

National Disability Forum: Focusing on Aspects of Childhood Disability and Childhood SSI

Wednesday, May 17, 2023

>> Hello, everyone, and welcome to Social Security's National Disability Forum on Focusing on Aspects of Childhood Disability and Childhood SSI Part 2. I would now like to turn it over to Steve Rollins, Associate Commissioner for Retirement and Disability Policy, at the Social Security Administration.

>> Okay, thank you, James. Good afternoon, and good morning to those on the West Coast. As James said, I'm Steve Rollins, and I am the Associate Commissioner of the Office of Disability Policy here at the Social Security Administration. I have the pleasure of welcoming you to our 24th National Disability Forum entitled, "Focusing on Aspects of Childhood Disability and Childhood SSI, Part 2." On behalf of Acting Commissioner Kijakazi, SSA executives, and everyone at the Social Security Administration, we thank you for joining us today and hope you're doing well. So I'd like to start by reviewing a few housekeeping items. First of all, 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. Additionally, this virtual forum is being recorded, and will be available in about four weeks from today on the National Disability Forum's website, which is www.ssa.gov/NDF, and

then in the outreach section it will be under today's tab, 5/17/2023. Secondly, I want to let you know that we have disabled the chat, microphone, and video feature for our attendees. If you did dial into this Teams meeting, please use your phone's mute feature. And the third thing, we are offering two accessibility features today: We have an American Sign Language interpreter, and then we also have closed captioning. If you would like to use closed captions, please go to your MS Teams toolbar, select the three dots titled "More," select "Language and Speech Option," and then select "Turn on Live Captions" option. And that should get you there. Okay.

So, now like all disability forums, today gives you, our stakeholders, an opportunity to share your unique insights directly with SSA and the policymakers within the agency. The NDF is not intended to be a means for reaching an agreement on any issue, and SSA's participation is only for the purpose of gaining insight by listening to the panelists and their responses to your questions or your comments. By sharing your thoughts and experiences with us, you really 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. The purpose of today's forum is to learn from our panelists and from you about how we can improve aspects of childhood SSI and childhood disability. During today's forum we'll focus on three topics: First, failure to follow medically necessary or prescribed treatment and problems receiving medically necessary treatment for SSI child recipients; secondly is transitioning out of childhood disability; and then third is the reality of provision of services for potentially disabled children. Dr. James Perrin will moderate today's panel discussion. After the discussion there will be an open questions and answer session. You may submit your questions for the panelists throughout the forum. As previously mentioned, now there is no chat feature

available for you to make comments, but if you do want to ask a question of our panelists or submit a comment, you can do so via email at National Disability Forum, and again that's all one word, @ssa.gov. Again that's NationalDisabilityForum@ssa.gov and please include your name in your email question. But when submitting a question please do not include any personally identifiable information such as Social Security Number or address. We'll be monitoring the inbox throughout the forum, and we'll share questions with the moderator. If your question is not answered during the forum, we certainly will make every effort to answer the question via email afterwards or share it with the appropriate SSA office. So now I'd like to introduce the moderator for today's forum, Dr. Perrin. Dr. Perrin has an impressive background. He's a Professor of Pediatrics at Harvard Medical School, and former Director of the Division of General Pediatrics at the Mass General Hospital for Children. He holds the John C. Robinson Distinguished Chair in Pediatrics at the Mass General Hospital. He was President of the American Academy of Pediatrics, Chair of its Committee on Children with Disabilities, and current Chair of its Committee on Child Health Financing. He also served as Past President of the Ambulatory Academic Pediatric Association and directed the Autism Intervention Research Network on Physical Health for seven years. Dr. Perrin was Founding Editor of "Academic Pediatrics." He studied asthma, middle ear disease, children's hospitalizations, health insurance, and childhood chronic illness and disabilities. To learn more about Dr. Perrin, our panelists, and SSA executives, please visit the National Disability Forum website, click on National Disability Forums from the right-side menu, then select the 5/17/2023 tab. We'd like to extend our sincere appreciation to Dr. Perrin as well as all the panelists for their participation in today's discussion. Dr. Perrin, welcome, and the floor is yours. Thanks.

>> Thank you, Steve, for that very warm welcome. I'm delighted to join SSA in welcoming all to this National Disability Forum Part 2 of Focusing on Aspects of Childhood Disability and Childhood SSI. Today we will have a closed discussion with four very good panelists, experts in their field. After the discussion we'll take questions via email, as Steve said, and as time permits, we'll share your questions with the panelists. If you do wish to ask a question or provide a comment, again, please include your name and location in your question, and the appropriate email address is, as Steve said, nationaldisabilityforum,-- all one word -- @ssa.gov. Before we begin this afternoon's discussions, I would like to take a few minutes to share some thoughts about the children's SSI program that arose in part from the previous forum and may help frame some of our discussion today. SSI is a critical program for children and youth, and it has -- with substantial disabilities. This program lifts large numbers of children out of poverty and provides their families with critical resources for the care and well-being of their children. And as we discussed in the last forum, and will likely discuss today, too, the complex determination process is often difficult for families with limited resources. Most striking is the decrease in enrollment in children's SSI over the past few years. Some, of course, related to pandemic closures, but much of this actually precedes the pandemic. And despite this increase in SSI enrollment, there is actually no evidence of decreasing rates of eligible conditions and severe disability among children and youth in the United States. Yet, since 2011 there's actually 200,000 fewer children on SSI today than there were at that point a decade or so ago. To the contrary, in fact, recent reports from the National Academy of Medicine and elsewhere have estimated that at least for children with severe mental health conditions -- and I suspect this is

true for other disabling conditions -- large numbers of likely eligible children have not enrolled in SSI. In other words, SSI under enrolls a large cohort of children who should receive services and support. I think all of us who are working in this field over the short term or long term very much appreciate the Social Security Administration's attention to these issues and are delighted to have these two National Disability Forums. We hope that working together, SSA can strengthen its work to identify and enroll eligible children. And some options that the last group began with, and we may want to have on the table that SSA could consider includes, one, a focused, dedicated permanent office within SSA for children and SSI to bring together specialists, expertise, and importantly agency coordination to address the enrollment and service challenges that are particular to families with children with disabilities. Second, is an effective targeted outreach and enrollment effort that is solely dedicated to children with disabilities. Making available an online and simplified application for children's SSI. Enhanced agency interaction with other key federal agencies, especially HRSA's Maternal and Child Health Bureau, but also education and other resources. And more active collaboration, which I know SSA has worked very hard on, but more active collaboration with key professional organizations to strengthen the SSA and State DDS workforce. Identify needs, address recruitment, and enhance awareness. Let's begin now the transition to today's discussion on Focusing on Aspects of Childhood Disability and Childhood SSI. Let me introduce our panel. We have four distinguished and very skillful people: Elizabeth Clark from the National Association of School Nurses, a nursing education and practice specialist with a long history and commitment to school nursing. Dr. Gloria Reeves from the University of Maryland School of Medicine, a child psychiatrist with a particular interest in emerging psychosis in childhood and opportunities for

prevention and treatment. Tony Lodge, from First Focus on Children. His work has focused a great deal on youth transitioning out of the foster care system, an area of great interest to many of us, and that was the discussion at the last forum. And Dr. Manasi Deshpande from the University of Chicago. She is an economist who has studied disability and other social safety net programs. Very skillful people available. More detailed information about these panelists can be found on the National Disability Forum website. I'm going to give each panelist a few minutes to provide some background on this topic and let me start with Elizabeth Clark.

>> Hello. I'm representing the National Association of School Nurses, or NASN. And NASN's vision is that all students are healthy, safe, and ready to learn. I have over 25 years of experience as a school nurse and school nurse administrator, and in my experience as a front-line school nurse I worked closely with students experiencing ability challenges. One of the benefits of being a school nurse is the close relationship that school nurses and other school staff develop with students and caregivers. We support students five days a week for their entire school career during the school year and often in extended school year programs. It is not uncommon for school nurses to have met the student and their caregivers in their early childhood program and are rewarded to see them graduate from the school system. These long-term relationships are key to establishing the trusted relationship that school nurses and other school educators have with students and caregivers. And I want to just take a minute and explain why I use the term "caregivers" rather than parents or families. As a school nurse, I acknowledge that not all students reside with their biological parents. Some students are cared for by grandparents, aunts, or uncles, are in the foster system, or even homeless. School nurses

care for the entire school population, especially the most vulnerable students, playing an essential role in keeping all students in school healthy, safe, and ready to learn. Thank you for inviting me to participate today on this discussion.

>> Thank you very much. Let me turn now to Gloria. I think you're still on mute, Gloria.

