I think, I agree, building things in ways that people want to be communicating with is how we need to kind of move in that direction. And thanks again, to Dane and Angela, for the interpretation today.

>> That is great to hear. It is always good to hear success stories. So, all right. So, the next question that I have is about organizational payees, assisting children approaching 18 to manage their benefits. How are organizations doing this, and how could they improve what they are doing?

>> I am not aware that they are doing anything. Organizational payees, you know, while they are monitored, the protection and advocacy agencies do monitor them, can be a problem.

Yeah, and I don't see them as helping with the exit at all. Yeah, I have always seen rep payees as

a significant imposition on a recipient because their basic notion of choice no longer exists. So, it is a significant, it is a significant taking of rights that we all just really take for granted.

Sometimes it is necessary, though. And I always thought that a good payee was one that put himself out of business, that they should not be just doling out funds. They should be working with their recipients. You know, helping them balance checkbooks, helping them make financial decisions, you know, and working with an ABLE account if they could do something that like. To allow a foster child who's in the system or anyone else in the system that has a rep payee, even if it is just mom and dad for their kid, you know, to leave that rep payee-ship behind and be able to deal with this. You know, to be able to deal with financial literacy issues, to be able to deal with savings, to be able to build a budget for basic needs. You know, I don't think we are preparing people with payees, particularly transition age kids to do that at all.

>> Thomas, you want to go?

>> Yeah, I just wonder, you know, to Ray's point if there would be an opportunity at some point for Social Security to kind of look at, more of a supportive decision-making model. Right.

Because I think what we want to do is make sure that people, gosh, we have been saying that, you know, do as well as they can, let's keep those expectations high. And, you know, supportive decision-making model I think we have seen can really you know make a difference in the lives of you know many people with disabilities. And maybe you know move people to a place where they can work, to raise your earlier point, maybe it is 20 hours a week, and you know there are

some benefits still being received. But that is a success. And I think a more supportive decision-making model could be part of that.

>> Thomas, can you explain a little more about what you mean by supportive decision-making just in case we have anybody on that may not know what you mean?

>> Sure. So in, in a lot of situations, sometimes with a rep payee, or higher, you know, different levels of people not having access to their own, their own money, but with a supportive decision-making model, an individual with a disability can receive you know some coaching and some training, and often involves family members as well to be able to help a person you know better understand not only the options available to them, but to make sure that they are pursuing what they want to be able to pursue. Kind of in an earlier example, just around ABLE accounts, you know maybe they really want to save for a car, or they really want to save for a house. But it, it brings a support team together to help a person you know better make decisions that they are full participants in. That they want to make sure that they are making decisions that support the goals and directions that they are most interested in. I probably could have done that a lot more eloquently. Sorry.

>> No, that was fantastic, thank you. Yes. So, it prioritizes the individual's sort of goals and wants and needs versus sort of allowing somebody to make the full decision on their own. And I think that is a good start towards helping somebody understand how to manage their own

money, right, is that you are providing them information and training and support on how to make those choices.

>> You know, Mia, we, I think we have to also recognize the different groups who have payees. By definition, you know, and I think it is a societal definition as much as a Social Security definition, if you are under 18 you cannot manage your own benefits. I know that is what my mom always thought about me. So, you know if you are under 18 you are going to have somebody else handling your money. But we need to again realize that an SSI kid who is in a poor household, may have parents who are using that money to keep the household together. And they may not have the skills, to teach financial literacy points to their child. So, I think we need to, you need to be able to graduate from this program, from the rep payee program, skilled, and not just have nothing. Again, I'm going to plug work incentives you know forever and forever. If we do allow that kid to take those paid work experiences while they are transitioning, that is really going to bring in extra money. And that is the point where we need to instill financial literacy not only in the child, but in the family. And so, we do have an opportunity to do that. I don't think we have the right tools to do it yet.

>> All right. My next question which has been sort of passed around particularly because you know we have bumped the age up for health insurance coverage, and other, other things. But should the age be raised up to 21 since those with disabilities can be in school until age 21? Would that be a better age for us to push for?

>> I would be happy to respond to that. I think that there is several reasons that, that raising the age to 22 or even up to 26 would be terrifically beneficial. I think that the child disability definition is more developmentally appropriate for the 18 to 21-year-old age group and a lot of, of young adults with disabilities are not in special ed or in the voc rehab opportunities, so they are not getting the advantage of this extension to 21, or 22. Also, I think with three or more years of eligibility, the young adults will better understand the process and the requirements for redetermination. And finally, I think that the, the sheer number of transitions that those who are 18 have to go through is daunting. And if we could spread this out a little bit, it is just, it is just overwhelming for those with disabilities. So again, I would give a great plug for raising the age. And I think, I read a very wonderful article by Sheryl Larson and Judy Geyer at the University of Minnesota on that topic.

>> Great thoughts. Anybody else want to plug in here?

>> Yeah, I agree with Peggy. I also think that it allows them, if you are getting off at 18, it is presuming that you are entering the workforce. And if you are entering the workforce at age 18, you are probably entering at a minimum wage. And I think by raising it to 21, or giving them the opportunity to get vocational training, you know, several years of college, maybe even being able to complete your college degree under your belt, so that we are allowing you the opportunity to invest in careers and skills, that will move you off of minimum wage into career pathways. And so, I feel like no kid at age 18 is, is ready to enter the workforce. I feel like that is a relic from you know the old days when you left school and went to work at the steel mills, and

you know were able to raise a family on that. And I think that we really need to look at that and look at how we can incentivize and use that as a mechanism to keep them engaged in and continuing their vocational training so that they have careers not just working at you know a minimum wage job for the rest of their life, which is going to be more likely put them back on to SSI down the line.

>> All right. Raymond, did you want to, I saw you come off, did you want to add anything?

>> I was, both of the women took the words right out of my mouth. I do think it would allow for a longer transition then we are allowing for now and a more effective one. But just to pick up on Jade's mention of the trades. You know, we can't, we can't continue to think the only way out of SSI is through a college degree. You know, I know we all thought that that was very generational when I was growing up. But right now, you know, the trades are big. They are necessary, and skilled supports that we all need. I just paid an electrician to come to the house and maybe that would have been a better outfit for me to work into retirement. They are expensive, they are well paying jobs and we need to -- I see a lot on social media about supporting trade schools and things like that. We need to institutionalize that.

>> Wonderful. Thank you. I think that we all know that the requirements to stay eligible on SSI are extremely complicated, even for the most educated individual. And one of my friends even talks about how you kind of have to become a lawyer in order to be able to keep your benefits and stay in line. I would love to hear from you all about how SSA can better communicate

information about SSA's earnings limits, what substantial gainful activity is, and, and also you know all of the other requirements that, that individuals have to stay on. Because I think for me, I didn't even know about some of these requirements until I made a mistake and earned too much money which was over \$20 during the summer while I was in college. And, again, I didn't know about the other program, because nobody informed me about that program, about students being able to, to earn more while they are in school. So, I would love to hear from you all on how we can better communicate that information.

>> I'm going to start with that one. I think Social Security needs to invest more in the return-to-work programs. I think they need people in the local offices, even the service representatives at the front desk to be better educated on what these work incentives are. We have benefits planners all over the place, but, still, nowhere near enough to meet the need, and lots of people don't know benefits planning exists. So, we have education, education, education, and an agency that really puts a priority on return-to-work efforts. And that's what I think is lacking right now. If the agency becomes the biggest barrier to somebody returning to work, despite all of these marvelous work incentives, you know, we're in a losing battle right now. Somebody in that local office needs to be available to talk to people, to answer questions, to devote work time that will get them work credit to figuring out these issues for people. And the biggest -- One of the biggest things that we have as benefits planners against us is that we'll talk to our clients. We will make sure that they understand exactly what will be happening to their benefits when earnings come into place. But if that same person goes to Social Security and is told

something different, they are going to believe Social Security; they are not going to believe a benefits planner. So, we need to get Social Security up to the skill level of benefits planners.

>> Does anybody else want to jump in?

>> Tom Foley should go first.

>> Oh, thanks. Tom. You know, I couldn't agree more. And Mia, I think we had very similar college experiences. You know, everything, as a young person I learned about benefits, I learned from friends. And, gosh, sorry --

>> 100%.

>> When you said you had to be a lawyer to understand this, I will confess, I am a tax lawyer by training, and I find the tax code infinitely more elegant and straightforward than I do all the benefits rules. Just yesterday I was talking with one of our subject matter experts and she just went three layers deeper than I've ever sort of been, and it's just completely overwhelming. So, obviously, you know, communicating the power of all these work incentives is critical, showing people the actual pathway to do it, because sometimes just reading the rules is so confusing. It's like, you know what, show me the path, show me what I need to do. Give me a decision tree or a decision guide or something like that that shows me how I can work, save a few bucks, and continue to build, you know, my employment capabilities. But I think I'd be remiss without, you

know, saying, boy, is there some way we could simplify some of this, because I don't think we should, you know -- is the goal to be able to, you know, have everybody up to date on the complexity of all of this? Is there some way we could move forward to make it a little simpler for everybody because I'm pretty sure we'd have better employment outcomes, there'd be better tax revenue outcomes, and would be good for the rules as well.

>> 100%. I think -- I mean, many of the people who are getting SSI, even SSDI, are getting it because they may have executive functioning issues. And then you're asking them to be able to have executive functioning to be able to stay eligible on SSI. And I think that is a significant concern for folks because it could mean that we are kicking off people who really do need the benefits but are just unable to stay in -- stay eligible for the benefits. Eric, I saw you jump on?