>> Sorry. Did it go off now?

>> Yeah. Super. Thank you. Thank you so much. I'm honored to join the team, this highly esteemed panel of experts. I'm presenting today information from my lived experience from many different pathways. So one is I'm a physician, so I'm a child and adolescent psychiatrist, and most of my work as a specialist is with youth and young adults with pretty complex serious mental illness. So most of my patients have four or five, six diagnoses and pretty complicated chronic conditions. The second is I'm a clinical researcher. So I conduct what I refer to as family-centered research, which is partnering up with community stakeholders to try to think a little bit outside the box about how to improve services for youth and families. But the third perspective I like to highlight is I'm a mother, and I think nothing informs your opinion on this topic more than your lived experience with your own families, and I think over the pandemic it's been a universal experience that we've all had family members in need, and often in

unexpected and challenging situations. So we think that that shared humanity is really important to frame the discussion on this important topic today. So thank you for having me.

>> Thank you very much. Let me turn now to Tony Lodge.

>> Hello. I am, my name is Tony lodge. I represent First Focus on Children. On this unique topic I have lived experience as a former foster youth, and a lot of my work has really been on not just mentoring, but also how -- the transition of children aging out of the foster care system and what opportunities are there for them, and how entities and organizations can provide resources for foster youth. A lot of my work has been centered around that, especially a lot of my policy work. So just coming from the background of a lived expert, I think, you know, having that lived experience brings great insight on this panel, and I'm grateful to join all my esteemed colleagues. But thank you. I'm looking forward to this discussion.

>> Thanks very much. Dr. Deshpande.

>> Yes, hi. My name is Manasi Deshpande. I'm an Assistant Professor of Economics at the University of Chicago. And a lot of my research has focused on children receiving Supplemental Security Income, and especially their transition to adulthood. So I've done some work on what happens to young people who are removed from SSI when they turn 18 as a result of an age 18

redetermination. And, you know, some of that work finds that young people who are removed from SSI when they turn 18, a small fraction of them successfully transition to the labor market in adulthood, but a much larger fraction don't successfully transition, and become more involved in the criminal justice system. And especially we see large increases when young people are removed from SSI in criminal charges related to income-generating activities. So things like theft; for men, burglary and drug distribution; for women, prostitution and fraud, identity theft. And we see this leading to also large increases and the likelihood of being incarcerated. And so I'm coming from a perspective of providing this research on what happens to young people when they leave SSI at 18 and how those programs, how those outcomes can be improved. I recently did a field experiment of providing information to families of children who receive SSI benefits about the likelihood that their child will be removed from SSI when they turn 18 and seeing if that could help improve children's outcomes. So in that study we don't find any changes in sort of children's educational behavior or achievement, but we do see in recent evidence that parents seem to respond to the information by working more themselves. And so that information may still be valuable to parents. So looking forward to the discussion that we're having today.

>> Thank you very much. As you can see, an interesting, diverse panel with good experience in several different ways that can really help us think through the issues. As Steve said at the beginning, one of the questions for today's forum is really the whole issue of children and youth with disabilities not necessarily following prescribed treatment, which is an area that SSA has focused on in recent years. And I think we'd like to learn more about your perspectives in that

particular area. Tony, maybe we'll start with you, and just the question of how best can SSA evaluate failure to follow prescribed treatment, especially in states that have limited, have restricted Medicaid and CHIP access?

>> Thank you, Dr. Perrin. You know, some of those questions, some of the stuff that I had recently looked up and kind of evaluated, I think sometimes it's the financial status, kind of if they can afford any treatments, and how SSA can kind of shed light on, kind of the individual perspective versus the entire macro. I mean instead of -- the micro instead of the macro. And when we're looking at kind of how SSA is used for some of these youths transitioning out, just from my lived experience, it wasn't one of the main things that I had really known about. So I think one of the big things is really trying to understand, okay, if young people are transitioning out and how youth can actually access some of this information, we need to look at some of the boundaries or the barriers that are already in place for youth to actually benefit from SSA and even knowing about it. Because when we hear about Social Security, something that came to mind is I knew that my foster parents would talk about it, but as a young person you don't really, you really don't know much about that information. And I think it is critical that some of these organizations that are transitioning youth out shed light on the Social Security Administration. And also partnering up with some of these private, whether it be group homes, whether it be foster parent agencies, I think that's critically important for youth as well who may not have guardians to, you know, give them that information.

>> So I think you've raised really good questions and issues about transition from SSI and how that really might work. It's a particularly important issue for children and youth in the foster care system, that transition. It's of course a problem, as Dr. Deshpande said for all ages, all children, whether or not in the foster care system. So let me get back to the question for the moment, which is the SSA interest in the issue of why or what can they do about children and youth who are not receiving prescribed treatment. As a clinician, I know darn well that I have to work really hard to get patients whom I prescribe anything to, to sort of say they're actually going to do it, and that's a part of our job as clinicians, it's also partly to understand what's happening in, for me as a pediatrician, what's happening in a family that may help or hinder the ability to really follow prescribed treatment. In many cases what I prescribe, frankly, isn't the highest priority on the family's work list. And that's some of the issues there. But what are some of the other insights you might have into that? Gloria, do you have some thoughts on that question? You must deal with that in psychotropics.

>> Well, as a fellow physician, I share your comments about the process of engagement around treatment and treatment planning. I think that starts at the very basic level of how we train providers. So when I went to medical school you're sort of trained with the assumption that people will want to take the treatments that you're offering or will understand them or will think about them the same way over the course of their illness, which is not the reality. So I think a lot of this, we need to retrain our workforce in how to best engage youth and families that they're working with and other caregivers to best support care. In the mental health field, we certainly have an uphill climb thinking about both practical and emotional barriers to care.

There's still very considerable stigma around any type of mental health services, and so even if somebody comes for an evaluation, at least about half of youth and families tend to drop out of treatment within the first few sessions. So stigma is a big challenge. There are also a lot of practical barriers around competing priorities. So if you have the audacity of trying to raise more than one child at the same time you have a lot of challenges in your week and in your schedule. And there's a disconnection of services. So I might be seeing a child who's receiving resources and services through school, through a mental health program, through a community agency, and they live in a household with other adults and other children who are also receiving services. So we need better coordination of care and thinking about how to support family units and not just a designated child.

>> That's very helpful, and I think it sort of does clarify some of the issues about the process of helping families get the services that they need, and work in that area. So Elizabeth, given your work in school nursing, tremendously important area for, you know, ongoing management of many chronic conditions, frankly, in schools, mental health, asthma, we can run through the gamut of all the things that school nurses are so incredibly engaged with. What are the strategies you're aware of about improving adherence to treatment?

>> Yes, thank you for asking that question. You know, school nurses can support providers and caregivers to determine if they really understand the recommended treatments and can provide also care coordination services to connect students to services in the community.

Oftentimes sometimes caregivers are uncomfortable speaking up to tell their provider they don't understand or, you know, they'll just sort of nod their head and not really know what's going on. And so school nurses can help with that in translating some of that medical information or recommendations into something that they understand. And as Dr. Reeves said, oftentimes caregivers are overwhelmed in just the day-to-day care of their child with disabilities or children with disabilities, and the ability to schedule appointments and follow-up with recommendations can also be a challenge. And so sometimes it takes the entire school team to support caregivers and also devising a school schedule and an individual education plan that meets the medically necessary and available treatment for that child. One other thing to mention, sometimes caregivers do not understand the referral process, and the benefit of a medical recommendation due to the complex medical terms that are used, or often their limited health literacy. And so sometimes school nurses interpret this medical barrier, and they serve as a bridge between medical providers and those treatment services, and really explaining those services and why they're necessary so that the caregivers understand that.

>> Thank you. You're building a very good case for several things here, Elizabeth. One is the importance of coordination; another is the importance of interpretation. I don't mean from one language to another, although often that's also an issue that we must address better than we're doing now at this point, but really that important notion that in the course of a child or youth's life experience she spends time in school, spends time at home, spends time in the community, et cetera, and the importance of the school experience for that young person's life and ongoing care is really very clear. So -- and I think you've raised some very nice issues that families face in

order to be able to get their child the treatment she or he needs or should have or whatever else. I think we've actually already several very difficult issues families face -- and there are different ways we can support families, understand their issues, and really discuss them more effectively than we're doing now. So I think this has really been very helpful in eliciting some of the issues that are here, and I guess I would go back and say several of us have already said that, you know, families have to make choices and children have to make choices. And trying to help them make choices is part of our tasks as clinicians. We can't enforce the choice, we can simply help with the choice, and help provide the best possible guidance in the choice. And then families really do make that choice as they go forward. Why don't we move on to some of the questions that Tony, you started with a little bit about the whole issue of transition; and Manasai, you also spoke about them, too. So among other things, how can SSA do a better job about informing childhood beneficiaries, childhood disability beneficiaries about the availability of local services, vocational or rehabilitation, work support, nutritional assistance program, especially SNAP, Medicaid, special education, it's a wide array of services. What are the strategies that Social Security Administration could use to help young people gain access to this broad range of needed services? Dr. Deshpande, do you want to start on that?