>> Mine is a little bit simple. It's really just requesting from SSA to ask policymakers and administrators of programs to help get your own information out there. So, for example, if there's an update to the POMS, on ABLE accounts, sometimes ABLE programs have to find out about it after the fact or kind of find out about it from third-party or what not. You know, we'd love to share the information. I know Tom Foley and his crew at NDI would love to put it in newsletters and put it out there in an email blast. We would love to be able to kind of illustrate that and present that out to the community. It's really just asking the Social Security Administration to say, hey, who can help us get the information out on the programs that we kind of interact with? I think it would be a good chance to utilize other resources like us to communicate updates and information on our programs.

>> And before you jump in, Peggy, I just want to remind folks, if you have questions feel free to put them in as questions. We will be jumping on to trying to answer some of those around 2:25. So please submit your questions, if you have them. Peggy?

>> Yes. I'd love to have the communication from SSI elevate health as part of health coverage, health care, as part of your research, your messaging, your ongoing work. It's a little bit buried in everything and it's so foundational to, you know, transition from pediatric to adult care, from childhood to adult public program benefit. But, just as with Special Ed, the transition planning doesn't have to have anything to do with health, and I think it's a little bit of a disservice. And to the extent that SSA could bring greater attention to the importance of health. Particularly during this age period when there's so many changes happening, I think that would be very important. Thank you.

>> Wow, I 100% agree. Raymond, you want to be the last one to say something on this topic before we move on?

>> I think one of the immediate things to make things simpler on the resource side would be to encourage your House members or senators to vote in favor of the Act that's pending that would increase the resource levels to 10 and \$15,000. You know, that is -- those are resource levels that most American families do not have in their accounts today. And that would take a

lot of the workload off Social Security and make at least resources almost a secondary consideration.

>> 100%. I believe that bill is bipartisan, so feel free to check it out. I think it's something around raise the asset limits. But anyway, I wanted to actually move forward to talk about a very specific program that a lot of folks know about but would like to really focus on it because it's intended to provide folks with some transitional services, and this is Vocational Rehabilitation Services. Now I worked as a Vocational Rehabilitation Counselor for about 6 years, so I have actually been on both sides as a client and as a counselor, but would love to hear from others, sort of what is Vocational Rehabilitation and what is the role in helping individuals transition from school to work?

>> I'll take a first stab at that. So, Vocational Rehabilitation historically has provided post-school services to help people achieve employment. Some states opted to do more work in the transition space; Maryland was one of those. And then, as a result of changes under the Workforce Investment and Opportunity Act, something called Preemployment Transition Services was created. It has a broader eligibility than Vocational Rehabilitation, which was good in that it provides more access to students while they are in school. One of the challenges is, unfortunately, while it expanded it didn't add extra resources and so it does mean that while Preemployment Transition Services are more readily accessible to a broader range of people with disabilities, many states have had to go on to wait list for services for some of the post-school more intensive services. And I think it's really important to note that not all kids on SSI

have an IEP, which means that they are not known to the school systems, and they don't get transition services. And I think that transition services are something that every kid should be getting whether or not they have a disability, you know, and that 504, because that's what helps provide that space to ensure that information is being provided to the individuals. So, you know, so starting at age 16 if you have an IEP, you know, at your IEP meeting talk about your transition goals, we can talk about Preemployment Transition Services, right. We can get you the information. You can apply, enroll, receive self-advocacy, work, you know, some things to help you down that pathway. So, I think that Vocational Rehabilitation is a really tremendous resource. I think that Pre-ETs is really important, but I think we do need to acknowledge the limitations, and that means that if you're on SSI, you turn 18, you haven't gotten into Vocational Rehabilitation, you could then apply and be placed on a waiting list which means that you wouldn't be eligible for Section 301. I mean there's this whole cascading domino sort of effect that is caused by the lack of resources. That said, everybody, everywhere who has, you know, any sort of disability and who is in high school should be encouraging application to receive the Preemployment Transition Services, because that is a space to start to provide that. It's not just for the students with the most significant disabilities, you know, it could be someone who has a learning disability. It could be someone who's on SSI, who doesn't have any academic support through school or any academic needs but could still benefit from that. So I think that those are some real important resources that we need to make certain that folks are aware of, and is there a way under Pre-ETS to then ensure that, you know, if there are youths on SSI who are getting into Pre-ETS, of course, we have to figure out how to make certain to get them into Pre-ETS, that we could be pushing some of this information to them as well. I think we need to be

looking at the places and figuring out how do we connect the dots better, and how do we find them where they are, and how do we get them where they need to go?

>> Right. Anybody else want to comment? Thomas?