>> Yes, thanks, Dr. Perrin, I can speak to that to some extent. So I think this is a really important question, and, you know, my research indicates that young people who are removed from SSI are really at high risk especially for criminal justice involvement and other poor outcomes. And so I think based on that research, one of the top priorities should be to try to connect these families with other sources of income that they can use, at least temporarily in the transition as

these young people try to transition into the labor market. And we don't know for sure, but it's possible that having other sources of income could reduce the likelihood of becoming involved in the criminal justice system, which could have good long-term effects. And what we see in this research is that once young people are involved in the criminal justice system it's very unlikely that they will leave that system and transition successfully to the labor market. And so it seems important at the beginning right when they lose SSI to first, you know, that they should have some income to rely on; and second, that they have a plan to successfully transition to the labor market. And so I think connecting families with those resources is important. I mentioned a field experiment that I had done recently where we provided information to families of children receiving SSI, so the children were between the ages of 14 and 17, and we provided parents with personalized information about the likelihood that their child would be removed from SSI at the age of 18 based on that child's characteristics. And what we expected to find was that parents might increase their investments in the child's education. We actually don't see that happening. That's probably in large part because these families are very resource constrained, and it's hard to make those investments even when we provide them with information and assistance in doing so. But as I mentioned, what we do see in very recent evidence that we've looked at is that parents, at least parents who were already attached to the labor force, seemed to work more in response to getting this information. And so it does seem like the information is generating some changes in, you know, how the family thinks about the child's future, and in particular a focus on trying to recover that income. But to me the kind of collecting all of this evidence together suggests that income is extremely important

during this transition, and so connecting families to either other income supports or, you know, encouraging parents to find a way to make up that income seems to be important.

>> I think there's lots of evidence that income makes a difference and trying to figure out good sources of income for households is a national strategy that is really worth exploring. But let me go a bit further with you on this question. So if I understand your study, you or your team provided some information to households about the child. The question I guess is really, so what in the world can SSA do? How can they do a better job of connecting people in the transition age to the variety of services that may help them? It has to be individualized, of course, because some people will need these services and some people will need those services, but what role could SSA play here? Any thoughts?

>> Well, I think the first one is information. And SSA has definitely made information available to families. But what our study shows is that providing this kind of personalized information does lead parents to have much more accurate beliefs about whether their child is going to get SSI in adulthood. And that seems like a first order issue. Right, if parents are just under the mistaken impression that their children are going to continue to get SSI in adulthood, they're potentially making very different decisions about their child's future and their family's future. And so I'd say that's the first order issue. That even in the context of SSA doing a lot to try to inform families about what's going to happen, our study shows that providing this personalized information still leads to big changes, improvements in the perception of parents about

whether their children are going to be removed, more accurate understanding of what's going to happen at age 18. So I would say that's the first thing. And the second thing is about connecting families to resources. And so our study doesn't speak as directly to that point, but what does seem to be the case is that once you properly inform parents about what's going to happen to their children at 18, they seem to be more receptive to making changes. In particular what we see is the parents working more, but potentially this information might make parents more receptive to information about voc rehab, about other income supports that might be available. So take-up rates for other income supports are not 100%, and so if you can provide information to families that, you know, their child might not get benefits in the future, that might increase the likelihood that the parents actually use the resources that you tell them about.

>> Mr. Lodge, what are your thoughts here? What could SSA do better than they're doing now about helping young people in the transition period? And you can certainly pick up if you want on foster care transition, a huge, complicated issue.

>> Yeah. I will, from my lived experience, I was very fortunate for kind of financial literacy in just being, having foster parents who kind of told me about my opportunities. There was something that I recently kind of researched, A Special Needs Trust, with SSA. I think as you pointed out and as Dr. Deshpande pointed out as well, kind of the lack of kind of finances from parents and foster parents, I think there needs to be at least some sort of collaboration in which the parents

don't feel strained that the young person is turning 18 and will lose some of those benefits. It can kind of put a, almost a trampoline of sorts to where that kid can jump and reach a lot of their peers in the pathway to the job market. From my personal experience, there is a program, obviously I think most people, the John H. Chafee program that pretty much helps transitional foster youth who are pursuing trade, college. But my foster parents, they got the information, I do remember, and they really homed in and said, hey, we need to start setting up money for you to propel to go to college. And you may have to work jobs after jobs, but we are kind of creating a financial literacy. And it's sort of a discipline of sorts through the youth. But that had not been practiced across not just the foster care system but just low-income families. And I think that is something that, you know, the Social Security Administration could definitely collaborate with how much availability of funds, the use of funds, and kind of creating state regulations that provide a learning mechanism for these families that can get these youth to a pathway to a positive outcome, that is, yeah.

>> Thank you. And we may want to get back to the special needs trust in a little bit. Dr. Reeves, you must be experiencing this with a number of your patients.

>> Yes.

>> And some of the issues that they face.

>> Yes. So in terms of throwing out a possible tool or a resource for solutions, I wanted to just share some thoughts. We've been doing some research on how to utilize community health worker workforce to try to help folks dealing with complex health issues, health management, as well as transition points in care. And one example to me that was so striking to be a part of and to witness this, that we all saw what happened when the nation tried to roll out the COVID vaccines. There was a lot of challenge about disseminating accurate information. There was a lot of misinformation being propagated about the information. And there was a real lack of distrust between individuals in the community and their health systems, their government, and other agencies. And what we found was the most effective strategy, or to really think about not just the message, but the messenger. So we engaged folks who were trusted, credible members of the community, people who grew up in a neighborhood, to be the voice of some of that frontline information. So training community health workers, that's a workforce that you could scale up quite quickly. The folks who have participated in those types of interventions are folks who really, you know, take great pride in their communities and great interest in helping community members, so a vested interest. And I have found they worked exceptionally well with medical teams, with health systems. We have a new pilot project we're working with the police department on, outreach through community health workers. So I think we really need to think about the messenger. The other thing I would say is that when you are a consumer of any kind of health services or community services, you really have kind of two choices. One is to call a hotline, and the other is to schedule an appointment. And when we think from a developmental perspective, young adults, except for, you know, folks who really have kind of

advanced organizational skills, a lot of times they don't fit well in sort of a scheduled appointment-oriented world. And so that's another opportunity where you can have a community health worker team provide ad hoc access which can be exceptionally helpful. So you're not dealing with a different crisis counselor on a line every time. You can build up a relationship with somebody. But you could structure it in a way so there's a little bit more flexibility in scheduling. So just some thoughts.

>> So several good ideas in there, and I'll just be anecdotal and share that when I was a very young doctor and putting out my shingle, I was running a rural community health center between -- in two small towns between Rochester and Buffalo, and I was fortunate enough to have some grant money to have some community health workers as part of our team. I had this, what I thought in those days was a very old, crusty community health worker who taught me a ton about the community. She wasn't that old, as I look back on it now, of course. But, you know, it's an incredibly valuable part of how we provide care, and my work has been predominantly among young people and their families with chronic diseases and disabilities. And the value of teams, as Elizabeth said before, too, the value of teams is very clear here, and to try to provide this kind of clinical care by just ordinary, everyday clinicians rather than a broader team, that makes a vast amount of sense here. That's not an SSA thing for them to sort of help us develop into teams, but it does point out the fact that good team members provide a huge amount of communication with families and with young people directly and can help in getting the word out more effectively than traditional physician-run practices often can do it. And that may be a point for SSA to figure out how to work better with the variety of

professionals and care people that determine youth with disabilities spend their times with. So I think there may be some lessons there. Again, how SSA can do it is a kind of interesting set of questions. So there are -- we just listed a whole bunch of really important programs for young people. You've listed, Manasi, the issues of really trying to prevent incarceration of young people by providing them with some sources of income functionally. But those sources of income could be very varied and can come things like SSA's Ticket to Work program, other strategies SSA has put into place for trying to improve young people's abilities to make some income after they are off the SSI rolls. How do we get that word better out to young people? Elizabeth, do you want to start?