>> Yeah, thanks, Mia. Yeah, just to follow up. You know, so I didn't discover VR until I was a little bit older and it, so I'm just reflecting, it made such a difference in my life. You know, I was pretty good at school, but what VR taught me how to do was how to look for a job, how to apply for a job, how to be prepared for my first job. And boy, if you get the right counselor, my counselor really challenged me. And, you know -- again, I knew how to do school, but I was not ready for the workforce, and VR was a big piece of that. And I think the earlier we can connect kids to those supports and to those opportunities, you know, the better off we'll be. I was sort of reflecting, boy, between SSI and VR, you know, they provide the supports that I needed to be able, not only to build an employment future for myself, but I've got three kids at this point, and we put two and-a-half of them through college. The boy is going to be the death of me but could not have happened without VOC Rehab and the support I had from SSI. And being able to marry those two together, it is a great first and second step to putting kids with disabilities into a place where they can be successful.

>> Thomas, can you talk a little bit about the services that are provided through VOC Rehab, particularly for transition youth? You're on mute.

>> Am I off mute?

>> Yes.

>> Okay, great. Sorry about that. Again, I came to it a little bit later, but for me, what it was really able to do was, it provided support, you know, through school. It provided, gosh, it taught me how to write a resume. It connected me with workforce. You know, again, my specific counselor -- my specific counselor, you know, challenged me to do better, and to you know, find the right place for myself. You know, sorry, Mia. I don't know if that's helpful, but, you know, those were some of the services that VR provided for me.

>> Yeah, no, that was great! Just to give a little bit more backing on that, you know, VR can provide evaluation. So, they can actually, if you say, don't have enough information on what types of accommodations you might need, on the job, you can go through evaluations, whether it is physical evaluations so they can pay for a doctor's evaluation. I remember as a counselor I even saw people for evaluations on plantar fasciitis. So, you can get a wide variety of medical evaluations. You can get psychological evaluations through them. And then you can also get occupational evaluations. So, what are the things that you enjoy? What are the things that you think you're good at? And try and help pick certain occupations that might fit within those parameters? And then, also, on-the-job evaluations where they can assess our executive functions on the job and see how well and what types of support you might need while you're on the job. They can also pay for internships and also on-the job training. They can provide

payments to personal assistance for a short period of time. And then, a wide variety of also the things that you are talking about, Thomas. So, they do have a wide variety. And I also do remember providing some of that benefit and analysis for individuals who are on SSI or SSDI. So those were all of the things that providers could, or counselors could provide for individuals who were receiving those services. The next question, and this is sort of one of the last ones before we go to the questions that we've gotten from audience members is, what should SSA sort of prioritize in terms of improving their services and reducing some of the roadblocks that individuals face?

>> Okay, I'll start again. Yeah, I think that what can be done, and what I said before, I'll reiterate that to get the return-to-work transition services up to a level of priority that it deserves. I think there's also a workload issue. Now I know that Social Security is understaffed. I don't know if I could handle the number of cases that those claims specialists handle, but we need to look at the work activity much vaster, and particularly for youth with that student earned income exclusion. If I'm telling a parent that don't worry about the SSI, nothing will happen because of this exclusion, and Social Security is not looking at those work reports and processing that work information for six or seven or eight months down the line, that is not helping. That becomes a barrier, because we're looking backwards. We're rearranging. There could be overpayments. There may not be overpayments. It just is a mess, and it doesn't help balancing the needs of a very complex system with the needs of transition.

>> Eric?

>> Thanks, Mia. I have a two-part. One is for the Social Security Administration, and one is from the Social Security Administration. So, I want to just thank the Social Security Administration for having this forum. I was there when ABLE accounts first got started. I was there when the very first ABLE account was enrolled, and even just having ABLE accounts mentioned at a forum like this is a really big deal. And I also want to acknowledge for those that may not know everything the Social Security Administration does, I think, Mia, don't quote me on this, I'm just going to pick a number, I think it's 70, over 70 million people receive Social Security benefits on a regular basis. And, with that, there's so much work that has to be done. There's a lot of recordkeeping, a lot of administration, by all the case workers, by the policymakers at your headquarters. So, one thing for us on the ABLE program side would be we would love to answer ABLE program related questions. We would love to be able to help give the field office answers on how ABLE accounts were administered or what's the recordkeeping or what reports can we do. Anything that we can help answer policy or program questions for the regional offices, we would love to give them the information. Again, there's so much work that goes on behind the scenes. I just want to make sure that if ever there's a chance to offer them support and give them direct feedback and information from programs, we would love to do that. Again, helping them to pay able to do their job. And then a little bit more on that. I often get questions on the Social Security Administration, right. I think representing a government program like we do, I think people will assume I'll know every single answer in the government, which is impossible, and anything that the Social Security thinks that we should be offering, I mentioned earlier about sharing information, do tap into partnerships, do tap into other groups, because we're just a

network and an avenue to share your own information. A lot of the reason is because the programs we run are interacting with Social Security on a regular basis. So, anything that we can do to help share your information on the other side of the public, please do ask us, work with us on how to do that.