>> Absolutely. Happy to do so. You know, I think it's important for SSA to really think about that educational outreach and how they can work with states, school districts, and schools and really getting, you know, to that local level. I know, you know, state SSA agencies can attend like educational leadership events to educate leaders on, you know, the importance of how we're all working together. And I know in many school districts, they already have sort of outsourced HHS workers for enrollment for Medicaid and SSNAP. And they work in the schools and they, you know, enroll families. They go to back-to-school nights or other school events, football games, you know, set up tables, parent-teacher conferences, those sorts of things. And so they're part of that trusted school community, and so, you know, parents feel that those things are accessible to them. And they have dedicated people for enrollment, which we all know is very complicated, to help them with those processes and get the paperwork that they need to do that. You know, I think those are some great ideas that, you know, people need to

think about the schools. School, you know, children spend a large amount of time in school every day. And school staff are eager to keep students in school, you know, with good attendance and having their medical needs met and their treatment in place, you know, certainly enhances school attendance. And so that's sort of the catch with those education leaders is, you know, they want their students in their seats in school in a classroom. And so, you know, thinking about rather than having siloed governmental agencies trying to think about how we can all work together for the benefit of children and youth.

>> Let me pick up -- very helpful. And picking up on one of your comments, Elizabeth, which is the notion that for some of the programs you mentioned, there are workers assigned, I guess, by the program, to help with enrollment. Is that something that SSA could do or do more of than it's currently doing? And how about specifically in schools?

>> Yeah, I mean, I think that would certainly be a dream to have that happen. And, you know, for me, I have worked in school Medicaid for about 20 years in several different school districts. And initially we worked to get some grants to have the community workers placed in the schools, and over time, you know, that's become sort of a standard. And so if SSA would entertain some sort of rotation or having those eligibility workers for SSA to be in schools and school districts, that would certainly be beneficial. And I think, you know, school nurses and school leaders can assist SSA in saying where the biggest need is, you know. There's data that we collect on students that are living in poverty that are receiving free and reduced lunch. We

know which students have disabilities and the services that they're receiving. So all that information, you know, could potentially benefit in working with SSA and providing those services in a school district to meet student needs. Manasi, what are your thoughts about, I mean, you've thought a lot about some of the income support programs that young people might become eligible for. You know, what are your favorites, and why, and what could SSA do to spread the word better?

>> So I think, first, one thing that's important to acknowledge is that there are limits to what SSA alone can do, and this is a problem that we have to address as a society. It's not something that SSA alone can say we're now going to connect -- we're now going to keep kids on SSI longer, or we're now going to connect them to a lot of financial resources, if those financial resources don't exist. I think at a minimum, you know, again, making sure parents are informed about that their kids might not get benefits at 18, that that's a very real possibility for a lot of young people receiving SSI, and then providing information about enrolling in other programs, you know. SSNAP would be one that comes most readily to mind, but there might also be more local resources that parents can use. And, you know, what Elizabeth said about information provided through schools resonates a lot with me, because I think what we learned through our field experiment is that meeting families where they are is very important. So we tried a number of outreach methods to parents, you know, for the purposes of contacting parents for our survey. We mailed them letters. We emailed them reminders, texted them reminders, provided financial incentives. Our response rates are still only around 20%. And so, you know, these families are, you know, highly mobile, they are extremely busy, they are resource

constrained, and so they may not have the time or the bandwidth to read every letter that comes to them in the mail, even if it has important information. And so, you know, I think through this field experiment, I have really thought about the importance of meeting families where they are, including in schools and potentially through health care providers, as well.

>> I think that's very helpful, and I wonder if I could push you or others in the panel to think of the other level of the system. You've been working a lot on the transition out of SSI. What about the transition into SSI? What are the ways -- I mean, I don't know how many of you have actually participated in an SSI application process. I certainly have in a couple different ways in my long-term history in this area. It's a pretty complicated process. You just made the point about -- a couple of you made the point about getting to families where they are, rather than having them to go to, say, a disability determination service office in the nearest big city to where they live. There are different ways of getting any access to the system. And I think increasingly in all the areas we work on, if you think about education, if you think about juvenile justice and preventive issues there, if you talk about health care, we're all moving to much more community-based services and programs unless, you know, bricks and mortar, institutional-based systems, not necessarily if you need some complicated surgery. But, you know, we're really moving to community -- what are the opportunities for SSA to move to more community involvement, especially around the issue of enrollment?

>> I'm happy to start just by saying that, you know, again pointing to some of my research on Social Security field offices, and I know you're talking about, you know, potentially moving beyond field offices. But I think it's important to emphasize that the field offices themselves are -- appear to be extremely important for enrollment, especially for SSI child applicants. So I have some research where we look at the effects of the closings of Social Security field offices over the last 20 years. So not the most recent closings during the pandemic, but the closings that have happened since 2000, between 2000 and 2015. And we find very large decreases, about 10% declines overall in disability applications. But those are especially large for SSI child applicants, closer to 15% declines in applications for childhood SSI, and a lot of those are among applicants who would have been allowed onto the program had they applied. So it's not just that these closings are discouraging people who would have been rejected from the program if they had applied. And so these -- even with a lot of information and assistance available online, these in-person services appear to very important, especially for SSI child applications, and that might include relationships that they have with the community, like schools, where they're trying to get documentation from schools, for example. So I'll just mention that point about field offices.

>> That's very helpful. Dr. Reeves, you looked like you have --

>> Yeah, I just wanted to make a comment a little bit about technology. And that is, you know, as we improve our ability to use machine learning and precision medicine strategies with

electronic health record data, there should be better opportunities for us to be much more proactive in identifying individuals who are eligible for all kinds of different resources, and be more proactive in initiating the outreach instead of, you know, whether or not somebody gets services shouldn't be dependent on your level of understanding about the system. There should be a way to kind of connect people with that information. The other thing is, you know, it's a simple thing, but if everybody had an internet hotspot and remote monitoring equipment and an adequate cell phone and keeping the light on for that equipment is somehow connected with at least updating your contact information briefly. I think -- I'm not an economist, but I think it's a really cost-effective intervention. And we know that more and more internet access is driving a lot of disparities with health care, and we certainly learned that over the pandemic. But thinking about technology-based strategies to help people stay connected, but then have collateral benefits of if you have a hot spot, you can connect with your kid's school better. You can read the emails from the school. You can connect with your health care provider through portals because nobody picks up their phone anymore. So we really need to rethink the technology tools to have universally available to families, and then also how to use electronic health record strategies to identify individuals who need more support or who are not connected from support.

>> Two very interesting, challenging ideas. Let me stick to the electronic health record for a moment question. So there's a ton of data in there that could easily help to identify people, young or old, eligible for a variety of benefits, programs, et cetera. Yet DHR's have never been designed to do that sort of work. And the schools also have a lot of records that they keep on

young people, not also designed to do that kind of identification. So I think I'm sort of asking a question of what would it take, and how could SSA play a role in helping to make those, you know, much more sophisticated data systems indicate eligibility for SSI? Are there things that they could do? Could SSA do something to work with a variety of data systems to improve identification? I could ask you which DHR you use, Dr. Reeves.

>> Yeah. We use Epic, which I think a lot of places use. So I think, you know, at a very basic level we need to have the right people at the table. So we need to have consumer advocates and representatives to think about who gets access to information about you, and how to do that in a way that will be engaging for individuals and not be perceived as a violation of privacy or autonomy. We need to have the folks who have the technology to develop those systems, and then have our clinicians and our health policy administrators at the table. So we need to have a pretty diverse group of experts to bring that together. But I do think that we are moving more and more towards modeling, you know, predictive modeling around folks who are going to have an abrupt rapid decline in their functioning, folks being able to predict different pathways of chronic health conditions and things like that. And so it would be great to be able to harness that in a way where we have all the right stakeholders at the table to guide, you know, future directions with that. But any opportunities to try to personalize resources and do more outreach, instead of folks having to come to us to ask for help, is I think a way to get started.

>> A great idea. I think the steps to get there are pretty complicated, but what a remarkable repository of information, and wouldn't it be great if we could find ways to really make it useful. Elizabeth, do you have views on this from your experience in schools and school records and school nursing?