>> I think you're absolutely right, Eric. Somebody once said it takes a village, and it does take a village to help a kid through transition, to become a worker, yeah. So, the more partnerships that we have, the best. And I just want to drop a note to consumers who might be out there, the Work Incentive Planning and Assistance programs that are supported by Social Security are available to you for benefits planning. There are other benefits planners out there who might be able to support you and the protection and advocacy for benefits -- for beneficiaries of Social Security have a priority for transition age youth. So, there are resources out there that you can tap into. If you want some information about the protection and advocacy agencies just Google disability rights and your state name and it's likely to show up.

>> 100%. Thomas?

>> Thanks, Mia. And just sort of related to that and especially around ABLE accounts, you know, we were talking earlier. I mean one of the great things about ABLE is that if someone has extra resources, they can put those into an ABLE account, and maybe that's the difference in qualifying for SSI, qualifying for Medicaid, you know, qualifying for waiver programs, or at least a waiver waiting list. So, I wonder if there would be any way that Social Security could include

that information, particularly if someone is turned down for benefits, you know, because of resources. So, you know, give people a tool that they can act upon, you know, in the moment, so that they can, you know, use SSI. They can maybe learn about VR. They can use ABLE accounts to be able to qualify for all the services we have been talking about.

>> Great. And Peggy? I also wanted to add as just a suggestion about, again looking at the research and data by state to better understand the age 18 loss and appeals, and also looking at that by race and ethnicity, and maybe rural and urban areas. I think it's hard to kind of design, improve communication and outreach without having some regular annual transparent information about the variation that's going on. So, I think that would be really helpful. Thanks.

>> I 100% back that, Peggy, on transparency and data. I would love to see that. Eric?

>> I didn't have a button to have a fireworks or smiley face go off –

[laughter]

>> -- but I wanted to come back on and add on to what Tom said. We've talked to regional offices. I myself have presented at regional offices in the Midwest and I know we don't want to ask the Social Security Administration to endorse a business product or one particular service out there. But I think having the opportunity, again, this is just a wish list since Christmas is coming around the corner, I might as well let you know, that possibly having someone saying

someone is over resourced versus the idea of what an ABLE account is. Say, there's a resource out there for you, there's another tool out there, another choice, another option. I think if we could get to a place where we are just promoting options and the idea of something, not just selecting one, right, just the idea of what an ABLE account is, I think that would be a tremendous resource to help people choose whether or not to spend down or choose to save money or possibly make them choosing whether they are going to stay on benefits or not. So that would be a little bit of an add-on. Again, maybe the next time we do the forum, the gifts, or maybe the little icon things would be here so we can press the fireworks and the confetti.

>> I think that would be really helpful because I remember going over earnings limit and being deducted -- having my earnings be deducted by nobody stated in that saying, Oh, we see that you're age 19. Are you still in school? Are you, you know, you could get into this school program for students if you're still in school. That was never suggested for me until -- I didn't know about it until I was outside of school. And so I was, you know, paying a bunch of money because I would take, you know, summer jobs to be able to pump up my resume for work after school. So, I think that is a fantastic idea, Eric!

>> So, I would just like to add, you know, I think that there's been a lot of work that's been going on in a number of states, around sort of connecting the partners and transitioning much better. And I would encourage Social Security to be looking at building and tapping into some of those coordinated partnerships, maybe engaging and sitting down at the table to say, what

strategies would work and how could we be pushing information out and what would be helpful in developing some coordinated outreach communication plans across partners?

>> Yes, that's a great idea. Fantastic! I am going to switch over to some of the questions that we've gotten from audience members. Some of them were submitted before this panel. Some of them have been submitted during this panel. So, I'm going to go through them as we go along. Feel free to send them to the administrators and it will get into my inbox so I can go over those questions. But one of the questions, this individual is wondering how brand-new legal advocates who may not be lawyers should be representing transitional age youth, what are the things that they can do to help transitional age youth?

>> As the lawyer in the crowd I'm going to start with that one. There's always a need for more representation for claims that are being processed by Social Security, either for benefits or during the age 18 review. But yeah, and Social Security does have a process. It involves and examines some studying where a non-attorney can provide representation and accept fees for that. So, there's that. When I was working in legal services we had many paralegals, as we called them, at the time who did fabulous jobs representing people for Social Security. You know, there's always the benefits planning route. You know, benefits planning is something I believe everybody on disability benefits or SSI should have benefits planning services before they try to work. There's a desperate need for more benefits planners. So those are two ways that non-attorneys are crucially needed in this system.