>> Absolutely. And I have to tell you, unfortunately some school nurses are still doing, you know, paper and pencil documentation. They don't have access to an electronic health care record, although many do. And sometimes it is a school district student system that is focused on education and not health, and so there are usually challenges in using them. The other thing, positive thing though, that has happened is that some children's hospitals and other hospital organizations have allowed school nurses to view health records in their electronic health record. And so I can give an example of the Colorado Children's Hospital, they've been piloting with several school districts where nurses can view their patient records, their student records, with parent permission. So they can see discharge summaries, they can see new orders. Because sometimes there is a difficulty with caregivers giving, you know, providing new orders for the school, and so you're not current on changes. I mean, we have students who are hospitalized in the ICU over the weekend and then come to school on Monday with, you know, limited information about what happened. So those sorts of scenarios are certainly helpful. I think there's a lot of work that can be done with electronic health records and sharing that information. It certainly would be ideal to have the ability to have some sort of a flagging system to say, you know, this patient or student, you know, has this level of disability and, you know, is there SSI or SSA, you know, interaction or involvement at some level. I know the school

district has a Child Find system, which is a federal requirement provided from public schools. And Child Find typically starts at birth for children with disabilities, and where they're evaluated and provided community services for early intervention. But Child Find is something that goes through the time graduates -- the student would graduate from high school. And so at any point, if a child were to be, you know, educationally determined as having a disability or receiving special education services, you know, that school staff also has the opportunity to connect the family and have a discussion with caregivers about SSI and SSA and supporting the needs of the child or the student.

>> That's a good place to get the word out, and an opportunity to do it and it would be great if we could do it more systematically as we go forward here as a strategy to help SSA succeed in really enrolling appropriate young people. That makes a lot of sense. So, you know, those of you who have worked in the transition area especially, what are your thoughts about what we know about how young people on SSI prefer to communicate? What are the things -- what's their preferred mode? I assume it's not by telephone. Dr. Reeves, do you want to talk about that?

>> Is there an SSA TikTok? Because that would work great, fantastic, for the young people that I interact with. I mean, I think people use a variety of different social media to communicate and to gain information. But I still think there is a strong place for the in-person connection. I love, you know, some of the messages that Elizabeth had about connecting at your school. That's

your neighborhood, that's your place. Those are people you know and you're familiar with. I also think that there's a lot of opportunities to partner around mental health challenges and accessing care and systems through front line workers. So there's been a lot of challenges in, and concerns in the community about interactions with the police, for example, but that's also an opportunity for tremendous growth. And I think partnering up mental health providers and community health workers in communities with those frontline workers can really get you access to folks who are in distress, for folks who are in crisis, and help connect them quickly to services.

>> Very helpful. Dr. Deshpande, thoughts about how best to connect with young people? What are the strategies to be used?

>> Yes. So I can't speak so much to the young people, but I can speak a little bit more to parents of the young people. And, you know, the comment, Dr. Reeves' comments about TikTok was interesting because what we did find in our study was that videos were the most effective way to communicate, even with parents. And especially when we're communicating relatively complicated information, things like, you know, probabilities, what is the likelihood that your child is going to be removed from SSI versus stay on SSI. We tried a number of different things like, you know, sending text in the mail, sending text plus graphics in the mail, providing static graphics on a website. And ultimately what we found was that a short video that includes graphics, and that presents the information in multiple different ways, was the most effective.

So, you know, if we're communicating something like a 70% probability, we express that in different ways. So 70% is 7 in 10 as, you know, most young people in this category are removed from SSI when they turn 18. And so we found that the video format, and also kind of the repetition of what is trying to be communicated and in saying it in many different ways was for us the most effective in communicating with parents.

>> So I think we're hearing several really interesting themes here. One of them is the theme of working with children and families where they are and trying to get them the resources they need in that context, and that's in many ways the best place for communication. Second is we're also hearing that given the breadth and complexity of children's disability, it's a pretty wide-ranging set of conditions and issues and how they'll manifest in a child's life, also means that there are many different places that may -- the child may interact with that might be a source of connection to SSA and the SSI program. And so the questions I guess there would be are there ways to get SSA more engaged in those varied communities that we've just listed here, varying from the early identification work that you mentioned, Elizabeth. Should SSA be a part of that effort, for example, in a more active way than it currently is? Are there strategies SSA could use to really make sure that hospitals and other places that are repositories of complex medical information would think about SSI as something that their clients ought to be learning about and potentially enrolling in? What are the ways SSA could really gainfully engage more in this process? Tony, any thoughts that you have given the changes you've seen and gone through? I think you're on mute.

>> My internet went lag, but could you say that question one more time?

>> Sure. So given the diversity of areas where one might identify a young person with a disability who should be eligible for SSI, and we just talked about anything from early intervention programs to hospital-based data systems, to schools, et cetera. What are the best ways for SSA to connect in such a way that young people who are identified that way would actually get access to information and potential enrollment?

>> You know, I heard a couple of good suggestions on, you know, kind of, you know, the social media aspect. Obviously we're trying to go to them and not necessarily come to us. You know, I think one of the big things, not just a pressure on parents to do so, but the youth in general just, you know, kind of putting myself in their perspective or, you know, having that proper invitation of, you know, kind of having accountability when you have a disability. It can be very tough sometimes to sign up for those services or even seek them out. I don't think -- I think we need to do a better job with some of these organizations, whether it be in school, whether it be in kind of, you know, agencies of understanding the empathetic aspect of, okay, not just using social media as a tool to invite them in, but having a disability in general and not a -- I think sometimes the pressure of folks with a disability, we don't do a good job of kind of uplifting their spirits in when you're trying to seek out, to sign up, or to benefit from SSI. And I think social media, despite all the controversy within it, it does a good job of putting that information

out there, and then even folks who don't necessarily have a disability also support it. It makes that person who does have a disability more accountable and wanting to seek out signing up or, you know, benefiting from any services that they may, you know, be qualified for. So, I mean, I think my big one is if I was a young person, you know, social media is kind of that tool, per se. And it doesn't have to be just TikTok, Instagram. There is WhatsApp. WhatsApp is a group of -- I have various folks in different groups. And if I have a whole group of people -- which I do -- who have a disability, and say, hey, this is how we got the information, and that information is then kind of leveraged throughout the community. And I think SSA can probably do a good job of like, you know, using those technological or social media tools to sort of invite folks in. But that's just kind of my perspective on it.

>> That's very helpful. So I think we're saying that SSA should upgrade its social media capacity and abilities and learn strategies to use social media to get to potential SSI recipients. It also can be a way to get continuing information, Manasi, for young people who are on SSI about what the next strategies are for them, too. So, you know, just building up a social media capacity, using all the new technologies, could be useful. So, you know, among the sort of technological strategies people have raised have been things like, you know, could we get an app that made it easier for people to talk immediately with an SSA employee to ask questions in real time, or something that could really directly help users in the application process, so that that app, I think, would not be easy to develop, it's such a complicated process. Or an app that connects users, SSA, state agencies, and all the resources we just talked about. So maybe an app that

said, you know, you're on SSI, these are programs you ought to know about, and this is how you access them in your community. Would any of those be helpful?

>> I think so. I mean, I think starting out with the social media entities that already exist, I know a lot of currently right now you have a lot of programs that will stream ads, or they'll show up, you know, at some point. I don't think that's necessarily the way people are seeing it nowadays, but they want it more so on an individual -- like yesterday I went to the SSA's Instagram social media account, and it just wasn't -- it's good, but it could be so much better. And then kind of directing links where folks can sign up and follow pathways to, you know, get their full benefits, or to be a part of an organization. I think sometimes even signing up for these things as a young person, even with a disability, especially if you're not in the in circle, or you're in rural America where tech is just not as heavy. A lot of this can be just as difficult as trying to get your taxes right. So how do you make a process that when people sign up or are trying to find information on, the simplicity of it. And so I do think people are more, right now the viewership on social media is pretty -- it's as big as, you know, than it has been in the past. And I think, you know, a lot of people are trying to find easier ways on how to access the information. And I don't think it necessarily has to be a brand-new app. I think you just need to highlight the things, the entities that you guys are already on, and just make it more simple or for people to be drawn to that information.

>> Thanks. And I think that that's a strategy that is certainly worth exploring here. So we're getting a lot of questions from the audience in a variety of ways. And one of the ones really -- some of them relate to the whole issue of application for SSI, which, you know, is a very complicated process and households, among other things, need usually to gather clinical data from the physician or other clinical communities that have seen the child, the young person. And similarly, teacher data is often required. You know, given the shortages of everyone, shortages of teachers, of nurses, of physicians, you know, one of the ways to sort of grease that process so that families aren't waiting a long time, or I as a clinician have an incomprehensible -- that's not quite true -- a hard-to-understand document that I'm asked to fill out by my local DDS. What are the ways of making that process better, helping families be able to access those data more effectively? Dr. Reeves?