>> Thank you. I'm going to go to the next question, which is, do you have suggestion -- one, is age 18 too young to transfer benefits to an individual? And if so, what age would be more appropriate? And then the third part of this would be, do you have suggestions on how to improve the process of transferring payments from the guardian to the individual?

>> All right, I was waiting for Pam to show up and do this one! [laughter] But I think that I agree with her, that, you know, the age 18 is the social and legal cutoff, I guess. You know, that's what we're all used to. Does it work for a transitions-age student with disabilities? You know, particularly, as people have pointed out, that we're moving from functioning on a general level to work? Maybe it doesn't. You know, and I frankly didn't even consider that until I saw some of these questions. And maybe 22, you know, or under age 22, and turning 26 might be better. And I forgot what I was -- where I was going. But I think that there could be a little more transition. How to transfer the money from the guardian. Again, we have two types of guardians. You have mom and dad, who are your guardians if you're under 18. And that should be a more easy transfer. However, we are depending upon parents to have the financial skills to help that transition. If it's a different kind of guardian, you know, that's a legal creature. You know, if you have been found incompetent by a court of law and have a guardian, transitioning is going to be much more difficult, and it's going to involve court processes, you know, along with trying to ramp up. Again, I think of all of these people who control Social Security funds for a recipient, I loved Thomas' presentation, you know, on the supported decision-making. That type of thing needs to be built into the responsibilities of the payee, so that the beneficiary receives and has as much discretion as can be allowed.

>> 100%. I think, as, from the perspective of a disabled person who went through this transition myself, I think the age, what should be the appropriate age, I think it should depend on the individual and their skills and ability levels. I think there are some individuals who should not be cut off from being able to access or be in control of their funds just as any other adult would be. While others, maybe with developmental disabilities, intellectual disabilities, it may be more of a supported model until the individual is able to fully control it, or to 21. I do think it should be related to sort of the individual's ability levels. Another question is, what steps should parents make to ensure benefits remain in place during the redetermination process?

>> I think participation is the first step. And if they are participating with this process from the first notice that they receive, then they're in a great place to make sure benefits are paid pending whatever decisions are made, and potentially during any necessary appeals as far as benefits can be paid during those processes. It's truly a matter of participating.

>> I'd love to hear from other panelists if you want to break in? Yeah, Thomas.

>> I'm sorry. Couldn't get off mute. No, I, you know, I think the parent part is really important. And, you know, one of the words that I keep hearing is "expectations, " right? And I think there's an opportunity for the parents to be as involved as possible. But I think at the same time, we need to message that, you know, parents, it's okay to have very high expectations of, you know, your kids with disabilities as well. And that all of the programs and the opportunities

that we talked about today are in place, so that, you know, parents can keep those expectations high, and people with disabilities can reach their full potential.

>> Thank you. Yeah.

>> Another suggestion might be to organize more training of family organizations like Family Voices that are in every state, and, again, build up some of that formal benefits counseling capacity. I think they end up doing a lot of it but may not be as informed as those on this call today, and so I think that there's some really wonderful family disability groups that could be brought in in a more organized fashion. We've been doing a lot of interviews with families, and so often we hear, you know, "My child's disability has not disappeared, and so I thought that they had SSI for life. I had no idea that at age 18, there's this process." And so, again, I think there's just -- we've got to come at it in a lot of different ways to remind people that this is coming up.

>> Yeah, 100%. Thomas? Did you want to add something?

>> Yeah, Holly just texted me a great reminder. One of the things parents can do is make sure that their child is really participating in an IEP, so that, you know, they can continue to receive under 301. Just important -- another important piece that parents can play.

>> Right. Eric?

>> I just want to put out ABLE accounts really quick. You know, for a family or caregiver supporting a child with disabilities, whether or not they're on benefits, ABLE accounts are just a tool, right? I'm just talking about ABLE accounts in general. There are so many things going on in the life of a caretaker or family member, but ABLE accounts are a tool, especially there's trust for the tool. I just had a webinar this morning with financial advisers, and they had various tools. So, I would think that maybe being part of the conversation of learning and listening and finding out all these different tools in the toolbox. I just want to make sure I add, again, ABLE accounts are a place to put benefit money. ABLE accounts are a place to put contributions. And you don't have to be on any benefits to even be eligible for an ABLE account. So, this kind of tool that ABLE account provides is a good chance for, if a person with disability is on benefits or not, and it's just another option in planning for the future.

>> Great. Peggy, did you want to add something?

>> Yeah. Another thought for parents is to, well before the age of 18, to get their medical and school records up-to-date and available. I know, a recent story of talking with a parent from Texas, her child has autism, and she didn't want to go through that process of the three-hour psychoeducational evaluation, and so she didn't while he was in school. And she said after leaving, she said the -- finding and affording that test so that she could put it into the application was ridiculously difficult.

>> Yeah.

>> So, making certain that while they're still in the child side of things, they get the current information, both medical and school, will be wonderful.

>> 100% agree with that part. Along with that -- oh, Raymond, do you want to add one more thing before we go next?

>> I just wanted to thank Peggy for the suggestion that we go to family-friendly sources. If we have family organizations in states where these families are finding trusting sources of information, that's where we need to go to get the information out.

>> 100%. And as Thomas was talking about earlier, as well, is, you know, the disability community is fairly well-connected, and a lot of times individuals get information from their friends, their colleagues, et cetera. So, I think it is really good to understand the networks and systems of information within the disability community and within the family networks. I wanted to hear from you all, what can SSA do proactively to ensure that individuals understand the process of redetermination and -- other than just, you know, sending notices, to ensure that individuals don't get immediately cut off?

>> I think, Mia, people have said on this call today quite a bit about the simplifying the information, communication, and even, down the pike, the application. It just seems as if it's far too complex and not proactive enough.

>> So, this is Jade.

>> I think -- Jade? Yes.

>> And I apologize, my camera and everything keeps freezing, so I'm so sorry if I get cut off again. So, you know, yes. I think that that, sharing that information, what does the process look like, what to expect, how you can prepare for it, putting that information out through the partnership organizations. But I also think that we need to acknowledge that while there are many good partners out there, particularly in the parent world, we have not done as good a job of engaging some of the partners that are reaching the most marginalized, right? Cultural competency and so forth. And that's where I think the churches and that role and that access and equity. You know, I pushed my parent center in Maryland under PROMISE, because they weren't really equipped to serve the needs of the population that we were serving on a variety of levels. And they've really worked to invest in that capacity. And so, I think that we need to also ensure that when we're partnering across all of these things, that we are reaching all of the populations and not just reaching the ones that are showing up, or that are comfortable. And I think that making it really clear, and helping -- you know, I have found in distributing information, the easier I make it, the more consistent I make it, the more that I push it out

consistently -- and I'm sending the same information to the individuals who are working with the families as the families are getting, right? And sometimes I'll even unpack it for them, because when the families get the information, they're not going to come to us. They're not going to go to Social Security with their questions, right? They're going to take to their IEP or the person that they know or their neighbor or whatever, you know, or the professionals. And so, ensuring that everyone's getting the same information and that we're empowering whomever are in these families' lives with the ability to then help them navigate and provide that and make it simple and clear, and don't mail it out in a letter. Because let's be honest, if it comes in an envelope from the Social Security Administration, it is likely not going to be trusted. It is going to be ignored, thrown away. That is not how people are accessing information anymore. Text messages, you know, through these trusted sources and so forth. But, you know, letters that come from the government are never, in these populations, but just generally, being well-received as something that's, oh, it's good news, you know? And that's just going to perpetuate the barriers.

>> I had another thought about having some family advisory group to help with producing, coproducing some materials, as well as a youth or young adult advisory group. Again, we don't want to always be communicating just with parents or caregivers, but also with the young people themselves. And I know from our work on health care transition, we have been gratefully guided by having youth and young adult advisers and family leaders. And I think that would -- may help going forward.

>> Good suggestions. Thomas?

>> Yeah, I just wondered, the piece about, you know, the mail coming in. I wonder if at the end of a redetermination, like a script could be developed that kind of highlights a lot of what we've talked about today. You know, not only benefits, but, you know, work incentives, VR, and just, you know, build that into the script, so at the end of every redetermination, everybody is, you know, ABLÉ accounts, everybody is hearing at least, you know, one-on-one, about some of the options that are out there and impactful that we've been talking about today.

>> Great. I got, actually, a really interesting question. And this question is, how does vocational rehab, and even, you know, an attachment with SSA, connect with private schools and homeschooled student?

>> So, I can -- excuse me. I can speak from Maryland's perspective. So, we do push out through some of the associations for homeschooling information. Again, if they use the online IEP, that information would be available. So, reaching out, also, to some of the disability groups, like Down Syndrome Society parent groups and so forth. So, using different modes of communication. And again, that's where really sort of looking at who are all of our partners at the table, and who are we missing, and how do we build inroads into that.

>> Fantastic. Anybody else want to comment? All right. One of the last questions, I guess, would be what referrals are appropriate for young adults transitioning to independence?

>> Yeah. I think there are a lot of them. And we've already spoken about a lot of them. But if it is somebody who is returning to work, I think a benefits planner is necessary. If it is some legal hurdle to securing a job, you know, if the wrong questions are asked during an interview, or someone with a disability is not being treated appropriately on the job site, the Protection and Advocacy agency is funded to help with those questions. Yeah, I think a Medicaid specialist, if the benefits planner is not really focused on that, might be helpful. And I'm going to go back to Peggy! You know, because those -- I think those family organizations are a really fine source of information and support that can be trusted.