>> So I just wanted to comment about, yeah, I think at a very basic level it would be helpful to have some kind of screening or assessment of family communication at the front line. So I have a lot of families who have literacy challenges, so, you know, severe dyslexia, or challenges reading above a, you know, first or second grade reading level. We have families that communicate in different languages. And so a lot of times I make assumptions about their abilities to communicate and I don't identify those barriers, so I've sent them on a wild goose chase of looking up forms and websites and they can't, you know, get the information they need. So if there's some way to sort of screen for that on the front end, what support you need with forms and reading and challenges and things like that and offering alternatives, I think that actually would be a good step to kind of get started, to be able to communicate better.

>> Other thoughts? Elizabeth, thoughts about the teacher questionnaire which is part of the system of -- in providing the data for SSA to make a determination?

>> Yes, I think that's a great question. You know, sometimes it is very challenging. Typically those requests go to the special education department, because most of the time those students are receiving special education services. And so oftentimes that helps to get the form to the right person that has that information that can document the disability that the child has. And so I think it's important for the school and the school district to have a system in place to receive that request and that signed release form. And oftentimes their release form doesn't come with a request so then you are waiting until you can see that release from the parent in order for you to fill out that form, right. So there are certainly challenges and I think, you know, having a system or process in place within the school when those requests come is helpful. I also do like the idea of, you know, a short, brief video series. I know there is a video available for teachers on the SSA website. I don't know if it's accessed. I would be curious to know, you know, do teachers know about that? Is that something, you know, if they're asking why am I doing this and, you know, what is my role, do they know to look there to get more information? So I think you know having more information is always better. And so you know having a system and information in place to help teachers would be ideal.

>> Any other thoughts on this question about how, I mean, so SSA has a really difficult problem. I mean, how do they access the people in the diverse places they may be, and how does it get the information that is needed in order to make a determination according to the rules that SSA must follow? And that is, it is a really long pattern from one to the other, isn't it? To get from, you know, identifying a potentially appropriate recipient to actually getting her enrolled and the steps in that process. I mean, you mentioned earlier, Elizabeth, the notion of workers who help people fill out applications. Is that something that SSA does? Is it something SSA should do?

>> I am not aware that SSA is doing that, but I would think it would be ideal if that would be an opportunity for them to assist with that one-on-one with families. Another area that I have seen as beneficial is many of the parent groups in schools have guest speakers, and so you know say a special education program has someone from SSA come and talk about what is SSA, what is SSI, how do you enroll, who do you contact. Giving them a face-to-face information, putting you know a face and name together. I think, you know, those sorts of things are incredibly beneficial to families. And again, meeting in a location where families feel safe, in the school setting; safe and familiar. And it is close to home, right. Maybe they can just walk over to the school and get that information and meet with those people that can assist them. I think that would be ideal if that is something that can be maybe looked at in the future. I know when I mentioned the Medicaid and SNAP outreach in the school, there was no cost to the school. The school just had to provide a space, a confidential space, a desk, you know, an internet line, a phone line, and the outsourced worker brought all of their things and were being paid for by

the county, you know, agency. And so I think there are things to think about that can certainly enhance this process for caregivers and children, because it is challenging. As you said, that application process is very difficult and many of our caregivers struggle with that process. And sometimes it just gets dropped, because they cannot complete it, and don't really understand what needs to be done.

>> And, and they do also face the fact that teachers are really busy, and they don't have the time to fill out the questionnaire. There is no teacher app I believe for a teacher to simply send the information in to SSA via an app. Or similarly for physicians, trying to fill out those forms. You know, it is not as if that's sort of part of the usual workflow of a day, which is often pretty busy. So you know these are difficult problems and ways to streamline them would make the whole process a good deal easier for everyone, families, SSA itself, and others. So looking for ways to streamline that process might be an important task ahead at this stage. Manasi, did some of your work also look at this set of questions?

>> So this, this set of questions around communication?

>> About communication but also helping to streamline processes.

>> Yeah. I mean that, to the extent, the extent to which I have worked on this question is looking at those Social Security field office closings. And you know the, you know, the evidence that we see there is that even when information is available online, in-person assistance seems to be very important. And that suggests that you know not only are field offices important, but also just that you know potentially providing more in-person assistance and information could increase SSI child applications. And so, you know, all of what Elizabeth said makes a lot of sense to me based on the, based on the evidence that I have, I have seen. And you know one thing to note is that when we looked at the Social Security field office closings, in what was driving the discouragement effects, the -- you know the reductions in applications as a result of the closing, we assume that we were going to find evidence that it was about, about travel time. That if your local field office closes, you have to travel farther to get to the next office and that is difficult for families. What we found instead is that most of that discouragement effect was being driven by congestion at neighboring offices. So the fact that one office closes, you have to, you know, the other offices become, become busier, and so people have to wait longer at those offices. They might have to wait longer on the phone to get someone on the phone. And so you know this idea of quicker access to someone who can help with the application through an app, for example, I think makes a lot of sense. At least it is something to try.

>> Thank you. That is, that is I think very helpful to hear in different ways so we might do it. Was the issue that you found that the materials were so complex that that personal contact was important? Or was it just that -- why do you think that personal contact was important rather than some kind of a web based or social media-based strategy?

>> Yeah, I mean, when we do, when we did our study, it is important to say that the -- there was information available online, DI application was available online at the time. But not the SSI application which might be part of the reason we find much bigger effects for SSI than we do for DI. Although we still find pretty sizable effects for DI even when that application was available online. And I think, yeah, I think a lot of it has to do with the complexity of the application process, and the fact that it is not -- it might not be a onetime thing. You might have to follow-up several times in order to complete your application, and that just requires a large, you know, someone to be very organized. If they don't have assistance, you know, with how to, how to get their documentation together.

>> Makes sense. Right. So you or maybe Gloria, much experience with vocational rehabilitation and vocational training programs for adolescents on SSI, what are your thoughts about them? How do we make them better? How do we connect better between SSA and voc rehab?

>> So I think there is a nice model for how to integrate educational vocational rehab into clinical care. We think about specialty care for individuals who have psychotic illnesses like schizophrenia. So the new model really puts everything sort of one-stop shopping. So you have your clinical care, you have your family, peer support person, and you have your educational vocational rehab specialist. And that is the person that people come in wanting to see. They don't want to see me and talk about medications. They want to hear about how to get a job, to

earn some money. And if it is presented in a way that you know it is really about your priorities and preferences for your educational work goals. That could be a very synergistic opportunity for engagement. So I would like to see more opportunities for co-located vocational rehab within clinical care and services. Because we find that is the reason that people want to come in and want to come back.

>> An important lesson, isn't it? And the opportunity again for SSA to figure out the best ways to connect recipients with things like vocational rehabilitation. Sure, it is an area SSA has worked very hard on in the last couple of decades really. But that is, it is one that really is important there. So you know I think your, you and others are listing a variety of programs that may really be beneficial to young people in the transition period. You started with some of the special, some of the trusts that you mentioned, Tony, at the beginning, that's just one example of things. But you know given your own experience, what would you list as the three or four or five programs that would have been helpful for you to know about in your transition or other people you have worked with going into transition?

>> Thank you for the question. I guess with my transition, it was very, very unique. I think depending, you know, when I look at youth transitioning, I always -- because I also do a lot of mentorship as well. And I think that is also a big area that we kind of have to focus on as well as kind of mentorship. It is one thing I know anybody successful that I had met or had made it to a place of stability, and they can always point to someone who kind of guided them in that way,

whether it be a mentor of some sorts. I think one of the resources kind of that I know from youth aging out of the foster care system, one of the big things that is always scary is you know where am I going to lay my head at, you know. Some of the universities as we had seen during the pandemic, were not willing to aid foster youth who were kind of pursuing their education which was a very small percentage allowing them to stay in the dorms. And so you had a lot of youth, during that pandemic, homeless or trying to find some place to go. And I think you know when you don't have kind of those relationships built up, it makes it very difficult for them to you know build these sustainable, such as you know getting an education, you know learning skill development, all of those come at the cost of you know having some place to stay and live. And I think one of the big things for me, and I really took it very seriously was you know making sure that I had my dorm was open, that my DCBS worker partnered with the school, made sure that hey, when he gets to this university, that is going to be available for him. Because he won't have a week to, you know, I have to have a place to stay after 18. And so when you have youth on that sorts, you know, I think that is one of the big things. I wish I had known more about housing, financial aid for college. I wish I had known more about -- even trade, trade schools, and what they can offer as well. But folks of a disability, they automatically cut a lot of opportunity out depending on their disability. And so I think you know we just need more of a kind of informational database that is telling folks. And it is one thing to see it, it is another thing to hear it from someone we care about, or who cares about us. And so whether that be the parents, whether that be the counselors at the school, whether that be you know whomever that may be, I think those things kind of need to be you know given out at an earlier timeframe. And that is why I mentioned the special needs trust. It doesn't just have to be

money. It also could be kind of informational accessibility. And so that is also a way to look at it, so nobody is caught off guard you know.