>> And I would add Centers for Independent Living, because we haven't mentioned them.

>> I also -- the referrals to coverage in care can't be understated. And I know I've been kind of a broken record on that. But, you know, they're shifting, at this age, between pediatric systems and adult systems. And, you know, the national data show that most young adults with special needs have not received any guidance from their health care providers about this transition and feel, again, it's a cliff. So, referrals -- and I encourage people to check out our website at gottransition.org. We have a lot of resources for youth and young adults and families and health professionals. But, you know, we try very hard that there be -- to promote a structured process for transition planning, for transfer into adult care, and integration and retention in the adult system. So hopefully health and health insurance is part of referrals.

>> Great. I was hoping you would jump on, Thomas! Can you go?

>> Sure. I just want to double-underline independent living centers, Protection and Advocacy.

This is Social Security, so obviously Ticket to Work would be huge as well. Even to the extent it's possible, disability-specific organizations. So, I'm a blind guy, so there's a number of, you know, blind organizations that I wish I had known about at 18 that I didn't. And then, since, you know, both Eric and I have been talking about ABLE, I would love folks to know about ABLE NRC and ABLE Today. You know, these are ways that people can really -- I said it before, but, you know, if you can save for your future, we're talking about hope. And I think kids with disability needs to know that there's a future out there and they're allowed to have hope.

>> Most definitely. Eric?

>> I was trying to do an illustration of a confetti cannon going off. I can't quite do it. But I mean, having someone being told that they can't have more than \$2, 000 is a profound statement. The next statement being "you can save more than \$2, 000 and keep your benefits, " is equally profound, but on the positive side, not on the negative side. And I think that's something that ABLE accounts really give, and I mean, if we're looking for another conversation, I know Tom and I are available to have this kind of forum again talking about ABLE accounts. He and I have probably plenty to talk about and plenty of people to bring to the table.

>> Okay, I think we can fit one more question in. And I've gotten a lot of questions about 301.

Can folks explain what Section 301 is, and explain why it's being underutilized, and how we can improve the issue?

>> I'll start out. I'm sure other people have something to add to this. Section 301 is a provision that allows benefits to continue to be paid after Social Security makes a decision that says you're no longer disabled and eligible for payments. So if we have a student in transition who loses benefits as a result of one of the age-18 reviews, if that student is continuing with their education until age 22 under an IEP and is actively participating, or if there's a student who's in a VR plan, or if there's a student who's working with an employment network, their plans, as long as the student's participating, they will receive both their cash benefits and health care, until that plan's finished. It's a big deal! Because Social Security says you are no longer disabled, which normally means everything is gone. So, this could keep benefits in place for somebody who's age 18 for another four years while they continue with their transition and doesn't derail the whole transition program.

>> Appreciate that. Does anybody else want to -- one more person want to jump in? All right! Well, I want to thank all of the panelists so much for joining us. I am going to give the mic back over to James.

>> Thanks, Mia. Great job.

>> Thank you. Sorry. Multiple James's! My name is James van der Schalie. I'm the Deputy Associate Commissioner in the Office of Public Service and Operations Support. And I'd like to thank our moderator, Mia Ives-Rublee, and all the panelists today. This was an excellent discussion. Also, thanks to all of you, our participants. As our Agency aims to better serve the public, forums and discussions like these present critical perspectives to consider and issues to address. One common theme that emerged throughout the course of this conversation is the need for better communication and education with all the appropriate stakeholders at the right time. There are so many resources out there to help individuals and families navigate our programs, but if we don't engage the right people at the right time to make them aware of the resources, we lose the benefit that those resources were designed to provide. I think this conversation covered a number of excellent ideas on the who, what, and when of ways communication and education of individuals and their families going through this transition can be improved. I also appreciated the conversations surrounding the barriers to access, both technological and educational or experiential, that needs to be considered when designing an appropriate communication and education strategy. We look forward to working both internally and with our external stakeholders to address these issues and refine our current processes and services to better serve the public through what can be confusing and often difficult transitions. Before we close the forum today, I have a few brief announcements. All of those who registered will receive an e-mail with a link to an evaluation for this forum. We appreciate you taking the time to complete the evaluation. It will help you -- it will help us improve our forums and offer topics in the future. If you have any questions following today's meeting, please reach out to us at nationaldisabilityforum@ssa.gov. That's all one word. Thank

you again for joining us. Remember to visit our National Disability Forum website at www.ssa.gov/ndf to learn about future National Disability Forums. Please stay safe and enjoy the rest of your day.

>> This concludes the Social Security Administration's National Disability Forum on Youth, Transitioning to Adulthood, and Preparing for an Age-18 Redetermination. Thank you for joining us today, stay safe, and have a wonderful day.