>> Very helpful. So you have listed several things there. Housing, pretty darn important, right? You have listed education, and a variety of educational resources. Pretty darn important. You have listed income support through a variety of mechanisms. Getting a job, having a, a special needs trust or whatever else is a way, and other ways of income. Other people are probably going to need nutritional services, right, too. And so a variety of things people will need and trying to figure out how do we really best help households and young people know about these resources in a moderately systematic way? I think, you know, I don't mean to understate how complicated a process this is for SSA. It is not really within their sort of statutory wheelhouse to be providing all of these connections. But we know, they know, all of us know that a young person can't deal with her disability simply by having the cash. That there is a real importance to having the connections with a variety of other sources of support. And that is I think really the complicated task that we are asking SSA to take on, and that they are asking us in turn to say, so what are the best mechanisms for doing that? What are the ways we can systematically do this in a way that is really efficient and helpful? So those are some of the questions that really do come up here as we think through. Any other thoughts any other panel members have on this question?

>> I would like to add just the medical or health transition which we haven't specifically you know spoken to. I know that transition from pediatric to adult care, it is a major hurdle for youth and their caregivers. And there has been a major focus in the last several years by the medical community to support that transition. I know school nurses as well can support transition. It is required in students with disabilities at the age of 14 to start talking about transition to adulthood, you know, what is after leaving high school. What is after turning 18 to 21 depending on your age and disability? And so you know it can be very complicated as you said, you know, going from a pediatrician or a specialty care provider they have had at a Children's Hospital since they were born to now finding an adult care provider. And medications, how do they receive them? Their parents used to pick them up or caregivers, and now they will be mailed to the dorm. I mean, you know, there is lots of things to think about in a health transition as well. It can also be very complicated. And what if they need assistance you know as a disabled young person? You know, they are in a wheelchair, and they need assistance in transferring or showering or some of those things? And so, so it can be very unique. You know, we want the youth to advocate for their needs, and to understand as much as they can, what they are going to need to be independent in their, their role after you know leaving home. And so I think there is lots of things to consider as well. And just that health aspect, in maintaining their health and health status and taking the medications and treatments that they need to be a healthy young person.

>> We have a number of questions that I'm not sure we are ready to answer, but at least I'll raise them having to do with children in immigrant communities, children of undocumented,

with undocumented parents, who may have disabilities. Any issues and strategies there? I'm not sure we have the people on the panel that necessarily have that experience, But I will ask the question.

>> I mean, I think that is where we really rely very heavily on different non-profit organizations to help support the big challenges about mistrust of engaging with any kind of system. So having someone who is a trusted credible member of, of that community sharing information is often a helpful first step. And then providing a lot of support around the, the social determinants of health, just how folks stay connected, things like around housing and food security and other things. But I think that really requires a lot of community partnership and community engagement because there is such a level of mistrust and concern and reasonable concern about what it means to interface with the system.

>> While I have you here, one of the questions we also have, is how early can a diagnosis of schizophrenia be made? At what youngest age?

>> Well, we know that schizophrenia prior to the teenage years is extraordinarily rare. So to make a diagnosis in a child who is kind of elementary school age, child is, it's just very, very rare, very unusual. So that, so if there is a concern about somebody in elementary school, or early middle school, it really would be beneficial to go to a child specialist to really do a full and

careful evaluation. There is a long list of things that, that can look quite similar to that. But certainly, in the teenage years is we start to see more classic presentations unfortunately. So it is a condition where onset in teenage years, young adulthood years is not, is unfortunately a developmental challenge, because that is when you are trying to be much more independent in your life and that's when symptoms often present.

>> I think that is an important set of issues here, that for a very young child, someone is raising the question of schizophrenia, you really want to get extremely sophisticated people evaluating that child. It is a very rare condition in younger people, in the pre-adolescent populations. Adolescent populations we, we much more commonly will see that, that condition at that point. So a couple of other questions we have had. We are going, yeah, we still have time for a few more questions. What can SSA do to address the decline in childhood SSI applications over the past several years? Any ideas and thoughts about that? I think we have ranged around some of those questions already today, different ways of getting the word out more effectively to potentially target populations. But what else do you think? Manasi, you talked about the closing of the Social Security offices is a pretty critical problem.

>> That's right, yeah. So we do see big, big effects of field office closings on SSI child applications which would suggest that providing more in-person information assistance could help with identifying children who should be receiving benefits and helping them enroll.

>> Yeah.

>> So --

>> And just to -- maybe there is some opportunities to connect with the new mental health hotline number, the 988 number, so people use that. People who are using that number are in a crisis situation, so those are folks with very complex needs and often don't even know how to get started with getting connected with resources and services. So that might be another opportunity. And it is a program that is run in all states.

>> Interesting one to choose.

>> And I would like to add, you know, I think thinking through when people access the health care system, those are the opportune times for people to get enrolled and to have that information. And so whether that is you know through schools and education of children receiving special education services, you know, emergency room visits, regular wellness checks in provider offices. You know, parents and caregivers are motivated when their child is identified with having a concern, right. And so I think that is the opportune time. Thinking through those opportunities of when health care is needed and recommended and then connecting that with that next step of enrollment.

>> So we are really hearing pretty consistently, the notion that there are many places for a potentially eligible child or adolescent might show up, might be identifiable, and you have raised, certainly someone in the clinical arena, certainly, but there are many others as well. And trying to figure out ways for SSA to have more engagement with those sites would be helpful. And the other one that Manasi is really I think pursuing actively is some kind of, I'm not sure what it is, a human contact, some kind of direct connection beyond a website would be really critical for this process to work a good deal more efficiently. I think that is it. So that we have had a series of questions relating to the issue of you know I'm a parent, I have some health problems of my own, and I may not be -- have very good language or I may have major dyslexia. You know, what can be done? For me, coming to that website and trying to build off the application or going to the office is incredibly difficult. What can be done to help out with parents who are going to face problems that vary from their own health issues, their own disability, to serious language communication problems, how do we -- any strategies for working on that area?

>> I think again, opportunities to partner up with community organizations, faith-based organizations especially, which are viewed in, by community members as sources of great, of credible information, as well as support. There is faith-based organizations in every neighborhood pretty much. So thinking about opportunities there for folks who are not connected with traditional health systems or community agencies.

>> And I would add schools of course to that --

>> Of course.

>> And I also think that you know maybe there is you know -- I had mentioned earlier some sort of enrollment, enrollment specialist that can help families whether that is you know care coordination or just basic enrollment into services. I think that would be incredibly beneficial for, for children and youth to be enrolled if there was a specialist assisting them.

>> So a good deal of discussion about how to decentralize part of the effort for enrollment, identification and enrollment. And what are the strategies to have, you know, even to collaborate? You know so Child Find people, you mentioned long ago, Elizabeth, are paid for. I can't remember how. I should know the answer to that. But you know they are paid for. Could, could there be some collaboration and work with them to sort of build that into their repertoire of things that they advise about? The EI programs that are around the country, do have, you know, for a variety of reasons a number of children with disabilities in the EI program, and, and some EI programs know a bit about SSI, but a lot don't. So again, how, how are those partnerships potentially developed that would make that work better for everyone involved?

>> Well, I can certainly start. I think as I mentioned, you know at a state leadership level, having state leaders working together, communicating about the need to increase enrollment and support families in the enrollment process, and you know perhaps they can do some brainstorming and then going to the local county or local community level, and having those stakeholders talk through that. Child Find staff in schools are typically paid for by the school district. They are teachers, school psychologists, nurses, you know the whole team there. And they provide free evaluations to determine whether or not students qualify for special education services. And that would be an opportune time to share information, you know, if there were a one-page flier with a local resource to say, hey, you know, contact this person, your child has a severe level of disability. And you know this is a potential something that you know you can look at to benefit your family and your child. And so I think it would be easy to do. Whether or not that would get done, I'm not sure. But there is certainly opportunities to do that, and again parents are motivated when their child is you know being identified as receiving additional services and that would be an ideal time to incorporate that.

>> It reminds me of some research one of my colleagues did some years ago about trying to get parents to stop smoking. At the time their child was hospitalized for asthma. It was an acute event. It sort of was a meaningful event to the families and one which actually had higher success rates than more traditional ways of trying to get parents to stop smoking. So you're really raising this issue, that make use of the opportunity that comes in these moments in order to -- let me pull down one other idea that I think you raised here that is quite interesting, which is you know could the state, there's a Disability Determination Service in every state. Needless

to say, they are not exactly well financed, but there is one in every state. Is there some way to give them a charge, and probably some additional resources at the same time by the way, but a charge to really do that kind of collaboration across state agencies that you just mentioned, Elizabeth, so that they did know about the Child Find programs in Ohio, and what areas it covered and didn't cover. And they can really collaborate with them then in that state, become much more expert. Is that a role we ought to be encouraging SSA to try to develop with the state agencies?

>> I think it is an incredible idea. I think it takes all of us that are interested in this and supporting caregivers and children and youth, and so you know I think if there were some sort of charge or recommendation, you know, from the top down, I think that certainly would be something that would benefit caregivers and their children.

>> In our last few minutes, we had a couple of questions back on transition, and I think important questions there. And I think one of the questions being raised is, I'm rephrasing it, so I'm not being very fair to the person that sent it in I'm sure, but why age 18 as the sudden cut-off? Does that make sense? What should SSA consider or what should the statutory writers for SSA consider here as the right age for transition? Tony, you want to start that?

>> Yeah, you know, from my experience, yes, some states you know it is 18. But there, my home state, Kentucky, the John C. Chafee Program, along with some of the state funds in education, and whether it be trade school or vocational training, they, you know, if you recommit to the state, you're able to age out after 21. I think, I'm not in -- I don't know the full scope on the entire nation, but for my home state that was key. I don't think, I don't think necessarily 18 should be the cut-off age now that we're facing a lot of barriers to independence. So just from my experience, because of those, that willingness to kind of have foster parents who are dedicated, allowing me to stay in really, but work at the same time, gain those skill sets, I think -- I don't think it needs to be 18. Because I don't think if you have a disability or if you come from a low-income area, you can lack some of the skill developments needed to thrive later on. And I think that window gives a lot of growth in between. Yeah.

>> Yeah, I think that is, that is really helpful. Part of that, Tony, how much is that related to the fact this is the foster care system, rather than non-foster care, SSI youth?

>> Repeat that again. Apologies.

>> No, certainly. So, so the foster care program has some better benefits with respect to aging out than the sort of, if I can call it the non-foster care SSI program. So part of, I suspect part of

what you succeeded in getting had to do with the fact that you were, had been in the foster care system. Maybe I'm wrong on that.

>> No. No. Yeah, I think, I think those same, whether it be you know kind of extended periods of time for foster youth aging out, should also be given to other populations as well, particularly those with disabilities. It is just harder to, I think, I think it is harder to find the resources. During my time in foster care, I had a foster brother who, he was a little bit slower. But finding the resources for him in kind of a very rural state was extremely difficult. So I think we need to make kind of heavy investments in like when they turn 18, okay, you can't, like in my opinion, you shouldn't, they shouldn't just go out on their own. But we need to kind of have, if that is a period where you know, whether it is an organization or a state, heavily invest. Okay, how do we seek out these you know possibilities for folks with a disability? And kind of find a ground on which they can grow and thrive and be a part of society? And not just for youth transitioning out of the system, but yeah.

>> Okay. Gloria, thoughts do you have on this question of age or transition?

>> Yeah, well, I'm all about extending childhood. And I think that, that really aligns well with what we are learning in neuroscience research about brain development and continue to evolve and emerge until you are 30. So, I think that extending it makes a lot of sense. I think the

other issue is the transition period needs to be done in an incremental and a thoughtful way. Any system that abruptly ends a lot of resources is asking for trouble. So having a transition period, allowing for incremental changes in resources or incremental access to new types of resources is really important.

>> And, Dr. Deshpande, do you have some thoughts on this too from your work?

>> Yeah, certainly from my work we know that removing kids from SSI when they turn 18 has just staggeringly adverse effects on these young people. And so I think it is, you know, very strongly worth considering you know demonstration to keep younger people on SSI longer, seeing if the effects of, of you know having them on SSI longer mitigates some of these negative consequences of removing them from SSI. Or you know even potentially having the review at 18, but not actually doing the removal until several years later, and so they have some time to understand that they are going to be removed and then a potential prepare for removal. But I think this is an excellent question, and something that is kind of a like a first order of thing that both SSA and you know more broadly in legislation that we should be thinking about.

>> Great. Well, golly, thank you, Elizabeth, Gloria, Tony, and Manasi, for your really marvelous time and the thought you have put into the responses to questions today, as we try to help Social Security strengthen its disability program for children and youth. I hope, I trust that

everyone who joins us today found it both beneficial and informative, even though of course we could not answer every question. Some of the questions people have raised are very, very interesting and important, and I hope that SSA will continue to do its very good work of trying to respond to those questions as it tries to move forward. Now, I want to thank Social Security for the invitation, really to all of us, and particularly to allow me to provide you with some important information. At this point, I'm going to turn this over to Jeffrey Hemmeter, who is the Acting Deputy Associate Commissioner in the Office of Research Demonstration and Employment Support for closing remarks. And I have got to say that office has been so helpful over the years, in any of us trying to understand more about SSI and SSA. And I just really appreciate the work of that office for the tremendous commitments and energy and output that it provides. Jeff?

>> Thank you and thank you for those words. Thank you, thank you, Dr. Perrin, and all of the panelists today. This is really an excellent discussion, and I want to thank all of the participants for participating. So it was great to extend last month's National Disability Forum with today's discussion, there are many common themes over the two events. Last month's forum generally focused on difficulty with SSA's forms, the local statutory and situational barriers, and the importance of networks. Today we heard more about the difficulty of engaging families and prescribed care and family prioritization, understanding coordination of care, including the transition to adult care. And also about the difficulty of parents and others from even understanding what is being requested on forms. We also heard a lot about issues related to the transition off SSI, and also about outreach to get people on to SSI. There were really some

interesting ideas about social media, partnerships, and communication. SSA has studied many of these issues, particularly the need for effective family services and for transition aged youth in various demonstrations, including the recently completed Promoting Readiness In Minors in SSI or Promised Demonstration in which we partnered with the Departments of Education, Labor and Health and Human Services. We tested a broad assortment of services and connections with state and local programs. And there are a lot of variety in approaches that providers took to communicating and engaging these families, including videos, social media, and other strategies like was discussed today. I encourage everybody to check out the findings from that study as we think about what services and approaches that might work. You can find that at www.SSA.gov/disabilityresearch/promise.HTM. Also, if you are not aware, I encourage you to check out SSA's youth page, www.SSA.gov/youth. It has several tool kits for transition aged youth, their families, and providers. This includes the annual notice mailed to all child SSI recipients ages 14 to 17 with information about the age 18 redetermination, work incentives, including ones that continue benefits past age 18, and about other programs for which they might be eligible. There was some great discussion today about some potential partners that SSA could work with to address some of these issues, such as schools and Child Find. If you are interested in testing those, there is an opportunity to actually test new opportunities for outreach and intensive supports and services to SSI eligible and potentially eligible youth and families, through our Interventional Cooperative Agreement or ICAP Program. Such tests can provide evidence for some of the ideas mentioned here, and we'll be announcing the next round of that soon. One benefit of the ICAP option is really trying to identify what works versus what just may seem to be a good idea, which is very important in the current environment of

resource and staff constraints. There is also data exchange opportunities that could help generate meaningful leads for contacts of potentially eligible children such as what was mentioned through Child Find. Interestingly, when discussing other services, vocational rehabilitation came up. One thing that many people don't know is that SSA actually does not have the authority to refer SSI recipients directly to vocational rehabilitation. I mention that just to highlight that there are some data showing and legislative barriers that many approaches we'll need to overcome as we address these, these issues. To close out, this is a very interesting discussion, and I want to thank all of you for sharing your thoughts and for providing SSA with important insights as we consider policies related to children and SSI. Before we close today's forum though, I do have a few brief announcements. All those who registered will receive an email with a link to an evaluation for this forum. We appreciate you taking time to complete the evaluation, as it will help us improve and offer topics for future forums. This email will also include a link to Engage SSA Campaign, Our online forum. This is an opportunity for you to chime in with any additional thoughts about today's forum as well as suggest ideas for future forums. If you have any questions following today's meeting, please reach us at:

Nationaldisabilityforum@ssa.gov. That is nationaldisabilityforum -- all one word -- @ssa.gov.

Thank you again for joining us. And please stay safe and enjoy the rest of your day. Thanks.

>> This concludes the Social Security Administration's National Disability Forum on Focusing on Aspects of Childhood Disability and Childhood SSI. Thank you for joining us today, stay safe, and have a wonderful day.